

The impact of communication skills training in the management of paediatric HIV

Examining the process of designing, implementing and evaluating a communication skills training programme for adherence counsellors in the South African context.

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ABSTRACT

This study examines the design, implementation and evaluation of a communication skills training programme for adherence counsellors in a paediatric HIV clinic. Effective communication is a pre-requisite skill for any counselling interaction. For both prevention and treatment, counselling is a critical component of the healthcare team response to the HIV epidemic. Given the shortages of healthcare workers in sub-Saharan Africa, task-shifting of the counselling role to less-trained cadres of workers is commonplace. In the multilingual, multicultural South African context, task-shifting coupled with the complexity of the message in paediatric HIV presents enormous challenges. In-service support for counsellors is lacking. Counsellor burn-out and fatigue is commonplace affecting the quality of counselling interactions.

Measuring the quality of communication in a multilingual context poses ethical and methodological challenges and is a neglected area of research. Traditional communication and counselling assessments appear to be largely taxonomic; lack cultural and linguistic sensitivity; and fail to acknowledge communication as a dynamic, two-way process. Mindful of these issues, this study utilized a non-taxonomic approach.

Verbal and non-verbal communication was analysed before and after the implementation of in-service training which was tailored to the specific research context. The training comprised a two day multidisciplinary team workshop followed by individual training. This consisted of video feedback and analysis of counsellors' own sessions and was attended by four counsellors. Results were recorded over an eighteen month period. Twenty-two consultations between counsellors and caregivers were video-recorded, transcribed verbatim and analysed using a hybridized form of linguistic analysis. Findings that demonstrated consensus, substantiation and cross-consultation occurrence were triangulated with thematically analysed interview data, patient questionnaires and researcher reflections. These methods are more sensitive to process than checklist approaches and individualised, complex dynamics emerged.

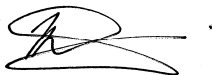
Communication barriers and facilitators were identified before training. Variations in communicative competence between counsellors appeared to be unrelated to prior training. After training, counsellors asked more open-ended questions, encouraged caregivers more, provided simpler explanations of treatment regimens and checked understanding more effectively. In response, caregivers initiated more questions. These findings suggest that communication training improves treatment literacy and results in interactions that are more patient-centered. Despite this evidence, the results suggest limitations to the impact of communication training given the lack of agency of women in South Africa. Interactions included frank and open discussion about cultural beliefs. However, this benefit may be lost due to poor healthcare team cohesion. In their roles as mothers and caregivers themselves, counsellors are effective patient advocates and bring their own lifeworld experience to the counselling interaction. These shared stories are testimonies to the resilience of women living in poverty. Whilst allowing for greater exploration of patients' cultural beliefs and explanatory models, communication training has limited impact in assisting counsellors with dealing with issues such as disclosure, non-adherence and scepticism about biomedicine. Results indicate conflict between patient-centeredness and perceived desired medical outcomes. Caregivers and counsellors appeared to engage in ritualistic dialogue when discussing certain topics suggesting that a shared lifeworld between caregiver and counsellor is insufficient to overcome barriers from the meso (institutional) and macro (broader socio-political) context.

An awareness of the impact of context is critical to our understanding of communication in a clinical setting. The results from this research have implications for the role of the counsellor within a multidisciplinary team and establish a need for communication specialists to work in a clinical setting within the HIV epidemic.

Keywords: Counsellors, communication, caregivers, paediatric HIV, communication training, adherence counselling, intervention evaluation

DECLARATION

I declare that this thesis is my own unaided work. It is submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been previously submitted for any other degree or examination in any other university.



Melanie Christine Evans

21st day of July 2010

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Austin Helza, 'Women hold up half the sky'

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List of Abbreviations

AI	Appreciative Inquiry
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
ATICC	AIDS Training Information and Counselling Centre
AUM	Anxiety/ Uncertainty Management (theory)
BMI	Brief Motivational Interviewing
CA	Conversational Analysis
CBO	Community-based Organisation
CHW	Community Health Worker
CI	Counsellor Initiated topic shift
DOH	Department of Health
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
ID	Identity Document
IFRP	Infant Feeding Research Project
LTFU	Loss to Follow Up
MI	Motivational Interviewing
MITI	Motivational Interviewing Treatment Integrity (manual)
NACOSA	National Aids Council of South Africa
NDOH	National Department of Health
NGO	Non-governmental Organisation
NSP	National Strategic Plan
NVP	Nevirapine
OSCE	Objective Structured Clinical Examination
PAR	Participatory Action Research
PATA	Paediatric AIDS Treatment for Africa
PGWC	Provincial Government of the Western Cape
PI	Patient-initiated topic shift
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission (prevention of vertical transmission)
RIAS	Roter Interaction Analysis System
SADHS	South African Department of Health Survey
SANAC	South African National AIDS Council
SETA	Sector Education and Training Authority
STD	Sexually Transmitted Disease
TB DOTS	Directly Observed Therapy, Short Course for TB
TBM	Tuberculosis Meningitis
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNICEF	United Nations' Children's Fund
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
WHO TTR	World Health Organisation Treat, Train, Retrain

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

This research explores what happened when a small group of adherence counsellors in a public hospital in South Africa received in-service communication skills training. This thesis emerged out of an interest in communication in paediatric HIV: a disease which has been proven to be both preventable and treatable, yet remains enormously challenging for all healthcare workers.

Positioned at the intersection of several disciplines, this research embraces methods of enquiry that cut across these fields, enabling exploration of issues relating to Adherence Counselling; Communication Training; Women and HIV, Paediatric HIV Care; and Counsellor-Patient Interactions.

Personal experience in analysing interactions using conversational and discourse analysis methods from the field of Health Communication, had demonstrated the value of examining the minutiae of communication in interactions to shed light on broader systemic issues in health care. Analysing the language and discourse of counsellors and paediatric caregivers in adherence counselling interactions, provides the opportunity to interpret their lived experience of HIV. In the context of a feminized pandemic, caregivers and counsellors share a lifeworld of womanhood, caregiving and poverty in which they have little agency. How this shared reality influences communication between caregivers and counsellors, has received little attention.

From previous research in interpreting in healthcare, I was aware of how institutional factors create a fragile working environment for community health workers (such as interpreters and counsellors) who are marginalized outside of mainstream medicine. In the current human resource crisis and given the demands of the HIV pandemic, the need for these cadres of community health workers has become even more established. However support and training for them is minimal. Exploration of the quality of counselling interactions enables us to examine whether the *ad hoc* employment of community health workers as HIV counsellors is an effective response to the current crisis or merely serves as a stop-gap solution.

Communication training has been shown to be both necessary and successful for other health professionals across a variety of contexts. However, the degree to which communication training can modify the communication in interactions between counsellors and caregivers in

paediatric HIV has not been explored. I will argue that the extent to which communication training can be effective is questionable, given the stigma around HIV, the limited training and support for counsellors, the associated institutional tensions for community health workers and the complexities of paediatric HIV treatment regimens.

The magnitude of the HIV/AIDS pandemic and the extent of its devastation in Southern Africa, needs no introduction. South Africa has the largest HIV pandemic in the world (UNAIDS, 2008) and almost half the national population are children (Children's Rights Centre, 2009). In 2006 in South Africa, an estimated 294 000 children below the age of fifteen years were living with HIV and an estimated 6% of all children born in South Africa are infected during pregnancy, birth or breastfeeding (Children's Rights Centre, 2009).

In all communities throughout the world, the economically and socially disadvantaged are most vulnerable to infection (Whiteside, 2002) and HIV/AIDS has increasingly become a disease of women living in poverty (Farmer, Connors & Simmons, 1996). The predominant mode of paediatric HIV transmission is from mother to child during pregnancy, birth or breastfeeding: modes of transmission that can be prevented (UNAIDS, 2008). Despite this, in 2007 alone, approximately one million HIV-positive pregnant women gave birth without access of prevention of mother to child transmission (PMTCT) services and nearly 400 000 infants were born HIV-positive (UNICEF, 2009).

Peri-natal transmission can be significantly reduced through antiretroviral therapy (ART), identification of HIV in pregnant women and provision of ART to prevent vertical transmission (Rhatigan, Jain, Mukherjee & Porter, 2009). Thus healthcare for children begins with preventative strategies that target their mothers long before they are born. Paediatric HIV care subsequently has two concurrent thrusts; PMTCT and providing ART to those children who are already HIV positive. In both of these, the fate of children is intricately linked to the quality of care provided to women. In the South African context, due to language barriers, this interface is often mediated by a counsellor. It is thus critical that we get this right.

1.2 HIV AND THE FEMINISATION OF THE PANDEMIC

Although initially slow to gain momentum, there is a growing body of research into women's issues in HIV. There is recognition that “women are buckling under the strain – besieged on one hand by high infection rates and on the other by the increased demands they face as caregivers and breadwinners” (Bellamy, UNICEF: 2004, p. 6). Some of these issues, such as their heightened vulnerability to infection, care burden, stigma and the feminization of poverty, relate to women worldwide. Others, including care roles within isiXhosa culture and transient migratory patterns, are locally relevant.

Recently, Marion Stevens (2008) has called for a paradigm that shifts away from one focused on maternal health to one that embraces women's sexual and reproductive health rights. While it is true that the needs of women are not identical to the needs of mothers, and that there is a need for research that differentiates between these, for the purpose of this research, as the focus is on caregivers within paediatric HIV, a maternal health paradigm dominates. Women's needs thus are presumed to be relevant to all female caregivers¹, but not vice versa.

In what has been termed ‘the feminization of the pandemic’, women are recognized as being both more vulnerable to HIV infection, and more vulnerable as a result of infection. Eight of every ten youths who are living with HIV are female (Children's Rights Centre, 2009). Brandt (2007) argues that HIV both fuels and is fuelled by gender² inequalities and the feminisation of poverty, and UNAIDS (2004) has acknowledged the differing social and economic impact of HIV on women. The experiences of men and women within South Africa differ significantly as described in more detail in *The South African Demographic and Health Survey* (SADHS, 2008). Skills associated with masculine constructs are more valued than those associated with female constructs and this impacts on access to and control of resources available to women to protect their health and that of their families (Shisana, 2004). Pervasive gender inequalities have resulted in rural South African women remaining the poorest and most disadvantaged of all population groups (SADHS, 2008).

¹ Defined within this study context, a *caregiver* is the person(s) who is/ are primarily involved in the daily practical and emotional care as well as the treatment decisions of the child patient with HIV.

² *Gender* as defined by Gupta (2000 in Shisana, 2004) is, “the commonly shared expectations and norms within a society about appropriate male and female behavior, characteristics and roles”.

Physiological factors as well as entrenched social and cultural norms render women more vulnerable to infection than men. Physiologically, this is due to a larger portion of the female genital tract being permeable to semen which contains higher concentrations of HIV than female secretions, that cervical ectopy facilitates infection in young women and because pre-existing STDs increase the likelihood of infections (Africa Region Gender Team, 2000, Baingana, Thomas & Ciamblain, 2005 & Strebel, 1995 in Brandt, 2007). The prevailing social norm is that women have older male partners, who are more likely to have STDs (Baingana et al., 2005) and that many women believe that men have the right to multiple sexual partners (Outwater, Campbell & Abrahams, 2005). In contrast, women with many sexual partners are regarded as dirty (Shefer, Strebel, Wilson, Shabalala, Simbayi, Ratele, Potgieter & Andipatin, 2002).

Gender inequalities are perpetuated by the construct that women should be “subordinate, dependent and passive, dictating silence regarding sexual matters and society valuing virginity and chastity amongst women (and not men)” (Africa Region Gender Team, 2000; Gupta, Whelan & Allendorf, 2003; UNAIDS, 2004). This perception contributes to women often being powerless in negotiating safe sex (Strebel & Lindegger, 1998). Whilst most countries have ratified the convention of the elimination of all forms of discrimination against women, few countries have implemented the conventions to which they agreed (Zung-Dirwayi et al., 2004 in Shisana, 2004). Society values women for their ability to reproduce and in their role as caregivers and mothers. In Africa, children are viewed as a symbol of wealth and a woman’s status is elevated with motherhood (UNAIDS, 1999; Gupta et al., 2003). Child-bearing is seen as a woman’s obligation and the caregiving role is one from which many women derive self-esteem (Kobayashi, 2000). Furthermore, the literature from developed and developing countries shows that HIV positive women have been shown to have a particularly strong need to maintain their parental status (Brandt, 2007).

Within African society, women are often treated as legal minors and are sometimes barred from inheritance and independent financial decision-making (Africa Region Gender Team, 2000; Gupta et al., 2003; UNAIDS, 2004). In the Western Cape, 90.5% of women reported that men alone or jointly had the final say in the number of children they should have, and 77.7% of women reported that men have the final say in what to do with money (SADHS, 2008). In terms of decision-making, women who have never been married, have the least autonomy in comparison to married, divorced or widowed women, and there is a large difference in decision-making between unemployed women (65%) and employed women (85%) (SADHS, 2008). Men have the advantage of better educational levels, with a 20%

more chance of having accurate knowledge about HIV and it is estimated that 80% of women worldwide lack the knowledge to protect themselves from infection (UNAIDS, 2005). Education was identified as the background characteristic that shows the strongest correlation with knowledge about HIV (SADHS, 2008). Misinformation about HIV and transmission exists, particularly regarding the belief that a healthy looking person cannot be carrying HIV. Lower education levels amongst women can be partly attributed to many women dropping out of school. Financial reasons have been cited for why 19% of women in South Africa do not complete schooling. The percentage of women who drop out of school due to pregnancy (7.4%) is exacerbated further by an increasing number of women leaving school to care for young children (SADHS, 2008).

In South Africa, gender-based violence against women is rampant (Jewkes, Levin, Mbananga & Bradshaw, 2002; Jewkes, Penn-Kekana, Levin, Ratsaka & Schreiber, 2001; Wood & Jewkes, 1997). In the context of antenatal clinics, 55.5% of women in a South African township reported sexual or physical assault from a partner, and 8% reported sexual assault by non-partners (Dunkle, Jewkes, Brown, Yoshihama, Gray, McIntyre et al., 2004). South African women beaten by their partners were 48% more likely to be infected (Outwater et al., 2005). Fear of abandonment prevents women from discussing fidelity or negotiating condom use (Gupta et al., 2003) and makes them more vulnerable to coerced sex, rape and dry sex (African Region Gender Team, 2000). Women experience pressure to feed their families rendering them vulnerable to exploitation, exchanging sex for money and less able to leave a risky relationship or negotiate safe sex (African Region Gender Team, 2000). Gender-based violence contributes to the vulnerability of women in South African society, rendering them even more susceptible to HIV.

Gupta et al. (2003) have called for gender transformative interventions that recognize and address gender differences and create conditions whereby men and women can examine the damaging aspects of gender norms and experiment with new behaviours to create more equitable roles and relationships. There is a need for structural interventions that go beyond health care, to reduce the inequalities that disempower women and girls and give them greater access to economic and social resources. Among the interventions proposed by Gupta et al. (2003) to empower women, are: the need to provide women with basic skills such as condom literacy, the ability to communicate with their partners about sex to reduce their risk to vulnerability and infection, and the provision of economic resources and assets, social capital and the provision of leadership opportunities so that they are empowered to have more

agency. Recently, Jewkes (2009) has called for a need for major transformation in how women are viewed in society in order for redress regarding women and HIV to occur.

1.3 CAREGIVING AND HIV

Fear of the illness makes parents less fit to meet the needs of their children. Parents, besides having HIV, still need to hold the sometimes contradictory positions of mother, wife, daughter in law and sister. They struggle with the dilemma of balancing self-care with care for others. As a parent, there is no time for yourself. (Nkunkwana, Caregiver of an HIV positive infant, PATA 2006 Forum)

UNAIDS (2008) called for recognition that children are dependent on adults for care and protection, in order for their rights (such as care, food and shelter) to be met, and so that they can access services such as birth registration, education, social security and health care (Children's Rights Centre, 2009). Caregivers need to be kept alive and healthy in order for children to be able to live in family-like environments (Children's Rights Centre, 2009). Women constitute the majority of caregivers in both the informal and formal sector (Baingana et al., 2005). In the formal sector, women earn less than men and are poorly paid. Many of the women participating in the 'care economy' are themselves HIV positive. When women are ill or die, children's care is subsequently affected (Children's Rights Centre, 2009).

Shared caregiving in African society differs from the caregiving in more Western, middle-class societies (Brandt, 2005a). In households with multiple caregivers, this may decrease the burden experienced (Brandt, 2007). Households are dynamic and emotional stability is not inherent or stable and is impacted on by household composition, finances and situational factors such as loss of job or pregnancy (Brandt, 2005a). It is estimated that 90% of the burden of caring for people affected and infected by HIV/AIDs, falls to women and girls. Both men and women tend to be cared for by female relatives, forcing them to forego educational and economic opportunities (Baingana et al., 2005). Orphaned children are more likely to reside in female-headed households. In two thirds of households, only women and girls are the primary caregivers, and they are the only caregiver in one third of households. Brandt (2007) argues that this 'norm' of assuming that caregiving is a naturally female role, renders it invisible. Women themselves even omit recalling caregiving as a part of their workload.

Women face a number of challenges in balancing their care needs with those of others. The dual role of being HIV positive and a caregiver often takes them away from other productive

tasks and women may neglect their own physical and emotional wellbeing due to symptoms of physical illness. Studies show a low orientation to health status among HIV infected women where large numbers of children are a source of competing needs and interests (Karus, Siegel & Raveis, 1999).

HIV stressors impact negatively on parenting. Parents prioritizing their own caregiving needs over their children's needs may lead to feelings of shame. HIV positive caregivers tend to have lower levels of effective parenting evident in decreased parental support for the child, fewer efforts at discipline and supervision, a neglect of the child due to reorganization of the family around illness, changes in family routines and parental absence. This lack of adequate care and control leaves caregivers feeling guilty and anxious (Fair et al., 1995; Foster & Williams, 2000 in Brandt, 2005b).

A number of studies indicate that caring is burdensome (Muller & Pienaar, 2004) and has been associated with increased depression (Van Servellen, Aguirre, Sarna, & Brecht, 2002). Depression in turn has been associated with maternal role difficulty (Milan, Ickovics, Vlahov, Boland, Schoenbaum & Schuman et al., 2005). However, caregiving remains prioritized and valued by women (Ciambrone, 2003; De Marco et al., 1998 in Brandt, 2007). It is precisely because women value childcare duties, desire to have children, prioritize children's needs over their own and feel excitement at an increasing number of dependents that Brandt (2007) has cautioned against the term '*burden of care*' being used too broadly.

1.4 VULNERABILITY AS OPPORTUNITY

Despite the depressing litany of factors that render women vulnerable to infection and the burden of care facing all women, it is precisely some of these very same features that provide health care workers with the opportunity to prevent paediatric HIV. One of the strongest motivating factors for HIV positive women to seek health care, is the health of their child. Concern for their children was *the* issue that compelled women to confront the potential implications of their HIV status (Brandt, 2005a). In South African society in which any number of factors might result in individuals choosing *not* to confront HIV and access care or HIV testing, it is perhaps ironic that it is the vulnerability of women to HIV, coupled with their motivation as caregivers to do the best for their child, that provides a window of opportunity to access health care. Women are most likely to attend clinics when they are pregnant or to seek medical intervention for a sick child. In a health care system in which loss to follow up of patients is one of the barriers to care, pregnant women are more likely to return for counselling and for follow up appointments as they are motivated by their concern

for the well-being of their child. So it is through paediatric HIV care, that health professionals are afforded the ideal opportunity to provide education and psychosocial support to women.

This positions clinics with a unique responsibility in the pandemic: An opportunity for access; and a burden of responsibility.

1.5 INTRODUCING THE RESEARCHER

I come from the field of Speech-Language Pathology and Audiology which encompass both the medical and educational spheres. From my research into interpreting and using narratives in multilingual consultations, I have experience in the qualitative research paradigm as well as the diverse South African health care context. From my lecturing to medical and the allied health sciences students at UCT, I have knowledge of health communication, principles of adult education and small group training methods which were invaluable in the development of the training programme used in this study.

The training programme developed for this research sought to provide in-service support to adherence counsellors by equipping them with basic communication skills that are contextually-relevant to the clinic in which they are working and to the South African context. At the start of this research, I was aware of the many factors that contribute towards making paediatric ART a challenge for caregivers. As this research unfolded, it became increasingly evident that the issues facing caregivers and counsellors, are one and the same. An integrated response that involves far more than just equipping counsellors with basic skills is needed, if women and children living with HIV are to receive the quality of care they deserve. This research thus describes the researcher's personal journey as participant observer in the process of developing, implementing and evaluating the communication skills training programme.

1.6 RATIONALE FOR THIS STUDY AND RESEARCH QUESTIONS

The literature in *Chapters 2 and 3* will establish the need for research to examine communication in counselling in the context of paediatric ART, a field as yet unexplored in the literature. Whilst a number of studies have recently emerged in the fields of adherence counselling, PMTCT and VCT, none of these studies have focused primarily on communication skills or on interactions between counsellors and the caregivers of children with HIV, but have focused instead on more advanced counselling skills. This is despite the acknowledged weakness of counsellor communication skills and the fact that communication

skills form the foundation for other counselling skills. Considering the many issues impacting on paediatric adherence, it is likely that analysing communication in interactions between counsellors and caregivers may yield rich data on communication and the lives of both counsellors and caregivers living with HIV.

In describing the interactions between counsellors and caregivers using the hybridized approach from the field of linguistics as outlined in *Chapter 3*, this research can attempt to describe the nature of counsellor-caregiver interactions and in doing so, shed some light on the following concerns:

- What verbal and non-verbal communication characterizes adherence counsellor-caregiver interactions in paediatric HIV?
- How do these characteristics impact on patient understanding and the rapport between counsellors and caregivers?
- How do counsellors and caregivers manage communication breakdown in interactions?
- How do institutional factors impact on the quality of adherence counselling?
- How does counsellor training suit the requirements of adherence counselling work?
- How closely does the work of counsellors match that described in the Department of Health (DOH) adherence counsellor job description?
- What impact has task-shifting had on the role of the counsellor?
- What evidence of counsellor role conflict can be found in interactions?
- How are multilingualism and communication generally managed within the running of a busy clinic?
- What role does the adherence counsellor actually perform within the clinic?
- How does the communication of the caregiver impact on the counsellor's communication; and vice versa?
- What impact does the counsellor's lifeworld have on the way that counsellors and caregivers negotiate between the voices of medicine and the lifeworld?
- How does the disease context of HIV impact on counsellor-caregiver communication?

Given the established weakness of counsellor communication skills, there is a need to develop and implement an in-service communication training programme to support counsellors working within a multi-disciplinary clinical environment to improve the quality of their interactions with caregivers.

This study advocates that language and interaction are the basis for developing a relationship between the adherence counsellor and the caregiver. A good relationship between counsellor and caregiver should result in the caregiver feeling more supported and this may impact caregiver well-being and understanding. Given the complex variables that impact on adherence and clinic attendance, it is unlikely that an improvement in communication can be directly linked to adherence or defaulting. Hence it is the interactive processes, including verbal and non-verbal behaviours, that are the foci of this analysis and not adherence.

In this study, I propose that the clinic as a whole, and the system within which the counsellors are working, impacts on the communication in interactions. Despite this, it may be possible to improve communication through training, although there may be certain systemic issues which no amount of individual or small group training will modify. Furthermore, counsellors can be supported in a process of reflection to learn to analyse their own interactions, to identify what communication works well and what doesn't, and to modify their communication accordingly. It is likely that changes in counsellor communication will invoke corresponding changes in patient communication. A workshop process, for the whole team and not just the counsellors, can highlight key language issues which will provide a framework within which counsellor interaction can be understood – rather than judged. By examining the interactive processes, which is only truly possible through detailed systematic analysis of actual counselling sessions (not role plays, and not through prescriptive, predetermined checklists), recommendations can be made regarding systemic barriers to effective communication.

In this research, it is assumed that transaction, namely the exchange of information in order to achieve mutual understanding can be improved by:

- Modifying factors inherent in the 'message' i.e. simplifying information and making it linguistically/ culturally accessible
- Modifying the manner in which the message is presented, also for the purpose of making it simpler and more linguistically/ culturally accessible

In addition, it is assumed that the quality of the interaction, namely the dynamics between the speaker and listener, can achieve greater collaboration by:

- Demonstrating respect for the conversational partner (through active listening, non-judgementalism, demonstrating empathy and attempting to obtain the caregiver's explanatory model)
- Open discussion of the 'meta' aspects of communication (through choice in the selection of the language of the interaction and acknowledging communication breakdown or lack of clarity)

This study examines what happens when a small group of counsellors received communication skills training. In addition to questions about the nature of adherence counsellor communication, a number of questions relating to communication skills interventions also warrant attention:

- What are the communication skills training needs of counsellors?
- How does communication skills training impact on counsellor patient interactions?
- What communication factors are not improved by counsellor communication skills training?

This research rests on the belief that while it is likely that some people are naturally better communicators than others, communication can be taught. Furthermore, communication can be divided into discrete skills that have been shown to increase understanding or contribute positively to the atmosphere of an interaction. However, communication is not about having a checklist of skills that if one includes them, one is a 'good communicator'. In communication in counselling for example, skills need to be encased in an armour of non-judgmentalism and empathy. Both non-judgmentalism and empathy may be considered to be approaches that frame communication rather than 'skill' in themselves. So whilst techniques which demonstrate empathy may be taught, the approach itself needs to be internally motivated.

A distinction needs to be drawn between informational and directive approaches and those that lead to behavior change. As summarized by Mash, Baldassini, Mkhathswa, Sayeed and Ndapeua (2008), an *informational approach* involves delivering predetermined packages of information with the belief that educating the client will lead to desired decisions and behavior change. A *prescriptive/ directive approach* assumes that counsellors will use their authority to tell their clients what they should do and what would be best for them. Mash et

al. (2008) advocate motivational interviewing (MI) as a contrasting approach which enables conversations about behaviour change, through collaboration, evocation and a respect for autonomy. In contrast, this study is concerned with the verbal and non-verbal facilitators and inhibitors in conversations with caregivers, and effecting caregiver behavior change is considered to be beyond the scope of this study. This study is a point of departure from general counselling studies as it focuses on evidence from interactions themselves to see what is (not) working and why it is (not) working.

The analysis of the consultation transcripts has purposefully chosen to be data led (around guiding topics) rather than following a checklist of behaviours. Taxonomic approaches such as these have a tendency to be critical and do not acknowledge what is working well. This can result, in the researcher's opinion, in unbalanced descriptions of counselling relative to an imaginary gold standard. An example within the South African context is the use of standardized tests for language assessments. We know from clinical tests on communication skills, that very few tests have been standardized for the South African population, and so comparison with Western norms is invalid. Given that communication skills throughout all cadres of health care workers (including doctors, nurses etc) are documented as needing training, it would be unfair to risk pathologising one sector, namely that of counselling. Counselling in HIV/AIDS has received a great deal of attention in recent years with many studies highlighting deficiencies in skill. Given the complexity of the task required, it would be interesting to establish whether anyone who counsels patients (doctors, nurses or pharmacists) can meet the standards described in the literature.

In examining the communication in interactions, this research raises numerous ethical issues regarding appropriate methodologies for an HIV context. The details of this undertaking and the thinking behind its design are presented in the chapters that follow.

1.7 READER ORIENTATION

The thesis that follows is structured as nine chapters.

The first three chapters orientate the reader to the study by reviewing the relevant literature and theoretical constructs.

This chapter introduces the reader to the background context of the study, and provides the researcher's personal rationale for exploring the topic. In addition, key constructs are defined.

The second chapter explores adherence counselling in paediatric HIV. The first part of Chapter Two focuses on women, children and HIV on the basis that the quality of paediatric HIV care is dependent on the quality of care afforded to women. Many factors impact on adherence for children, including the lifeworld of women, paediatric treatment complexities and systemic factors such as human resource shortages. Task-shifting, a response to the shortage of professional health care workers, has given rise to the emergence of community health workers (such as counsellors) who receive limited training. The second part of Chapter Two focuses on adherence counsellors. The degree to which adherence counsellors can communicate effectively with patients is influenced by role conflict and their limited training. Existing counselling intervention research utilizes predominantly taxonomic 'checklist' approaches which fail to recognize the contribution of the patient in the dynamic communication process, pay limited attention to the disease context of HIV and fail to explore the shared lifeworld of women. This chapter motivates for a need to improve counsellor communication skills through training, and to explore counsellor-patient interactions using more culturally and linguistically appropriate approaches.

In the third chapter, theories relevant to the examination of communication in interactions are presented. A definition of communication as a dynamic, two-way process which involves both the exchange of information and the exploration of the patient's illness experience is described. In order to assess communication within this definition, a hybridized linguistic method of enquiry that adopts a data-led, non-taxonomic approach and recognizes the contribution of both communication partners, is necessary. Motivation for improving communication through training interventions is founded on the basis that communication breakdown commonly occurs in medical interactions and is detrimental to the provision of quality care. This chapter establishes a need to explore communication in interactions within the disease-context of HIV using analysis methods that are applicable within the multilingual/multicultural South African context.

In the fourth chapter, methodological considerations in intervention studies are explored. A distinction is drawn between assessment and evaluation. Chapter Five outlines the research methodology chosen, mindful of the methodological complexities outlined in Chapter Four, as well as the advantages of using techniques of analysis developed within the fields of linguistics (such as following a turn by turn analysis method as used in Conversational Analysis) and anthropology to the field of paediatric HIV. Chapter Five includes a summary of the findings of the two published pilot studies (Penn & Evans 2009; 2010). In addition, the methods of developing and implementing the training programme are described. This

training programme designed was influenced by the results from Chapters Five and Six as well as relevant literature.

The results of this research are presented in Chapters Six and Seven. This written account of the process consists of baseline (pre-intervention) measures which are described in Chapter Six. These are contrasted with the post-intervention measures in Chapter Seven. The baseline measure includes the examination of the physical environment in which the study took place (the description of the clinic context) which is a combination of detailed descriptions from ethnographic inquiry and interviews with participants, and the results from the analysis of the video recordings and transcripts of the communication in counsellor-patient interactions.

Chapter Seven contains the comparison between the baseline results in Chapter Six, and those that describe the communication after training. In addition, key themes that emerged across the consultations are described.

These results are discussed in relation to the background literature in Chapter Eight and the intervention is evaluated. Lastly, the conclusion and recommendations are described in Chapter Nine.

1.7.1 A note on the presentation of the data

Many materials were developed in the process of implementing this research. Wherever possible, these materials have been attached as appendices rather than included within the body of the dissertation. The results from the pilot studies that influenced the design of the training programme used in this study are published elsewhere and are not included in full (Penn & Evans, 2009, 2010).

As this is a qualitative study, illustration of the results is heavily reliant on examples from actual transcripts of interactions between counsellors and patients. It is important for quoted examples to be captured in their original form (usually in isiXhosa in this study). However, to enable easy reading of the researcher's argument, selected English translations of excerpts are included in italics within the body of the dissertation.

These examples are referenced to their case (by a letter of the alphabet) and to their position within the case (by a number). At the end of each section selected transcript quotes have been included as examples. The original, *untranslated*, transcription is written in normal script. The translated script is written in italics as illustrated in Figure 1.1 from consultation G line 87 [G87].

C: Akho mbuzo akukho nto ingenye ofuna ndiikucacisele yona mhlawumbi? <i>Is there anything else that you would like me to explain to you?</i> P: (Clears throat) Into endifun' uyicacelwa iyenzeke into yokuba umntwana ke abe HIV kodwa wena mzali awunanto? <i>I would like to know if it is possible for a child to be HIV positive while the parent is negative?</i>
--

Figure 1.1 An example of the presentation of transcribed and translated data

1.7.2 A note on the terminology used

Adherence vs Concordance: Adherence refers to the consistency with which patient behaviours and intentions match the recommendations of the health professional (Houts, Doak, Doak & Loscalzo, 2006; Garcia & Cote, 2003). An ideal within a patient-centered paradigm, is the attainment of 'concordance'; namely a therapeutic partnership between a patient and a health professional in which agreement is reached on whether, how and when medicines will be taken (Marinker & Shaw, 2003).

An adherence counsellor within the South African context is typically a lay counsellor trained by a non-governmental organization (NGO) working alongside professionals in a public health setting (Evangeli, Engelbrecht, Swartz, Turner, Forsberg, & Soka, 2009). In South Africa, adherence counsellors undergo only brief training in a combination of client-centered and directive approaches to counselling in contrast to Western models of counselling in which training is typically of longer duration. In a paediatric HIV context, adherence counsellors work one on one with the caregivers of HIV positive children, to provide educational and psychosocial support centered around promoting adherence to ARVs. Adherence requires conversations to empower caregivers to make significant transformations to challenge their traditional role, personality and identity (Buskens & Jaffe, 2008).

Caregiver: Defined within this study context, a caregiver is the person(s) who is/ are primarily involved in the daily practical and emotional care as well as the treatment decisions of the child patient with HIV. This term is used inclusively of biological and adoptive parents, as well as individuals who have taken on this responsibility without legal process (Children's Rights Centre, 2009). In this study, in most cases, the caregiver was the child's mother, but in some cases it was the child's grandmother, older sibling or aunt. One of the caregivers in this study was the father of the child accompanied by his girlfriend.

Coloured population: In South Africa, as a product of the classification system during apartheid, people of mixed race are described as 'coloured'. This is contrasted with 'Black' people who are of African origin. In the Western Cape province where this research was

conducted, coloured people speak predominantly English and Afrikaans, and black people speak predominantly isiXhosa.

Counsellor (rather than lay counsellor): Counsellors in South Africa are often referred to as ‘lay’ counsellors, a term that indicates that they are non specialist counsellors i.e. they do not hold a professional degree. The term ‘lay’ has been applied to other *ad hoc* positions in health care, such as interpreters, and holds negative connotations. With respect for the wishes of counsellors, the term ‘lay’ has been omitted. This is, however, worth mentioning as it is necessary for comparison with other studies in which this term is used.

Interpreting vs Translation: *Interpreting* is the verbal adaptation of material across a linguistic barrier, and differs from *translation* which is the written adaptation of a print form (Javier, 2007).

Patient: Although the term client is also commonly used in the context of accessing psychological support, the term ‘patient’ will be used throughout this dissertation in acknowledgement of the health care context. Patient will be used to refer to either the caregiver or the child accessing treatment as both are recipients of care within the clinic.

Vertical transmission: With respect of the wishes of some HIV positive mothers³ the term vertical transmission will be used throughout this dissertation instead of mother to children transmission (MTCT). Where specific sites/ programmes are labeled as offering prevention of mother-to-child transmission (PMTCT) services by other sources, this has been retained, as mother-to-child transmission is not considered to imply blame to the mother (Children’s Rights Centre, 2009) and so is commonly used.

Voluntary Counselling and Testing (VCT), adherence counselling and PMTCT counselling: Much of the literature reviewed in this thesis refers to ‘counselling’ generally. In reality, however, numerous different sub-types of counselling have developed in response to the HIV/AIDS pandemic. For the purpose of this study, a distinction will be made between ‘adherence counselling’ which will be applied to counsellors whose primary function is to support adherence on an ongoing basis, and other types. Adherence counsellors differ from counsellors involved in Voluntary Counselling and Testing (VCT) which is short-term counselling focused on the event of testing for HIV, and counselling in PMTCT, which

³ Odetoyinbo, R. (2009). Community Statement read at the IAS 2009 Pathogenesis Conference, Cape Town, South Africa, on behalf of the Community Advisory Group (CAG)

focuses on preventing transmission of HIV from mother to child and is used exclusively with pregnant women. Recently, emphasis has been placed on PMTCT-*plus* which aims to provide a link between PMTCT services and paediatric care.

The aim of PMTCT feeding counselling is to provide mothers with sufficient information and support to be able to assess the comparative risks and benefits of breastfeeding versus formula feeding, so that she can make an informed choice to which she'll be able to adhere (Buskens & Jaffe, 2008).

HIV/AIDS counselling in South Africa broadly covers a range of treatment and prevention strategies (Evangeli et al., 2009). For the purpose of this study, adherence counselling can be contrasted with voluntary counselling and testing (VCT), in a number of ways: VCT is focused around the central act of testing for HIV and the outcome associated with such a test. It involves education and support that is usually viewed as the point of access into the health care system. VCT is often the starting point from which treatment and the associated adherence counselling may follow. In contrast, adherence counselling is focused on all aspects relating to preparing for and maintaining adherence to ART. It is not centered around a single event (such as testing) but is considered to be broader, having both educative and supportive functions on an ongoing basis. Adherence counselling is not a once-off event; but rather a process. Adherence counselling can entail educational and psychosocial support in the form of group therapy. However, for the purpose of this study, adherence counselling is used to refer only to individualised therapy encounters between a counsellor and a caregiver(s).

1.7.3 Methodological constructs relevant to this study

Code-switching and Code-mixing: *Code-switching* can be defined as the juxtaposition or alternation of material from two or more languages or dialects and can be regarded as an umbrella term which also incorporates code-mixing (McCormick, 1995). However, the two can be differentiated as code-switching is often used to refer to the alternation of elements longer than a single word, in contrast with code-mixing in which the alternation is often of just single words (McCormick, 1995).

Conversational Analysis (CA) in summary : As CA will be described in Chapter 3, only the key aspects are summarized here. CA analysts examine turn-taking sequences, which are considered to be the basic foundation of conversation (Jones, 2003) within naturalistic interactions that are not artificially staged by the researcher (ten Have, 2000). Descriptions of

observable behavior provide the ‘evidence’ of the success or breakdown of communication as well as repair attempts (Perkins, 1995) which are analysed within the conversational context and the responses of each conversation partner. The potential of CA as a research tool has been criticized for its lack of structure and definition in comparison to quantitative research. Ten Have (2000) argues that although studies using CA do not usually have rigorously pre-defined frameworks, they do follow a degree of structure as the researcher follows a protocol of systematic analysis. CA provides the researcher with a valuable method of identifying linguistic, cultural and social themes and dynamics that facilitate or inhibit communication. CA has not been used in this thesis; however, the technique of structured turn by turn analysis commonly used in CA has been followed.

Ethnography: Ethnography is a method of reflecting the social world and behavior of the study population (Galanti, 1999). Ethnographic data collection involves using a number of methods and sources with a small group of people in a specific environment. The analysis calls for the interpretation of meanings of certain actions in striving towards understanding people and in the development of new theoretical ideas (Hammersly, 1998). The application of ethnography to the social and health sciences and to clinical encounters is strongly supported (Flick, 2002; Harrison, 2002; Lincoln, 1992; Scheper-Hughes, 1990; Simmons-Mackie, Damico & Damico, 1999). Particularly in the South African HIV/AIDS context with the added complexities of multilingualism and multiculturalism, ethnographic research can be used to complement other quantitative and qualitative methods in which more structured research methodologies can have limited application (Geertz, 1996 in Flick, 2002).

Process: Reference to the communication *process* is necessary as research shows repeatedly that prescriptive lists do not provide practical recommendations for improving communication (Pillnick, 2002).

Taxonomy: (1) The classification of organisms in an ordered system that indicates natural relationships; (2). The science, laws, or principles of classification; systematic and (3) Division into ordered groups or categories

Topics: Segments of talk that stand together because they are about the same thing.

CHAPTER TWO

ADHERENCE COUNSELLING IN PAEDIATRIC HIV

In this chapter, adherence counselling in the field of paediatric HIV care is described within the diversity of the multilingual, multicultural South African context. The purpose of this chapter is not to present an exhaustive literature review of paediatric HIV or adherence counselling, but rather to highlight those aspects of adherence counselling and paediatric HIV care that render them interesting and complex in terms of communication. Adherence counselling is a critical component of the health sector response to the HIV/AIDS pandemic and effective communication between health professional and patient is a prerequisite for any counselling interaction.

Part One of this chapter describes how multiple variables such as the complexity of paediatric treatment and the caregiver's lifeworld impact on adherence to ARVs. The fate of paediatric health care is dependent on the quality of care afforded to women which is compromised by health system constraints.

Part Two of this chapter examines recent counselling research with particular attention to communication issues. Wherever possible, reference is made to South African studies and to research from the rest of Africa, which has greater applicability than that from non-African developing countries (Iliffe, 2006).

CHAPTER 2 PART 1: ADHERENCE FOR WOMEN AND CHILDREN

Adherence⁴ refers to the consistency with which patient behaviours and intentions match the recommendations of the health professional (Houts et al., 2006; Garcia & Cote, 2003). Adherence requires the patient accepting and understanding the message from the health professional, and understanding that this requires an action to be taken, as well as executing the recommended action (Houts et al., 2006). Medicines only work when taken correctly (Bonnacorso & Sturchia, 2003) and although there are infinite incorrect ways of taking medication, there is only one correct method (Pilnick, 1999). With the advent of ARVs in combination with prophylactic therapy for opportunistic infections, HIV/AIDS is now a treatable, chronic disease (Kim & Farmer, 2006). Current ARV therapies require that patients remain on ARVs for the duration of their life (Altice & Friedland, 1998).

⁴ *Adherence* is preferred to *compliance* (which is sometimes associated with submission and passivity) as adherence implies patient participation in both the choice and administration of a selected treatment regimen (Altice & Friedman, 1998).

At both an individual and a population level, lapses in treatment have dire consequences. Effective ART can suppress the amount of virus and reduce viral replication to undetectable levels, however HIV remains in the reservoirs of CD4 lymphocytes and if ARV medication levels drop, the virus can then rapidly multiply (Rhatigan et al., 2009). Resistance to ART can develop if there is active viral replication below optimal medication levels, resulting in treatment failure and the need to switch to second-line treatment regimens (Rhatigan et al., 2009). An estimated 40-60% of patients have levels of adherence less than 90% and an adherence level of 80-95% is required for maximum suppression of viral replication, slowed progression to Aids, decreased mortality rates, prevention of viral resistance and encouragement of immune reconstitution (Bartlett, 2002; Gross, Bilker, Friedman & Strom, 2001; Ickovics & Meade, 2002; Nischal, Khopkar, & Saple, 2005; Paterson et al., 2000). Non-adherence is a real public health threat as rapid viral rebound and drug-resistant strains of HIV being transmitted to new hosts are the consequences of ARV discontinuation (Chun, Davey & Engel, 1999).

An ideal within a patient-centered paradigm, is the attainment of ‘concordance’; namely a therapeutic partnership between a patient and a health professional in which agreement is reached on whether, how and when medicines will be taken (Marinker & Shaw, 2003). The term concordance fits particularly well within a patient-centered paradigm in which it is acknowledged that both patient and health professional are experts in their own right, and may differ in their health beliefs. In any successful therapeutic encounter, mutual respect and the formation of a therapeutic alliance is needed in order for these individual health beliefs to be shared (Marinker, 1997 in Marinker & Shaw, 2003). Concordance focuses on the process of interaction rather than individual behaviours (Weiss & Britten, 2003).

Adherence can be achieved without the ideal of a ‘mutual alliance’ associated with concordance. However, quality care within a patient-centered approach, necessitates concordance. Adherence is measurable too whereas concordance is more subjective. One of the advantages of studying interactional behaviours is that, however subjectively, a comment on degree of concordance can be made.

2.1 ADHERENCE FACILITATORS

Proven factors promoting adherence in resource-poor settings include home visits (Weidle, Wamai, Solberg, et al., 2006), the use of community health workers to administer directly observed therapy (Farmer, Leandre, Mukherjee, Claude, Nevil & Smith-Fawzi, 2001),

reducing pill burden, actively managing side-effects, and involving family and community members in medical management (Rhatigan et al., 2009). Education improves adherence to ART regimens and feeding practices (Besser, 2002). Counselling and support improve quality of life (Besser, 2002). Activities that reduce patient barriers to care, encourage patient entry to care and ensure follow up and retention, are critical (Rhatigan et al., 2009). Measures such as waiving user fees, transportation allowances and food supplementation can reduce these barriers (Rhatigan et al., 2009). Recent ethnographic research indicates that individuals taking ART routinely overcome economic barriers through deliberate strategies in which adherence is prioritized (Ware et al., 2009). Particularly when providers expect adherence and make their expectations known, responsibility is created on the part of the patient to adhere (Ware et al., 2009).

In the South African guidelines on ART for children, a number of strategies to promote adherence have been identified (NDOH, 2005 p. 98). These are summarized in Appendix I. All of the recommended strategies are reliant on effective health professional-patient communication.

2.2 THE COMPLEXITY OF ADHERENCE

HIV care is complex and life-long, and numerous social and economic barriers need to be addressed for effective care delivery (Rhatigan et al., 2009). The previously held misconception that adherence is impossible to achieve in resource-poor settings has been negated by several studies in developing countries (Coetzee, Boule, Hildebrand, Asselman, Van Cutsem & Goemaere, 2004; Mills et al., 2006b; Nachega et al., 2004; Orrell, Bangsberg, Badri & Wood, 2003; Rhatigan et al., 2009; Weidle et al., 2002). Non-adherence can be intentional or unintentional, and is defined by Bartlett (2002) as any of the following: A delay in seeking treatment, missing follow-up appointments, skipping doses, overdosing, taking treatment inappropriately or at incorrect intervals, not adhering to prescribed diet restrictions, or cessation of treatment. Patient age, gender, and knowledge of HIV and socio-economic status have not been shown to impact on adherence (Orrell, 2003; Nachega et al., 2004). However, more than 200 other variables have been linked to adherence (Vermeire, et al., 2001; Nischal et al., 2005). These can be divided into disease, treatment, patient, systemic, and linguistic variables summarized in Table 2.1 and briefly discussed thereafter.

Table 2.1 A summary of disease, treatment, patient and systemic variables impacting on adherence

Disease variables	Stigma Patient perceptions and beliefs about ARVs Political denialism Increased stigma for women due to the associations with mother to child transmission
Treatment variables	Complexity of regimens Side effects and opportunistic infections Mixed messages about treatment
Patient variables	Intent and beliefs Psychosocial well-being Motivation Lifestyle pattern
Systemic variables	Access: Financial, transport, linguistic Patient dissatisfaction Health Professional and patient relationship
Linguistic variables	Poor communication Lack of trust with health professionals Understanding instructions Health professional communication practices Difficult-to-discuss 'taboo' topics

2.2.1 Disease variables impacting on adherence

HIV is regarded as a disease of deviants that is linked to sex and death (Sontag, 1991). As a result, many patients fear disclosure which can impact on adherence (Mills et al., 2006a). Fear of stigma is regarded as being a major obstacle to prevention, care, testing, disclosure and treatment seeking (Jewkes, 2006; Brimlow, Cook & Seaton, 2003; Foreman, Lyra & Breinbauer, 2003). Furthermore, patient perceptions and beliefs about ARVs may lead to non-adherence (Garcia & Cote, 2003; Bartlett, 2002) and may prevent PLWHA from living positively (Nyblade et al., 2003). This is particularly relevant in the South African context in which political denial about HIV/AIDs and the delays in rolling out ARVs have contributed to some of the perceptions about ART. In paediatric HIV, women experience additional stigma as HIV is transmitted from the mother to the child (Cohen, 1994).

2.2.2 Treatment variables impacting on adherence

Although there are mixed results from research into treatment variables such as the impact of the complexity of HIV regimens on adherence (Ickovics & Meade, 2002), some studies have found that increased complexity can lead to non-adherence (Mills et al., 2006a). In HIV care, ARV regimens may comprise more than 20 pills a day and many patients need to take additional medication for opportunistic infections or side-effects. Regimens differ in terms of storage and dietary requirements (Bartlett, 2002). Patients experiencing side-effects from treatment or who believe that treatment is worsening their condition are likely to be less-adherent (Chesney, 2000; Murphy, Roberts, Hoffman, Molina & Lu, 2003). Severity of symptoms and the presence of opportunistic infections may motivate patients to adhere

(Ickovics & Meade, 2002; Catz, McClure, Jones & Brantley, 1999), however fatigue, illness and pain can also lead to treatment cessation (Bartlett, 2002; Chesney, 2000; Gordillo, Del Amo, Soriano, & Gonzalez-Lahoz, 1999). Some studies have shown no such impact of clinical stage on adherence (Orrell et al., 2003). Other factors cited as impacting on adherence include tolerability of the regimen, availability of drugs, the pill burden, dosing frequency, food requirements, convenience, toxicity and drug interaction profile (Van Deventer & Radebe, 2009).

Mixed messages about treatment can lead to adherence difficulties. This is supported by findings from changing regimens during pregnancy and in infant feeding research (Cooper, Harries, Myer, Orner & Bracken, 2007).

2.2.3 Patient variables impacting on adherence

Patients may be unintentionally forgetful or may choose not to take medication as it is disruptive to daily routine (Bartlett, 2002). Patient variables that impact on adherence include decreased quality of life due to HIV/AIDS and family and work responsibilities (Mills et al., 2006a). Psychosocial factors include depression, mood or substance abuse (Ickovics & Meade, 2002; Mills et al., 2006a) as sufficient quality of life (mental health, coping and level of social support) is necessary to achieve adherence (Brandt, 2005b). Motivation to begin therapy, ability to adhere and lifestyle pattern are among the many factors that contribute to adherence (Van Deventer & Radebe, 2009).

2.2.4 Systemic variables impacting on adherence

Systemic variables impacting on adherence include a lack of access to medicines (Mills et al., 2006a), patient financial security, access to transport, availability of childcare and accessibility of clinics (Ickovics & Meade, 2002). Accessing the health care system is particularly challenging for patients experiencing linguistic barriers (Cuellar & Fitzsimmons, 2003). Patient dissatisfaction with the health care system can lead to treatment avoidance (Chesney, 2000). Health-professional patient relationship is relevant, as providers who are perceived as competent and trustworthy may result in better adherence (Ickovics & Meade, 2002; Stein, Lewin & Fairall, 2007).

2.2.5 Cultural and linguistic variables impacting on adherence

Poor health professional-patient communication is a linguistic variable that can contribute to poor adherence (Britten, Stevenson, Barry, Barber & Bradley, 2003; Hill, 2006; Mishra, Hansen, Sabroe & Kafle, 2005; Skoglund, Isacson & Kjellgren, 2003; Sleath, Roter, Chewning & Svarstad,

1999). In their review of factors impacting on adherence, Van Deventer and Radebe (2009) mention the lack of trust between clinician and patient, a lack of patient education and an inability of patients to identify their medicines, as communication-related variables leading to non-adherence.

In order to adhere to medication regimes, patients need to understand instructions from their health professional (DiMatteo & Chow, 1995), however this is difficult for patients as many fail to raise concerns and questions or ask for further clarification if instructions are unclear (Bridson, Hammond, Leach & Chester, 2003). Poor patient understanding of their disease and its treatment is well-documented (Kemp, Floyd, McCord-Duncan & Lang, 2008). There is a need for information to be presented to patients simply and comprehensively in a culturally and linguistically appropriate manner, and for patient understanding to be checked (Watermeyer, 2008). Caregiver understanding is particularly critical in paediatric HIV as the dosing is more complex.

Numerous health professional communicative practices have been identified as barriers to communication in HIV interactions. Some of these such as a failure by health professionals to verify patient understanding of information (Kemp et al., 2008; Britten et al., 2000), or giving conflicting information to a patient about treatment (Britten et al., 2000) occur in any medical interaction. However a number of disease-specific barriers also exist. For example, although HIV necessitates discussing sex, death and other sensitive topics, some health professionals experience embarrassment when discussing these taboo topics and fail to talk openly and honestly with patients or use euphemisms which then reinforce misunderstandings (Fallowfield & Jenkins, 1999; Britten et al., 2000). Professional detachment and judgmental attitudes about HIV prevent health professionals from establishing the patient's explanatory model (Fallowfield & Jenkins, 1999). Misunderstandings about adherence to prescription medicine have been attributed to patients not offering information about themselves and to health professionals not seeking information from patients (Britten et al., 2000). Failure to investigate patient expectations, culture and beliefs may lead to a breakdown in communication (Elwyn, Edwards & Britten, 2003).

2.3 PAEDIATRIC HIV TREATMENT COMPLEXITIES

The CHER study (Violari, Cotton, Gibb, Babiker, Steyn, Jean-Philippe & McIntyre, 2007) has demonstrated the benefits of starting children on ARVs as early as possible. Health professionals may experience increased pressure to prepare caregivers for starting to administer paediatric ARVs sooner. This could be problematic given the many factors particular to pediatric treatment regimens that make them even more complex to administer than adult ARV regimens.

Children, defined as persons under the age of eighteen years, make up a diverse group with a wide spectrum of needs (Children's Rights Centre, 2009). In 2008, UNICEF issued *A Joint statement on advancing Child Sensitive Social Protection* in which consideration for children means early intervention for at risk children to prevent harm; awareness of the vulnerabilities and capacities of children at different stages in their life cycle; consideration for age- or gender- specific needs, making special provision for reaching vulnerable and excluded children who struggle to access services; adapting services to accommodate children; ensuring access to information for children; involving children in decision-making and recognizing the importance of their contribution to the national HIV response (UNICEF, 2008).

A number of important factors have been identified as diminishing adherence in children, namely drug side effects, adverse events, intercurrent illness, caregiver illness, caregiver otherwise occupied, patient resistance to taking medications, drug stock-outs, change of practitioner or absence of practitioner and frequent daily doses (DOH, 2005). The guidelines for the management of paediatric HIV in children recognize that there are special care needs related to managing ART in children which make adherence a serious challenge for children. This is because children may need special formulation of the drugs (e.g. solutions); some medications have a very unpleasant taste; a caregiver needs to be present to administer the drugs; adjustment of the dosage in relation to the child's growth and organ maturation needs to occur; ART needs a supportive health care, family and community environment; the guidelines for the administering of ART to children are different to those for adults; and there are relatively few formulations of ARVs available for children. Watermeyer (2008) has summarized additional considerations that pharmacists need to provide to caregivers which may be relevant to others members of the healthcare team, including: how to open child-proof lids, keeping medicines out of reach of children, not sharing medicines between children and strategies for hiding the unpleasant taste of medicines such as giving a child ice to numb the tongue or mixing it with vitamin syrup or peanut butter. In addition to the factors mentioned above, Table 2.2 proposes a number of additional complexities that can be assumed, based on the researcher's review of instructions for administering ARVs to children and information provided on particular medicines used in paediatric ART.

Table 2.2 Additional complexities in paediatric ART proposed by the researcher based on a review of instructions for administering ARVs to children and information available on medicines used in paediatric ART

Multiple regimens in one household	Caregivers may be caring for more than one child on ARVs in a family and dosing and regimens may differ for each child and each adult in the house.
Weight bands & calculations	Dose calculations are based on a child's weight. Weight bands for different drugs differ (e.g. in Cotrimoxazole prophylaxis, dosing is divided into weight bands of under 5kg and 5kg - 13.9kg whereas in Multivitamins, the categories are under 10kg and then 10 – 30kg).
CD4 count as a % calculation	Whereas adult CD4 counts and viral load are measured as a count, children's CD4 count is measured as a percentage as absolute CD4 count is less constant in children and more age-dependent than percentage CD4. Percentages may be more difficult for parents to understand than a single threshold as used in adults.
% threshold variations	Depending on the child's age, the percentage threshold for paediatric staging varies. For example, for children over 5 years, a CD4 count of less than 15% or less than 200 cells/mm ³ equates to WHO staging 1 or 2, whereas for children between 12 months and 35 months, CD4 of less than 20% or less than 750 cells/mm ³ equates to WHO stage 1 or 2.
Difficult concepts e.g. prophylaxis & exposed	There are a number of complex concepts which caregivers of children on ART need to understand. An example of a complicated concept is the use of the word ' <i>prophylaxis</i> ', meaning ' <i>advance protection taken to prevent disease.</i> ' Cotrimoxazole prophylaxis is started from 6 weeks of age in all HIV exposed and infected children as well as exposed and uninfected children. It may be difficult to explain the reason behind why some children are 'exposed and infected', whereas others are 'exposed and uninfected', because of semantic difficulties in equating exposure with infection, and as it cannot be predicted which children will fall into which category.
Changing maternal care needs over time	The literature on the needs of caregivers of HIV positive children, suggests the need for a dynamic approach to supporting caregivers as their needs change over time. As antibody tests for HIV only lose maternal antibodies at approximately 12 months, PCR testing is used as it allows for diagnosis at 4 – 6 weeks after birth and this is standard practice in South Africa (DOH, 2005). Lazarus, Struthers & Violari (2009) found that the period prior to obtaining the baby's PCR results was emotionally stressful and involved active mental preparation. Mothers of HIV positive babies were very distressed and expressed guilt and a sense of responsibility (Lazarus et al., 2009).
Abbreviations, common & scientific names of medications	A number of different medications are used in combination in paediatric ART. The medications themselves have complicated scientific names, which have been complicated further by assigning 'common' names to them that have no bearing on their scientific names. For example, in the first line regimen, Stavudine is called d4T; Lamivudine is 3TC, and Lopinavir/ritonavir is called Kaletra. Only Efavirenz, abbreviated to EFV, resembles its scientific name. In the second line therapy, Zidovudine is called AZT; and Didanosine is called ddl. Sometimes, medications have more than one scientific name (e.g. Stavudine is also called Zerit). Abbreviations themselves may be tricky to remember. With the emergence of many new generic versions of drugs, this has become even more complicated.

Variations in timing of ARVs	The timing of taking ARVs varies. Some tablets are taken once daily in the morning (e.g. Bactrim), others once daily in the evening (e.g. Efavirenz), but most are taken twelve hourly (e.g. Zidovudine, Stavudine, Lamivudine, Kaletra, Nevirapine and Abacavir). Some ARVs can be taken on an empty stomach or with eating (e.g. Zidovudine, Stavudine, Lamivudine, Kaletra, Efavirenz, Nevirapine and Abacavir), whereas others have specific requirements (e.g. Didanosine must be taken on an empty stomach, half an hour before eating or two hours after eating, and needs to be taken separately to all other medication including ARVs, food and drinks).
Changes in caregiving	Young children are dependent on caregivers for measuring and administering the medication to them, and because caregivers might be employed or may not be at home over the time when dosing needs to occur, and as there are fixed intervals between when tablets can be given, there may need to be more than one caregiver involved in administering the medication. Caregivers may be variable and may fluctuate as household dynamics change.
Variations in packaging	There are variations in packaging and labeling used for medications, even within one hospital. Usually either the common name or the scientific name is used on the packaging of the medications, but seldom both. For example, Lamivudine is labeled as such on the 10mg syrup, whereas on the 150mg tablets, both 3TC and Lamivudine appear in one packaging format in a white bottle with a white and blue sticker label, but in another format using a white bottle with a brown and orange sticker label, only the name Lamivudine appears.
Tablet appearance	The colours of tablets and capsules often change with different dosages. For example, Stavudine 20mg capsules are green, 30mg capsules are maroon/orange, and 15mg capsules are green/ maroon. This is helpful in terms of understanding changes in dosing, but can lead to confusion as different medications may have the same coloured capsules. For example, Stavudine 20mg is green, and the Efavirenz 200mg is also a similar green capsule. However, not all tablets change in appearance with changes in dosing. For example, the Didanosine 25mg, 50mg and 150mg tablets are identical in colour and size, contrary to the expectation that the higher dose would be bigger. However, in the case of Didanosine, the printing of the dose on the tablet itself, distinguishes the one from the other which is helpful.
Different formulations of one drug	Some medications come in syrup, tablet and capsule versions (e.g. Kaletra). If a caregiver is familiar with using one format of Kaletra, and then due to stock-outs or accessing the medication at a different facility (e.g. whilst on holiday), may be confused by a switch to another format of the same medication. Children may also struggle to swallow tablets and so may need to use syrup formulations at young ages.
Changes in regimen	Depending on how children respond to ARVs, regimens may need to be changed, resulting in caregivers needing to learn to administer a new regimen. For example, children may need to be switched to the second line regimen if virological failure ⁵ occurs. Clinical reasons for switching to the second line regimen includes a lack of growth, loss of neurodevelopmental milestones or development of HIV encephalopathy, new evidence of stage III/IV disease or recurrence of prior opportunistic infections (NDOH,

⁵ Virological failure is defined by the NDOH (2005:84) as 'a rebound of viral load to baseline'.

	2005). Immunological reasons include no improvement in CD4 value despite at least 24 weeks of therapy, confirmed return of CD4 percentage to below baseline or more than a 50% decline in CD4 percentage from peak in the absence of concurrent illness to explain the CD4 decline (NDOH, 2005). This may be, but is not always, due to poor adherence. Once virological failure is diagnosed, it is recommended that change occurs early. Some children experience side-effects such as lipodystrophy which is a fat redistribution syndrome that affects 18-33% of children (usually from Stavudine or from Zidovudine) in which irreversible peripheral wasting of subcutaneous fat occurs with an increase in central fat in the abdominal girth with breast enlargement. Abacavir is then substituted for Stavudine. If viral load is unsuppressed, children require a complete change of regimen and it needs to be explained to caregivers that this will prevent a worsening of symptoms but may not necessarily result in improvement of current body appearance.
Measuring	Pediatric formulations are often not pre-measured and require that caregivers use syringes to measure the correct dose.
Storage	Some pediatric regimens need to be stored at particular temperatures which require refrigeration (e.g. Stavudine syrup) and necessitates electricity supply which can be a challenge in rural and impoverished areas. Access to refrigeration is important in selecting the form of medication (e.g. Stavudine capsules can be used and dissolved at each application for families that do not have fridges) and impacts on the shelf-life of medicines (e.g. Kaletra only has a six week shelf life when not kept in the fridge). Discussion of these factors with caregivers is important so that the correct choice of medication occurs.
Additional support	Care needs change as children mature. In addition to requiring ART, HIV positive children might have additional support needs such as OT, physio etc.
Transport	Transporting older children to the clinic may place additional financial strain on parents.
Nutritional demands change	Nutrition is paramount for all children in a family and parents can not be expected to provide nutritional supplementation to only one child in a family; it is thus conceivable that nutritional supplements may be shared. Nutritional supplementation also varies as children grow.
Disclosure to children	As children grow and develop and come to realize that they need to take the medication whilst others do not need to, they might resist taking the medication. In addition to dealing with parental guilt, caregivers need to be prepared to answer their child's questions as they mature. As many HIV positive children now survive into adolescence and adulthood, caregivers and health care workers face new challenges in dealing with changing psychosocial needs with the onset of adolescence.

This table suggests that there are many factors which could contribute to treatment being additionally complex in children on ARVs which may be difficult to communicate. Some of these factors are directly related to existing paediatric ART regimens (e.g. packaging, formulations) whereas others are a product of the chronic nature of ART (e.g. changing needs as a child grows).

2.4 THE CAREGIVER'S LIFEWORLD: A CHALLENGE FOR ADHERENCE

The stigma associated with HIV/AIDS infection, the lack of women's empowerment, and the deficiency of appropriate and culturally sensitive clinical support services, even in facilities providing PMTCT services, means that many women go through their ordeal alone, confused and afraid. (Besser, 2009)

Despite the unique opportunity of access that PMTCT and paediatric care affords, adherence remains a challenge for many women. Certainly, political and institutional factors are significant contributors, but factors particular to the circumstances within which women in South Africa live play a major role. In Africa, burden of disease is impacted on by social and political circumstances such as poverty, conflict, nutritional status, education, distribution of resources and sanitation (Van Rensburg & Ngwena, 2001). According to Habermas's (1984) theory of communicative action, 'system', which is the economy and state that holds power over individuals, can be distinguished from 'lifeworld', which is the individual's framework through which communicative action takes place (Habermas, 1987). Lifeworld concerns that are central to both their HIV positive status and their position as caregivers impact on adherence and according to Habermasian theory, will frame caregivers' discourse. Central lifeworld concerns are summarised in Figure 2.1 below and discussed in more detail thereafter.

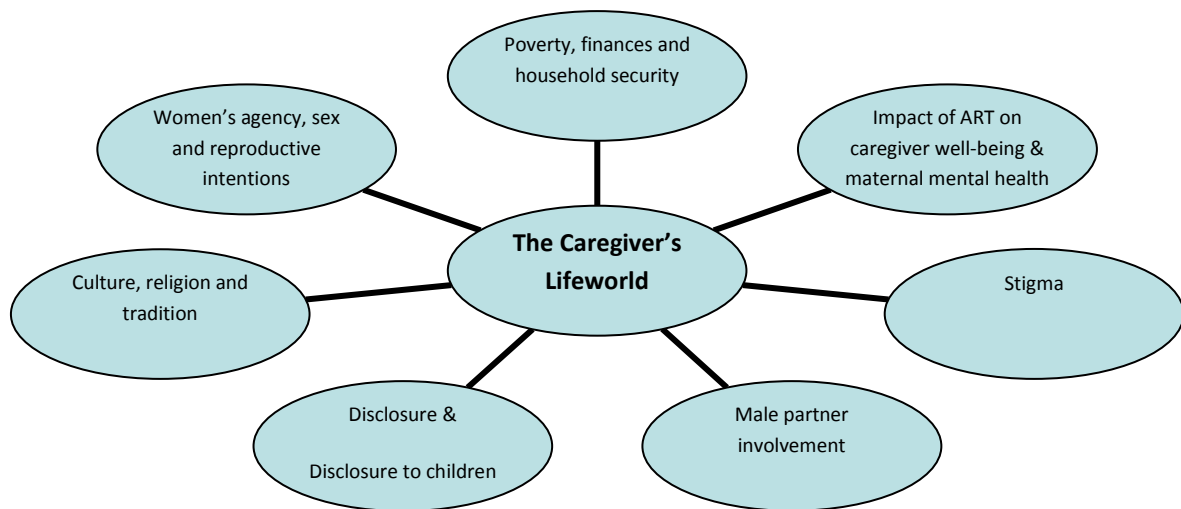


Figure 2.1 Lifeworld concerns impacting on caregivers' adherence to paediatric regimens

2.4.1 Poverty, finances and household security

South Africa has one of the largest Gini indexes in the world, indicating that there are great divides between the rich and poor (Swartz, 1998). HIV is salient at certain moments such as when diagnosed or ill, but for limited periods only, whereas poverty is constant (Brandt, 2007). Household income and not individual income are important predictors of women's adjustment (Brandt, 2007). Living in a household without a stable, predictive income was *as distressing* as being HIV-infected (Brandt, 2007). HIV/AIDS and poverty are cyclical (Whiteside, 2002). Lindegger and Wood (1995) conceptualized poverty as a 'path of least resistance' within which HIV thrives. The poor are more susceptible to communicable diseases such as HIV, due to the existence of malnutrition and parasitic infections (Stilwaggon, 2006 in Brandt, 2007). Poor women are less able to negotiate within sexual relationships as they are dependent on partners for economic reasons (Shisana, 2004).

The cumulative effects of gender, race and socioeconomic status place women at risk for mental health illnesses. Poverty places many women at risk for mental health illnesses by virtue of being black, poor, single parent households, and so HIV is an additional strain on top of this. Poor women are consumed with coping with the everyday demand of putting food on the table, and are unable to save and make contingencies for emergencies or unplanned disruptions to their lives. Negative life events are profoundly disruptive to poor women and an association between women's depression and negative life events has been found (Olley et al., 2004).

2.4.2 Maternal mental health and well-being

Particularly when first diagnosed, HIV positive women experienced the negative, damning social discourses associated with HIV (Rohleder & Gibson, 2006). The literature suggests that ART has a different impact on caregiver quality of life relative to the length of time on HAART. Adherence has also been known to decay with time (Gross et al., 2001) and this poses a particular challenge for ongoing therapeutic support.

Within low and middle-income countries, perinatal mental health is a neglected area of focus (Honikman, Field, Kafaar, Fawcus, & Flischer, 2008). In South Africa, one in three women experience depression during and after pregnancy (Perinatal Mental Health Project (PMHP), 2008). Psychological distress in mothers can have a long-lasting physical, cognitive and emotional impact on children through effects on the foetus and disruption of the maternal-infant relationship (PMHP, 2008).

In Khayelitsha township in the Western Cape for example, the prevalence of postnatal depression is 35% (Cooper, Tomlinson, Swartz, Woolgar, Murray & Molento, 1999); three times the average in developed countries (Warner, Appleby, Whitton & Faragher, 1996). The negative cycle of ill-health and poverty is particularly problematic for women during and after pregnancy. Those most in need of support, have the least access to it (Kopelman, Moel, Mertens, Stuart, Amft, & O'Hara, 2008).

Corrigal et al. (2007) outlined certain 'critical periods', where particular stages of the life-cycle are associated with higher risks for mental illness were identified, namely: early childhood, adolescence, early adulthood, and the peripartum period. In her review of the psychological and psychosocial functioning of women and mothers infected with HIV, Brandt (2007) concluded that the levels of depression and mood symptoms in HIV positive women tended to be elevated in comparison to other women from the same communities. However, evidence of other mental health difficulties was inconsistent and may simply reflect high levels of disturbance independent of HIV status.

Women's perceptions and subjective experiences are more important than objective, measurable characteristics of themselves and their living environment in determining depression and anxiety. Consequently it is the individual's perceptions of their illness, rather than objective health status, that is predictive (Brandt, 2007). No aspect of women's care roles make a significant contribution to poor mental health. However, there is some indication

that caring for an HIV-infected child or an adult with special care needs was associated with greater depression in women. While the demands of other care roles may have been considerable, the normalization of women's care of children within the dominant culture may have rendered these roles taken-for-granted thereby diminishing the extent to which they could potentially undermine women's well-being (Brandt, 2007). A detailed discussion of coping is beyond the scope of this thesis, but can be found in Brandt (2007) as it relates to poverty and HIV.

2.4.3 Stigma

Stigma is defined by Goffman (1963, p.13) as “an attribute that is deeply discrediting” and is defined by society on the basis of what society regards as being different or deviant. As a result, a stigmatised person is one who possesses qualities or characteristics that are different and deviant, creating a “spoiled identity” (Goffman, 1963). Physical deformity, moral transgression and membership in a despised group are identified by Goffman (1963) as the three causes of stigma. In health care, stigma is greatest when the condition is viewed as the responsibility of the individual (Nyblade et al., 2003) or when it is perceived as a threat to society (Gilmore & Somerville, 1994). In the case of HIV, this is both the physical threat of contamination through sex, as well as fear of moral contamination by being associated with PLWHA. Stigmata are physical evidence of the ‘abominations of the body’ (Goffman, 1963, p.14). In the case of HIV positive women, stigmata manifest in symptoms such as weight loss, ill-health and skin rashes. Goffman (1963) states that stigma is more often associated with feelings of disgrace and shame rather than any physical evidence of disease.

Within the context of PMTCT, women are stigmatized threefold, namely as women, as HIV-positive women and as HIV positive pregnant mothers (The PANOS Institute report in Baldassini, 2006). Women's subordinate role in society intensifies the stigma of HIV (Soskolne, 2003). Stigma reproduces existing inequalities of class, race, gender and sexuality (Parker & Aggleton, 2003).

On the surface, many women will state that they experience little stigma in their community, however narrative analysis has revealed highly stigmatised women who struggle against the negative notions of their own self-constructs (Rohleder & Gibson, 2006). This supports Stein's (2003) argument that surveys of stigma do not measure actual incidents of discrimination and that stigmatisation and anecdotal accounts may be a better measure of real stigma.

Different types of stigma have been described in the literature (Uys et al., 2005). External stigma is the stigma from others directed towards PLWHA and is characterized by avoidance, moral judgement, unwillingness to invest in PLWHA, discrimination and abuse. Internal stigma is the response of the PLWHA to outside stigma and results in the PLWHA stigmatising themselves and is characterized by self-exclusion from services, poor self-perceptions, social withdrawal, overcompensation and fear of disclosure. This is also referred to as 'self-stigma'. Secondary stigma is the stigma experienced by those associated with the PLWHA such as family and friends. Perceived stigma is the fear associated with disclosing one's status, whereas enacted stigma involves acts of discrimination.

For people living with HIV, stigma is regarded as being a central force in their lives (Fife & Wright, 2000). Fear of stigma results in individuals hiding their status and appearing to pass as HIV negative (Stein, 1996), which is unsurprising given that HIV positive women or women with STDs are regarded as being deviant and dirty (Shefer et al., 2002). Factors that fuel stigma include fear of contamination (either physical or symbolic), social inequality and differences, fear of societal collapse and the need to protect one's own identity (Campbell, Foulis, Maimane & Sibiya, 2005). Religious beliefs may contribute to stigma as HIV is sometimes interpreted as punishment from God (Nyblade et al., 2003).

HIV stigmatisation is evident in the socially constructed metaphors of AIDS as plague, evil and sinful (Sontag, 1991), and as death, punishment, crime, war, otherness and horror, and the person living with HIV portrayed as villain (Gilmore & Somerville, 1994). Rohleder and Gibson (1996) contended that the prevailing discourse of HIV as sinful, evil and deviant would therefore be incorporated into the identities of people living with HIV. Through narrative analysis of HIV positive women in Khayelitsha, internalized negative social discourses were shown to become part of their self construct. Additionally, these women resisted their stigmatised identity and attempted to "fend off the 'spoiled identity' by splitting off these bad representations and projecting them outside of themselves" by projecting the status of 'bad other' to people who do not yet know their HIV status, and by conceptualizing their own self as consisting of a past, unhealthy self and a present, healthy self (Rohleder & Gibson, 1996, p. 36). Women portrayed HIV as a type of punishment for which they had been 'sentenced' for being dangerous and deviant (Rohleder & Gibson, 2006).

The word 'HIV' is regarded as being unsayable and is often either not mentioned in interactions between health professionals; HIV is referred to as 'it'/'this' disease', or in

euphemistic terms (Almeleh, 2006; Uys et al., 2005; Delbene, 2003). Uys et al. (2005) investigated the names used for HIV in five African countries, because naming reflects the beliefs held by individuals and society. Uys et al.'s research was conducted prior to the advent of mass ARV rollout and needs to be interpreted within the perception at the time of HIV as a certain death sentence. Some of the words used for HIV in South Africa were neutral or factual descriptions (e.g. 'Three letters/ words' (HIV) or letter place such as 'House in Venda' (HIV) or 'Ace' (AIDS). Neutral words are regarded by Uys et al. (2005) as being euphemisms. Other diseases such as TB are used as a euphemism to disguise HIV (Rohleder & Gibson, 2006).

In South Africa, other words for HIV have a more negative slant and are indicative of underlying stigma. Some words used for HIV are related to attributional characteristics on how HIV is transmitted e.g. 'Loose ladies' or 'Prostitutes'. As sexual behavior is a private topic which people find difficult to discuss, it is unsurprising that people have developed oblique terminology when referring to it (Uys et al., 2005). "And yet precisely what privacy means in the midst of an epidemic of shame, is far more complicated than I ever imagined" (Steinberg, 2008, p.8).

Others words used for HIV refer to death descriptions such as 'following time' (referring to a funeral), '*sephamola*' (the snatcher) or 'Eating plastic' for HIV in Malawi, which refers to a well-known danger that goats incur when ingesting plastic. A number of expressions refer to stigmata of the physical characteristics associated with HIV e.g. 'Elongated people'; 'Hair wiped away'; '*Grootoogsiekte*' (Big eye disease). In Swaziland, the lingering nature of the illness is referred to as '*Lutakufane*' (i.e. something with no start or end) and the commonness of HIV is expressed through '*Lombulalave*' (the nation's killer). Uys et al. (2005) described the lowered tones and veiled words used by participants in their study as indicating their fear and awe of HIV. Many of the words used to describe HIV apportion blame to women in particular.

Rohleder and Gibson (2006) recommend that supportive counselling for people living with HIV needs to be aware of this lack of self realization of being stigmatised, and that counselling may assist women in working through their damaged identity. Uys et al. (2005) have made a number of recommendations for health professionals to avoid perpetuating stigma through language. In interactions with patients, factual references should consistently be used for HIV and AIDS. Health professionals should explore the terminology used in particular communities as it will assist with identifying the nature of stigma for particular

groups and can allow for the development of anti-stigma messages. Furthermore, clear articulation of achieving life goals even with an HIV-positive status, is needed.

2.4.4 Male partner involvement

Bwirire et al. (2008) describe the ‘disconnect’ that arises out of mothers and father not having testing at the same time because in Africa, it is rare for men to accompany women to antenatal clinics or during labour. Traditionally men have been perceived as playing an unsupportive role to HIV positive partners. In the South African context, migrant labour, rampant unemployment, and discourses surrounding men and domestic violence have made it difficult for men to live up to the socially defined role of father and breadwinner (Campbell, 1992).

Richter, Manegold, Pather and Mason (2004) have challenged the perception that men are not involved in contributing to children’s well-being, and believe that we are locked into our stereotypes of viewing men as irresponsible, neglectful, abusive and irremediable. Indeed, Brandt’s (2005a) research in a peri-urban context demonstrated that as brothers and heads of households, men are supportive and they play multiple roles in women’s lives either directly to them or through other household members. Another study by Montgomery, Hosegood, Busza and Timaeus (2006) in rural KwaZulu-Natal, has indicated that men were involved with their families and households in a variety of ways, and that they care for patients and children, they provide financial support for immediate and extended family members, and when present at home, enable women to work or they provide support for other households. However, their role in these activities remains unacknowledged by female respondents and field assistants (Montgomery et al., 2006). Montgomery et al. (2006) attribute our perception of men’s roles to the influences of contemporary and historical social, cultural and economic processes. Within the clinical context, male partners remain uninvolved. The perception of clinics as the spaces of women and children dominates. This is a barrier to care as it impacts on the extent to which men support partners in this context. The need for recruitment and training of men as community caregivers has been recognized with the National Strategic Plan (2007 – 2011), and there has been a drive to try to increase male involvement in clinics.

HIV positive women have expressed sadness and loss in the area of relationships as a product of their HIV status and have expressed the feelings that through sex they become dangerous to others (Rohleder & Gibson, 2006).

2.4.5 Disclosure including disclosure to children

‘Silence’ through non-disclosure adds to the burden families face as it can leave parents feeling isolated in facing and dealing with the consequences of being unable to fulfill their dreams of what being a parent might mean. In the face of pervasive stigma, disclosure carries significant risks for mothers and their dependents (Buskens & Jaffe, 2008; Medley, Garcia-Moreno, McGill & Maman, 2004). Fear of stigma results in people living with HIV not disclosing their status to others which in turn impacts on the levels of support they receive (Almeleh, 2006; Hackl, Somlai, Kelly & Kalichman, 1997).

Disclosure is a prominent coping strategy which is informed by the information available to women at the time of disclosure and their individual beliefs (Brandt, 2005a). Disclosure can be a positive means of accessing social support and treatment, potentially reducing AIDS-related stigma, but, importantly, not to disclose can be strategic and allows women to manage the available support (Brandt, 2005a). Strategic non-disclosure can minimize risk and vulnerability and promotes resilience in women (Brandt, 2005a). Disclosure involves balancing the notion of ‘private good’ with ‘public good’ (Brandt, 2005a). In some instances, non-disclosure could be a request from a partner or household head (Brandt, 2005a). Women disclose selectively and deliberately. Non-disclosure is attributed by women to attempts to avoid anticipated stigmatizing behavior and attitudes (Brandt, 2007). The negative consequences of disclosure have potentially negative effects on women’s psychological well-being: Hiv-related stigma predicted depression in women and an association between depression and disclosure, women who had disclosed had fewer symptoms than those who had not.

Whether or not a woman had disclosed her status impacted on the social pressures experienced regarding reproduction (Cooper et al., 2007). Women who were married and who had not disclosed their HIV status felt pressurized to have children to avoid raising community suspicions; women and men who were known to be HIV positive and wanted to have children, was also considered to be socially unacceptable. “Women found themselves particularly pressurized by such attitudes, and this may have acted as a constraint to disclosure of their HIV positive status” (Cooper et al., 2007, p. 281). A list of reasons identified by health professionals from paediatric clinics in sub-Saharan Africa for why they feel that mothers don’t disclose their status can be found in PATA (2007:81-82).

Disclosure of HIV status to children is an under-researched area, particularly within the South African context and it is enmeshed with social, familial and cultural complexities (Lesch et

al., 2007). Generally, disclosure to children is advocated as it is believed that knowledge of HIV status may impact on adherence to ART and influence children's health-related decision-making. However, disclosure presents unique challenges as healthcare workers and caregivers may have contrasting ideas on how much information to divulge to children and at what age disclosure should occur. Health care workers tend to support disclosure whereas caregivers may show some reluctance to do so (Lesch et al., 2007). Recent research has emphasized the importance of the health professional's role in communicating with caregivers as critical to supporting caregiver disclosure to children.

Concern for their children was the most compelling reason for women to confront the implications of their HIV status (Brandt, 2005a). Women reported fear of dying before the child is old enough to care for themselves and having less energy so the child will have to do more for himself (Brandt, 2005a). Mothers often perceive consequences of disclosure as more negative than their children do and no relationship between child adjustment and mother's disclosure of HIV status has been found. Women who had disclosed to their children reported a closer relationship with the child following disclosure (Brandt, 2005a). Rates of disclosure to children range from 28 – 80%.

Most of the reasons given in the literature for caregiver reluctance to disclose are linked to fears of stigma and discrimination (Lewis, Haiken & Hoyt, 1994; Meyers & Weitzman, 1991). There is fear that a child might inadvertently expose the HIV status of other family members or that they might disclose indiscriminately to others (Waugh, 2003). In addition, the disproportionate impact of HIV/AIDS on vulnerable members of society (Lewis et al., 1994; Meyers & Weitzman, 1991), the multigenerational impact of HIV on family configurations (Bor & du Plessis, 1997; Pfaff, 2004), parental guilt regarding mother to child transmission (Cohen, 1994; Lipson, 1993) and the caregiver perception that it is distressing to name the disease (Lipson, 1993; 1994) are other reasons cited in Lesch et al.'s (2007) review on HIV disclosure to children.

In one study, 83% of caregivers felt that the primary caregiver was best placed to disclose, and 16% felt that a health care worker such as a doctor, nurse or counsellor, should do so (Moodley, Myer, Michaels, & Cotton, 2006). Given that many caregivers do not speak the same language as the doctors, it is likely that counsellors will need to support this process either in their role as interpreter, or in counselling consultations themselves. Moodley et al. (2006) recommended that that provision of appropriate biomedical information was needed,

as well as emotional support (for both the child and the caregiver) and practical guidance on when and how best to raise this topic with children. The National Department of Health has made recommendations for disclosing to children and what to say (NDOH, 2005:116) and Lesch et al. (2007) propose a move away from viewing disclosure as a traumatic episode to one in which information is shared on an ongoing basis in a dynamic process-oriented approach. Whilst an individualized approach to suit each caregiver and child's needs is advocated in the literature, the following general communication strategies are recommended: open dialogue in multiple conversations, discussions of who needs to be told before the child is told, and cultural sensitivity towards discussing sexual issues (Lesch et al., 2007).

2.4.6 Culture, religion and tradition

Patient trust in the health professionals and the health care system is shaped by their beliefs of disease causation, medication, treatment and healing (Schaafsma, Raynor & de Jong-van den Berg, 2003). In South Africa, a system of traditional healing operates parallel to the 'Western approach' of the public health care system (Van Rensburg & Ngweni, 2001). Whilst uptake of public health sector services is high, many who access these services retain traditional beliefs about disease and healing, so many needing healthcare access either traditional or Western health services or both (Ellis, 2004; Herselman, 2007). The number of traditional healers in Africa far outnumbers health care professionals and it is estimated that 80% of patients consult traditional healers prior to seeking hospital care (Gumede, 1990 in Watermeyer, 2008). This is particularly the case with sexually transmitted diseases (Van Dyk, 2001). In 1998, regulation of traditional healers began, marking government acknowledgement of the importance of traditional healing (Baleta, 1998). It was hoped that traditional healers would not result in patients delaying accessing services, but that they would work collaboratively with the public health sector instead (particularly in rural areas) in providing support to patients living with HIV (Sidley, 2004; Homsy, King, Balaba, & Kabatesi, 2004).

Individual member beliefs about health and disease may differ considerably within a particular cultural group (Mullin, Cooper, & Eremenco, 1998). Within an African traditional framework, beliefs about disease causation are attributed to the wrath of ancestors and rituals may need to be performed for the purpose of healing (Schapera & Camaroff, 1991). No fixed relationship exists between causes and symptoms (Camaroff, 1981). Some of the causes for illness within traditional medicine may be natural (germs), pollution through ritual impurities (death, reproductive harm, violation of sexual prohibitions), disharmony with ancestors,

failed human relations or witchcraft (Van Dyk, 2001). As HIV does not manifest in symptoms on the genitalia, it is often not believed to be an STD and so HIV is often attributed to witchcraft rather than infection (Van Dyk, 2001).

There is widespread concern that alternative disease explanations may lead to non-adherence of medical treatment or the use of potentially dangerous traditional remedies instead (Levin, 2006a). Patients from all socio-economic groups consult traditional healers. There is concern that the traditional healing practice of treating chronic illnesses with once-off remedies will result in patient unfamiliarity with the Western practice of taking medicines for extended periods (or life long as is the case with ARVs) and that patients may not tolerate side-effects (Burroughs, 2003 in Watermeyer, 2008).

Traditional beliefs about HIV can also be interpreted from the words used for HIV. In Malawi, '*Odwala kanyera*' means someone who has sex with a woman after having aborted (Uys et al., 2005). In addition, the description of 'the living dead' which is used for people with HIV, has interesting connotations as there are strong taboos in some cultures against being in contact with either the bodies or the possessions of the dead giving rise to the question of whether fear of contagion also extends to the fear of magical contamination by the dead (Uys et al., 2005).

Most harmful sexual practices originate in patriarchal societies that promote the superiority of men over women (Shisana, 2004). Circumcision is an example of a traditional custom that has been shown to have positive health benefits. However, other traditional practices that are considered to have potentially negative health benefits, include mixing ARVs with traditional medicines.

Traditional customs extend beyond healthcare to caregiving practices such as infant feeding which has recently gained much prominence in the HIV literature. Prior to the accessibility of ARVs, breastfeeding became discouraged in HIV positive women because of the risk of transmission through breastmilk. However with the proven success of ARVs and PMTCT through exclusive breastfeeding, and given the benefits that this does provide, UNICEF and WHO are once again promoting breastfeeding unless safe and exclusive formula feeding can be guaranteed. The result of the change in message, is that mothers, the public at large and even healthcare workers have become confused about infant feeding. Although it is now well-established that either exclusive breastfeeding or exclusive formula feeding should be selected, the confusion that was created by the mixed messages persists. As a result, the

seemingly contradictory stances of Western and traditional medicine have been emphasized, when in reality, the endpoint is agreement: it is the mother's choice.

In South Africa, provincial populations experience considerable circular migratory patterns (SADHS, 2008) and the legacy of apartheid and labour migration have had a major influence on the patterns of family formation and household dynamics (Montgomery et al., 2006). Anthropologists have studied the impact of these provincial migrations extensively (Spiegel, 1986, 1987; Spiegel, Watson & Wilkonson, 1996;). Both men and women have been shown to be highly mobile, with studies estimating that nearly 50% of all men and 40% of all women aged between 25-29 years are non-resident (Hosegood & Timaeus, 2001 in Montgomery et al., 2006). When men return home from seasonal work to their community of origin, the vulnerability of women left behind increases significantly because wives and other long-term sexual partners find it extremely difficult to insist on condom use when men have been away for so long and have been working to send money back home (Gupta et al., 2003).

In the Western Cape, it is customary for isiXhosa families to visit their relatives in the Eastern Cape for extended periods, particularly over school holidays such as over the December/January 'Christmas' period. In addition, families often have as many as 25% of family members living outside the nuclear family. Grandparents often take care of younger children in rural areas, whilst parents seek work in urban areas. Family composition is fluid and dynamic. These migratory patterns present considerable challenges for continuity of care with ARV adherence as there are disruptions to appointments as well as changes in caregiver.

2.4.7 Women's agency, sex and reproductive intentions

From the results of their study on culture and sexuality of Southern African women, Susser and Stein (2000) recommend that each community needs to be studied independently because of differences in local situations. Communities differ in terms of employment and access to resources for men and women, level of political awareness, and the perceptions of the boundaries of sexual authority for men and for women. Susser and Stein (2000) concluded that women are not helpless victims, but rather active participants in search of a way to protect themselves in sexual situations. However, their methods of sexual negotiation are limited by cultural and historical perceptions of the bounds of the human body.

Reproductive desires are diverse among HIV positive men and women and are modified rather than removed by being HIV positive (Cooper et al., 2007). Naturally, fears of infecting a partner and/ or the infant were deterrents, as well as perceived community disapproval of

HIV and reproduction (Cooper et al., 2007). Many respondents nonetheless reported strong desires to experience parenthood within the prevailing social and cultural norm of South Africa that encourages childbearing and holds motherhood in high esteem. Knowledge of the prevention of perinatal transmission through ART to women, has altered perceptions in favour of childbearing (Cooper et al., 2007). Despite this, most HIV positive women do not discuss reproductive desires and intentions with health care providers in HIV care or general health services because of anticipated negative reactions and “the few who had done so perceived the counselling environment to be mostly unsupportive of open discussion on these issues” (Cooper et al., 2007, p. 274).

In most societies, and in Africa particularly, motherhood is seen as a normative and defining feature of women’s adult lives (Kirshenbaum, Hirky, Correale, Goldstein & Johnson, 2004). Significant social status is assigned to women who bear children, and childlessness carries negative social consequences (Doyal & Anderson, 2005; Sonko, 2004). Factors that promoted desires to have children were the desire for parenthood and to experience pregnancy, that children signify hope and a reason for living (having children signified normality), the desire of individuals to leave something of themselves, social expectations regarding reproduction, strong partner expectations and because family formation is seen as a necessary and natural part of marriage (Cooper et al., 2007). Factors mitigating against desires to have children were fear of unprotected sex, concerns about vertical transmission, fear that pregnancy may damage their own health by hastening disease progression and fears about caring arrangements should participants die. Losing a child to AIDS deterred future child bearing (Cooper et al., 2007).

2.5 RESILIENCE AND SUPPORT FOR WOMEN

“Mothers: Our community’s greatest and most inexhaustible resource” (Besser, 2009)

Despite the many challenges that HIV positive women face, the narratives of HIV positive caregivers reflected continuing engagement with life despite living with HIV (Brandt, 2007). Women are not passive recipients of their stigmatised identity, but actively challenge and try to fend off ideas that others have about them (Rohleder & Gibson, 2006). For many women, HIV can be considered to be part of a cluster of stressors that are related to society and context, less serious than crime, however no different from violence and unemployment (Kalichman & Simbayi, 2003). Although the circumstances within which women live are

similar, there is a great deal of variation in terms of how caregivers are able to manage caring for an HIV positive child. Van Deventer and Radebe (2009, p. 52) remind us that:

... the challenge with providing an optimal service is that each person has their own story and many need individual attention. Without this understanding, and good relationships between personnel and patients, the battle for optimal care within the ART programmes can not be won.

Support for HIV positive caregivers comes from a number of different sources, among them, the family, the community, the health care institution, and the provision of social welfare. Within a traditional African framework, healing occurs within the community and family in a social setting with family members in attendance to support and accept the sick person (Van Dyk, 2001). The stigma associated with HIV, fuelled in part by the medical fraternity's emphasis on confidentiality and the right to privacy, is a significant care barrier as it has resulted in secrecy and a breakdown in support from family members and the community.

HIV positive women have difficulties receiving support from family. Siehnhold (1999) found that women experienced the highest support from medical personnel and the least from their families. People Living with HIV/AIDS (PLWHA) are less likely to receive support from a parent (Sambamoorti, Crystal, & Dermatis, 1995).

Non-attendance of support groups is associated with greater anxiety and depression (Brandt, 2005a). Support groups can provide a better understanding of disease, assess divergent beliefs and attitudes, improve coping skills and inform decision-making.

An additional form of support provided to women is in the form of social welfare through access to government grants. There are many barriers to accessing existing social assistance grants: the poorest have the least access to these grants and accessing child support grants is particularly difficult in rural areas. In the period from 1998 – 2003, there has been an increase in the number of children accessing grants (SADHS, 2008). Provision of social assistance is viewed by the Department of Social Development as the largest poverty alleviation measure undertaken by government and it has been shown to have been highly beneficial for recipients (Corrigal et al., 2007). However, a review of social security in South Africa during 2000-2002 highlights several problems. Among those eligible for social security under the current system there is a large gap between who is eligible and who receives the grant. Reports

indicate the most poor are unable to fulfil these requirements due to insufficient means to pay for the necessary documentation or for transport to the relevant government departments such as the police, home affairs and social services. Furthermore, the number of children in a house is not considered (Corrigal et al., 2007).

More recent research, however, shows that HIV positive women receive better support than HIV negative women in the context of PMTCT (Brandt, 2005b). Caregivers of HIV positive children have better access to social grants as the clinic serves as a point of access for money from government and NGO welfare services.

2.6 SYSTEMIC CHALLENGES IN THE PROVISION OF PAEDIATRIC ART IN SOUTH AFRICA

A number of systemic barriers prevent the effective provision of paediatric ART in South Africa. These include retention in care, a lack of child-friendly services and, most significantly, a shortage of human resources.

An ongoing challenge in the health sector is retention in care. A recent study in France following patients who were lost to follow up (LTFU) indicated that mortality risk was increased five-fold for patients who had returned to care after being lost to follow up than those who were never lost (Walensky 2009). Reasons for LTFU of mothers in PMTCT programmes include not being prepared for HIV testing and its implications prior to attending the antenatal clinic (ANC), fear of stigma, discrimination, household conflict and even divorce on disclosure of HIV status, lack of support from husbands who do not want to undergo HIV testing, the perception that one is obliged to rely on artificial feeding which is associated with social and cultural taboos, long waiting times, inability to afford transport costs and because PMTCT was perceived as benefiting the baby and not the mother (Bwirere et al., 2008). In the context of PMTCT, LTFU was considered to be a product of passive resistance which characterized many infant feeding counselling encounters (Buskens & Jaffe, 2008) which has prompted the call for a need to address these community- and provider-related operational and cultural barriers that hinder the overall acceptability of PMTCT (Bwirere et al., 2008).

Within the Western Cape, there is a need to reduce the amount of time it takes for patients to get onto treatment at sites as patients are easier to manage if treatment is started earlier (it can take 4 to 6 weeks to prepare the patient for starting ART) (Abdullah, 2005). There is a need

for child-friendly services in clinics to make clinic visits more bearable for children, and so that caregivers can feel supported. Clinics need to have a facility that cares for both caregivers and children together. Within the clinic, caregivers need to have a safe place within the clinic where their child can be looked after whilst they see the doctor.

2.6.1 Human resource shortages

The nature of the health system itself can constitute a barrier to access, particularly as South Africa, like many other African countries, is plagued by a shortage of skilled health care workers (Abdullah, 2005). In sub-Saharan Africa, this is considered a crisis due to significant emigration of trained professionals, difficult working conditions, poor salaries, low motivation and a high burden of infectious diseases (Zachariah et al., 2008). Many programmes lack the capacity to provide ongoing education and support to pregnant women (Besser, 2002). In South Africa, there are only 77 physicians and 408 nurses per 100 000 population, with a vacancy rate of approximately 35% of public health sector posts for doctors and nurses (HST, 2007 in PATA, 2009). At current patient loads, doctors have sixteen minutes per patient and nurses have twelve minutes per patient (Besser, 2008 in PATA, 2009). Besser lists the numerous duties nurses need to perform in these twelve minutes in the context of PMTCT. Without additional human resources such as expert patients or mentor mothers, completion of these tasks is just ‘magical thinking’.

Within under-resourced settings, a rigid hierarchy and poor communication between senior and junior health professionals works against community empowerment (Nair & Campbell, 2008). Overburdening in the public sector extends beyond health professionals to other public servants (Nair & Campbell, 2008). Deficiencies in human resources may result in health care workers feeling helpless, powerless, emotionally stressed, fatigued, fearful, angry and frustrated (Rohleder & Swartz, 2005). This impacts on the quality of care perceived by patients as reported in studies on health care worker attitudes. Women reported that fear of judgmental attitudes from healthcare workers prevented them from discussing reproductive options (Cooper et al., 2007).

2.6.2 Task-shifting

The shortage of health care workers has been identified as a threat to universal prevention, treatment and care (WHO, 2008). *Task shifting* refers to the process whereby tasks are delegated to health workers with lower qualifications, either from one group of health care workers to another (e.g. doctors to nurses) or from professional to lay health workers (Philips,

Zachariah & Venis, 2008). For the purpose of this study, both are referred to under the umbrella term of community health workers⁶ (CHWs). Community-based volunteers for directly observed therapy, short course for TB (DOTS) is a well-known example of task-shifting to CHWs (Philips et al., 2008). In South Africa, task-shifting is needed, particularly given the challenges posed by the scale-up of HIV/AIDS care (WHO, 2008).

The WHO's 2006 recommendation for task-shifting as a response to the human resources crises in the health care sector, is the revisiting of the idea of CHWs that gained popularity in response to the 1978 Alma Ata declaration of primary health care for all. Schneider, Hlophe and van Rensburg (2008) provide a comprehensive review of task-shifting and community health workers in South Africa over the last three decades. In the late 1970's and 1980's, success was reported with employment of CHWs at a local level, however problems were incurred with rollout at a national level in developing countries. Some of the reasons cited for this in the literature were poor integration, conflict with health care workers, unrealistic expectations, unsupportive environments, poor supervision, a lack of appropriate training, high turnover, poor quality and poor cost-effectiveness. As a result, CHW's declined in popularity over the next two decades in the context of a severe economic crisis (Abbatt, 2005 in Schneider et al., 2008).

Although a decline in popularity of the idea of CHWs is reported in the 1990's, a number of successful programmes employing CHWs were reported over this period in Brazil, India, Haiti and Rwanda. A characteristic shared by the health care systems in which these programmes were successful, is the presence of strong political support, that the programmes were embedded within communities, CHWs were provided with appropriate training, strong supervision and appropriate remuneration. In programmes in which highly specific tasks were taken on by CHWs (such as TB DOTS and malaria), success was also reported.

It is perhaps unsurprising then given the crippling shortage of qualified health professionals coinciding with the unprecedented scale of mass ARV rollout, that South Africa, along with other countries trying to deal with the HIV pandemic, turned once again to CHWs as a

⁶ After Schneider et al. (2008, p. 181), 'community health care worker' is used as an umbrella term for all community or lay workers in the health sector who are "local inhabitants given a limited amount of training to provide specific basic health and nutrition services to the members of their surrounding communities". In 2004, a National CHW policy framework was adopted in South Africa. Like Schneider et al., in this dissertation it is assumed that CHWs may be unpaid volunteers or paid workers but that they are not professional employees of the Ministry of Health, and may be employed either full-time or part-time.

solution. In recent years, South Africa has seen a resurgence in the trend to employ CHWs in the health and social development sectors, with 62445 CHWs estimated as being employed in 2006 as home-based carers alone (DOH, 2006). In addition to the number of CHWs rising, the number of specialized categories of CHWs has also risen. There has been an emergence of numerous different types of CHWs specific to HIV, for example adherence counsellors, mentor mums, milk moms, peer educators, adherence monitors, defaulter tracers etc. In HIV, an added benefit is that task-shifting allows for greater involvement of peer groups and people living with HIV (Bwirire et al., 2008). In the early days of the ARV rollout in South Africa, international NGO Médecinès sans Frontiers (MSF) proposed that “treatment would only work if animated by a social movement of lay people and ARV users” (Steinberg, 2008, p. 85).

South Africa makes extensive use of lay counsellors who are now considered to be part of the counselling team (Buskens & Jaffe, 2008; Rohleder & Swartz, 2005; Zachariah et al., 2006). They now feature in both the National Strategic Plan (2007) and in medium-term human resource plans for the health sector (NDOH, 2006a in Schneider et al., 2008). In reviewing the policy features of CHWs, Schneider et al. (2008) highlight government avoidance of being the employer of CHWs (Schneider et al., 2008). The unusual position of the South African government funding NGOs to employ CHWs, but not directly employing them themselves, raises questions about the long-term commitment of the National Department of Health (NDOH) to this workforce (Schneider et al., 2008). Although the NDOH pays the salaries of CHWs, they are not regarded as being state employees (but are contracted to NGOs that receive state support to employ CHWs). This roundabout method of employment has been documented as causing (probably legitimate) feelings of being undervalued and unsupported, with CHWs feeling that they lack job security and career path development (Schneider et al., 2008).

“Their status is considered intrinsically inferior by both themselves and other health workers, and relationships with professionals are generally precarious” (Schneider et al., 2008, p. 185). The inferiority invoked by the title of ‘lay counsellor’, highlights their low rank (Rohleder & Swartz, 2005). Rohleder and Swartz (2008) caution that against the backdrop of apartheid, black women (who constitute the largest group of counsellors), who have historically been regarded as inferior, continue to feel as if they are regarded as inferior because of the title ‘lay’.

Schneider et al. (2008) document that even given the existing systemic constraints, CHWs serve an empowering role that serves “as a bridge between patients/ communities and the

health system, creating a voice for people living with HIV, fulfilling identity-related needs, institutionalizing notions of volunteering and building lay knowledge and expertise on health issues. They are often community-oriented if not always community-based” (Schneider et al., 2008, p. 185). Schneider et al. (2008, p. 186) caution against the wholesale incorporation of CHWs into the civil service as the blurring of boundaries between CHWs, volunteers and other participation is not wholly disadvantageous. “The open-ended and dynamic nature of the infrastructure allows for inclusiveness, local flexibility and the expression of a range of different motivations.” They recommend perceiving CHW participation along a continuum, from patient experts, to volunteers, stipended CHWs, mid-level workers and professionals.

WHO’s Treat, Train, Retain (TTR) initiative is proposed as a means of allowing ART roll-out in contexts with human resource shortages (Philips et al., 2008). However, task-shifting poses a new challenge, namely how to maintain quality of care (Philips et al., 2008; Zachariah et al., 2008), addressing institutional and professional resistance (Zachariah et al., 2008), sustaining motivation and performance and preventing deaths from health workers with HIV/ AIDS (Zachariah et al., 2008). Philips et al. (2008) call for the involvement of health staff and policy makers to be involved in setting measurable targets and indicators for what they believe to be an acceptable level of quality care. It is documented that lay workers can do clearly defined tasks, however quality is compromised with every task that is added to the job description (Mullan & Frehywot, 2007, Dvolvo, 2004 & Lewin, Dick, Pond, et al., 2005 in Philips et al., 2008). Thus, it is important “to ensure that new cadres have dedicated responsibilities (i.e. are specialized) are not overburdened or face a progressive increase and diversification of workload” (Philips et al., 2008, p. 682).

Philips et al. (2008) warn that task-shifting alone is not a panacea and on its own, is unlikely to significantly increase ART capacity. Researchers caution against using the employment of lay workers as an excuse for failing to remedy deficient public health services (Philips et al., 2008; Walt, 1992; Zachariah et al., 2008). Philips et al. (2008, p. 684) call for “exceptional measures... to address the current human resource crisis and these [need to] go beyond task shifting alone’. A number of recommendations have been made by Philips et al. (2008), Schneider et al. (2008) and Zachariah et al. (2008) for effective task-shifting have been summarized in Appendix II.

Around the world, a mismatch between the language of the service provider and the patient is an acknowledged barrier to providing quality care. In South Africa, the position of cultural mediator/ interpreter has emerged and has become formalized within the health sector as a

CHW. There are parallels between the institutional difficulties described in the interpreting literature (Drennan, 1999) and those in the CHW literature.

Institutional constraints, and unrealistic role expectations are among the sources of conflict that impact on interpreting performance (Hsieh, 2006). Contextual factors including institutional culture and policies significantly impact on how interpreters mediate provider-patient relationship, treatment choices and cultural conflicts (Kaufert & Putsch, 1997). Institutional factors include the institutional culture, hierarchy, policies, regulations and the environment (space, awareness of the time; doctors in a hurry and patients wanting more time).

There are a number of suggestions for managing role conflict in interpreting (Hsieh, 2006) which may be relevant to other cadres of CHWs. There has been a call to understand the mediated context from the interpreter's perspective, in order for the dynamics of encounters to be fully understood and to examine the interdependence of all the participants' communicative behaviours as well as the larger communicative context, rather than just 'blaming' the interpreter (Hsieh, 2006). Other recommendations include the creation of boundaries, that interpreters need to consciously choose what role to play (i.e. being an advocate when needed) in order to avoid role conflict and the redefining of relationships and identities. Interpreters may have to help define the role for the doctor and the patient (i.e. telling the doctor that he may need to give more examples or telling the patient to tell the doctor all of their problems).

Published evaluations of CHW training programmes are rare (Han, Kim & Kim, 2007; Winangnon, Sriamporn, Senerak, Saranrittichai, Vatanasapt & Moore, 2007). There is a need for research at a local level in order to be able to accurately assess the impact of interventions on CHWs.

2.7 SUMMARY

This chapter section describes how paediatric ART is dependent on the quality of care afforded to women. Given the feminization of the pandemic and the lifeworld of women living with HIV in South Africa, care providers face many challenges in addressing adherence. This is further complicated by a number of treatment complexities particular to paediatric HIV.

Within the health care system itself, human resource shortages constitute a major barrier to providing effective care. Although task-shifting is a formalized attempt to counteract the lack

of trained health professionals in resource-constrained settings and although guidelines exist to promote effective task-shifting, research suggests that the health sector risks repeating mistakes made in previous decades with community health workers. Evidence of these difficulties is also mirrored in recent interpreting literature.

As a result, it is likely that cadres of CHWs such as adherence counsellors, many of whom are women living with HIV, are multiply disadvantaged. The degree to which the tenuous position of CHWs impacts on the quality of adherence counselling merits exploration. Ironically, there may be benefits in the degree of separation between adherence counsellors and the professional health sector in allowing CHWs to explore the patient's lifeworld with greater ease than other health professionals are able to. By analyzing counsellor-patient interactions, we may be afforded a better understanding of the impact of the position of CHWs on the quality of care provided. Furthermore, we may be afforded glimpses of the shared lifeworld of women living with HIV and the impact that this has on adherence.

CHAPTER TWO PART TWO: AN OVERVIEW OF COUNSELLING RESEARCH IN SOUTH AFRICA

2.8 INTRODUCTION

Following on from the previous section which described the context of a feminized pandemic in a health sector plagued by healthcare worker shortages, the second part of this chapter highlights the many challenges adherence counsellors face in coping with the burden of HIV.

This section outlines the health sector response to the HIV care for women and children in South Africa and examines how communication and counselling are addressed in two relevant policy documents, namely the *Guidelines for the management of HIV-infected children: Caring together for life* (NDOH, 2005) and the *National Strategic Plan 2007 – 2011*. The history of counselling within South Africa provides the background to perceived counsellor role conflict which has been identified in research. Studies in three different types of counselling, namely VCT, PMTCT (feeding) and adherence are described with particular attention to the lessons learnt from intervention studies in these fields. The adherence counsellor job description from the Department of Health and models of counselling in the Western Cape are described to provide the policy context for examining counselling interactions and the attention to language and communication issues within local research.

This chapter will argue that communication specific research is lacking in HIV counselling, and that existing counselling research does not utilize methods that are appropriate for examining the interactional process within a multilingual, multicultural context.

2.9 THE HEALTH SECTOR RESPONSE TO HIV CARE FOR WOMEN AND CHILDREN IN SOUTH AFRICA

As a result of apartheid, the South African health care system was fragmented and there were gross inequalities in services (SADHS, 2008). After political stalling, provision for antiretroviral (ARV) rollout in the public sector was finally approved in South Africa in 2003 (Nattrass, 2006). Recently, a number of guidelines and legislation on the management of HIV in women and children in South Africa have been published. Among these are the *Guidelines for the Management of HIV-infected children: Caring together for life* (National Department of Health (NDOH), 2005), and the *National Strategic Plan 2007 – 2011* (NSP, 2007). Although many other useful guidelines exist, the 2005 NDOH guidelines and the 2007 NSP are the most relevant and were reviewed to establish what counselling provisions have been

made for children and caregivers, and what attention is given to communication issues within these guidelines.

2.9.1 Guidelines for the management of HIV-infected children: Caring together for life (DOH, 2005)

This manual was developed in 2005 by clinicians and members of the South African National Paediatric HIV and AIDS consensus team at the request of the Chief Directorate for HIV and AIDS, STIs and TB. It covers general guiding principles for management of HIV in children, the clinical features of HIV-infection and related infections, caring for exposed and infected children, nutritional support, palliative care, ART, adherence, counselling and disclosure among other topics.

Within the guide, the importance of counselling caregivers of HIV-infected and uninfected children is emphasized. Vigilance and accurate counselling of caregivers is recommended at every visit to the primary healthcare centre (NDOH, 2005, p. 20). The guide clearly positions counselling as integral to the management of all children affected by HIV, and the onus is placed on the health care provider to ensure appropriate counselling. “Even though the counselling task can be delegated to a lay counsellor, the health care provider must make sure that the essential psychosocial issues have been dealt with appropriately” (NDOH, 2005, p. 25). Exit interviews after lay counselling are specified in order for the counsellor to convey all of the essential information to the health care provider. Counsellors should feed back to the rest of the therapeutic team, to get a better profile of patients and their environment (NDOH, 2005, p. 100).

The guidelines recognize that care and support can be provided at a primary level and recommend that when referral is needed, a clear explanation of the child’s illness, a referral letter and a follow-up plan are provided. Counselling is prescribed as part of the ongoing support for parents and caregivers of children on ART (NDOH, 2005, p. 79). Effective and informative counselling services need to be operational within the health-care system as a requirement for ART to be implemented (NDOH, 2005, p. 79). As adherence does not correlate with gender, cultural background, socio-economic or education level, or language barriers between provider and patient, it is not possible to predict which caregivers will adhere well. Therefore, all caregivers require a comprehensive plan to support adherence, particularly as adherence decreases as time progresses (NDOH, 2005, p. 96).

Caregiver information needs are recognised, and the guide specifies that all caregivers of children in outpatient care need to know the clinical features requiring urgent attention by a health care provider. Counselling of the mother at routine visits is recommended, during which potential common HIV-related features in both the mother and child need to be brought to the mother's attention. It is a pre-requisite for commencing ART that caregivers understand that a responsible individual and a treatment supporter must administer the drugs daily on a long-term basis, that ART is life-long therapy, the prognosis of the condition, the side-effects of the medicines and their mode of action (NDOH, 2005, p. 80). Social criteria which are important in ensuring the success of ART, recommend disclosure to another adult living in the same house (NDOH, 2005, p. 81). It is recommended that the caregiver's health and that of other family members is enquired about, that all family members have access to medical care, and that wherever possible, HIV-positive mothers and children receive medical attention at the same time and in the same facility (NDOH, 2005, p. 82).

In providing counselling and support, the guide recommends that health professionals should be trained in counselling, which should be available at all clinics. The role of NGOs, CBOs and traditional healers in providing counselling and support for PLWHA is recognized and health professionals are encouraged to establish a network of local support organizations and to refer patients whenever appropriate (NDOH, 2005, p. 22). Training is also recommended for all healthcare team members regarding ART and adherence and should be offered and updated periodically (NDOH, 2005, p.97). Intensified counselling and support are recommended with sub-optimal adherence (NDOH, 2005, p. 97). Appendix I summarises the types of counselling recommended in children on ART in the 2005 NDOH guidelines.

Good communication and strategies for ensuring good communication are surprisingly not specifically referred to. However they are implicit in the recognition of the caregiver's and the child's right to participate in activities and decisions that affect them and in the guiding principles of being compassionate and showing empathy, maintaining confidentiality, establishing clear two-way communication and involving all health care personnel and caregivers in important patient care decisions. Cultural and linguistic appropriacy of communication are also not explicitly mentioned, however are implicit in the principle of not discriminating.

Good clinician-patient communication is also implied in the recommendation that "supportive and non-judgmental attitudes and behaviours will encourage patient/ caregiver honesty about

adherence and problems” (NDOH, 2005, p. 97). Furthermore, in the pre-test counselling recommendations, reference is made to asking questions in a sensitive manner, finding out how much the patient already knows, offering information, discussing the client’s possible responses and an awareness of the patient’s concerns (NDOH, 2005, p. 112). In the post-test counselling, good communication strategies that are referred to include having a face to face encounter when giving results, familiarisation with patients details prior to meeting with the patient, allowing the patient to express emotion, allowing time for silence for bad news to be absorbed, the potential for confusion as a result of the ELISA test not reflecting the infant’s status and the window period, communicating clearly and gently and dealing with immediate feelings, giving the client time to understand and discuss the result, providing information in such a way that the client can understand, encouraging the asking of questions and supplying written information (NDOH, 2005, p. 14).

The guide recognised that in the initial rollout of ART, children would be cared for in accredited units, which were likely to be tertiary institutions. However, as the programme expands, so stable patients would be referred to primary care facilities where the necessary expertise, drug stocks and nutritional support were available (NDOH, 2005, p. 78).

2.9.2 The National Strategic plan (NSP) 2007 – 2011

The NSP was finalized in 2007 under the direction of the South African National AIDS Council (SANAC). The children’s sector and the women’s sector comprised two of the seventeen civil society sectors represented at SANAC. The NSP is an intersectoral response to HIV/AIDS which emphasizes the importance of a more collaborative and holistic approach to addressing HIV/AIDS. The two over-arching goals of the NSP are to reduce the number of new HIV infections by 50%, and to provide an appropriate package of treatment, care and support to 80% of all people diagnosed with HIV, and their families (Children’s Rights Centre, 2009). The Children’s Rights Centre has published a useful resource for individuals and organizations working with children, titled *What does the National Strategic Plan on HIV and AIDS mean for Children?*

In addressing the treatment needs of children, the NSP acknowledges the research by Violari et al. (2008) in showing that administering ART in HIV positive infants immediately after diagnosis reduces the chance of a child dying by 76 % (rather than waiting for their CD counts to drop or other symptoms to appear). The NSP makes provision for access to free, quality health-care in a child-friendly setting; early diagnosis of HIV infection and regular

CD4 count monitoring; the provision of ART where indicated; prophylaxis and treatment of opportunistic infections; monitoring of adherence and rapid follow up of young patients who discontinue treatment and treatment to keep caregivers alive and healthy for as long as possible.

The Children's Rights Centre (2009) has identified a number of ways in which the NSP treatment component needs to be strengthened. It recommends that sites need to be accredited for treating both adults and children and that mothers and babies need to be treated together, that support to parents needs to be enhanced to ensure compliance with treatment programmes, that monitoring the nutritional status of infants on formula feeding is needed as formula is often shared with others in the family who require nutritional support, and that resources to assist with the disclosure to children need to be developed.

In addressing the issue of care and support for children, counselling is specified in the NSP provisions of paediatric palliative care, nutritional support, psychosocial support and counselling. It sets targets for providing psychosocial support for children and adolescents including counselling for bereavement, disclosure, adherence and sexual aspirations, as well as increasing the number of districts with accessible social and mental health services.

Similarly to the guidelines for ART for children (NDOH, 2005), the NSP recognizes the role of CBOs and NGOs in providing counselling support. Provision is made in the NSP for recruiting and training new community caregivers and CHWs, in ensuring that all community caregivers receive nationally determined stipends, that standards and career pathways for community caregivers as mid-level workers according to the national qualification framework and that the support, mentoring and supervision of community caregivers is strengthened.

In reviewing these guidelines, it is evident that considerable resources and effort have been spent to prepare positive policy frameworks, however few of them specifically address communication issues, yet this surely lies at the heart of prevention and effectiveness.

2.10 HIV COUNSELLING IN SOUTH AFRICA

Counselling has long been recognized as important to the prevention of HIV and in providing support to those affected by the disease. Right from the start, the centrality of counselling to the government's response to HIV was touted. Counselling is recognized as an important component of HIV/AIDS care and is essential in South Africa given the burden of disease (Rohleder & Swartz, 2005) and the growing demand for ongoing counselling to alleviate the psychological stress. Within the South African public sector, it is common practice for lay

counsellors who are trained by non-government organizations to work alongside health professionals (Rohleder & Swartz, 2005; Evangeli et al., 2009).

In the early 1990's, NACOSA developed a national HIV/AIDS counselling strategy (Nulty & Edwards, 2005). Subsequent to this, the lay counsellor project was established in 1996 to train counsellors across the country. Minimum training standards, ongoing in-service training, regular support, supervision and mentorship were specified in the manual for training HIV/AIDS counsellors.

In 1998, the Department of Health Provincial Government of the Western Cape (DOH PGWC) entered into a partnership with specific NGOs such as Lifeline⁷. Since then the Department has continued to fund NGOs who select lay persons from within the communities they serve and refer them to training-accredited organizations such as the Aids Training Information and Counselling Centre (ATICC). In the Western Cape, more than 500 counsellors are employed in partnership with the Department of Health in the Western Cape (C. Jacobs⁸, personal communication, 1 March 2009) and many others may be working with NGOs.

In 1999, Richter and colleagues conducted an audit of counselling services across the country. The audit concluded that counselling is based on two competing and incompatible formats, namely non-directive client centered counselling versus a health educational approach (Richter, Durrheim, Griesel, Solomon & Van Rooyen, 1999) and this has been supported in more recent studies (Buskens & Jaffe, 2008). At the time, the majority of HIV/AIDS counsellors in South Africa were fulltime nurses or lay counsellors, most of whom had received VCT training of one week's duration (Richter, van Rooyen, Solomon, Griesel & Durrheim, 2001). Of concern back then, was that organisations lacked supervisory frameworks to support counsellors and there was a lack of attention to data collection that could be used to evaluate the service (Richter et al., 2001). In addition, Richter et al. (1999) found that counselling was provided in an educational rather than a client-centered model, is predominantly a once-off encounter, gender issues are difficult to discuss with male counterparts when counsellors are female, and many counsellors themselves cannot live by the advice they are giving patients (issues such as disclosure, communication with partner about sexual risk and protection and use of condoms).

⁷ *Lifeline* is a NGO that operates in South Africa and provides counselling for bereavement, trauma, HIV/AIDS and children amongst other issues. More information is available on www.lifelinewc.org.za.

⁸ C. Jacobs is the ATICC manager and Deputy Director of the HIV/AIDS/STI and TB Directorate

Furthermore, Richter et al. (1999) found that South Africa was underserved by counselling services and that there was high expectation of the role of Voluntary Counselling and Testing (VCT), particularly as services were thinly stretched. Limited support and mentoring was available for counsellors and that counsellor training did not prepare them for group and community-based interactions. Nursing and lay counsellors were not shown to differ in level of competence (Richter et al., 1999) however more recent counselling interventions showed lower baseline communication levels for counsellors, and less improvement than their nursing counterparts (Mash et al., 2008). Richter et al. (1999) described how, in practice, counselling has come to extend far beyond the traditional role concept, and counsellors provide welfare services which are unavailable from other sources.

The absence of welfare provision in SA at the time of the evaluation, led Richter et al. (1999) to conclude that HIV/AIDS counsellors were a *de facto* welfare response. In addition to the planned interpersonal encounters between counsellors and patients, counselling appeared to cover a multitude of interventions, further complicating evaluation methodologies. Within the South African context particularly, Richter et al (1999) identified counselling activities as ranging from negotiating access to health services, liaising with landlords and employees about work and accommodation in the face of discrimination, providing support to families and attempting to link families with NGO support. Poverty was identified as a major contributing factor.

Within this audit, lack of exploration of alternative approaches to traditional one on one counselling was identified. However, whilst most counsellors endorsed the need to move beyond individual counselling, they were still trained in this way, and lacked the skills to do group and community work, and the constraints of the medical setting itself may have prevented this (Richter et al., 2001).

Richter et al. (2001 p. 154) cautioned against “counselling being inappropriately assigned responsibility for the major proportion of all non-medical services in response to the epidemic, including welfare support” and identified a need to address structural interventions to co-ordinate, expand and deepen counselling across all sectors, as well as setting clearer goals for counselling and its functions, and the clarification of welfare, psycho-social and medical services, along the continuum of care. Almost a decade later, these same sentiments have been echoed in the task shifting literature (Zachariah et al., 2008).

In response to this audit, a number of studies have examined different aspects of HIV counselling within South Africa and neighbouring Southern African countries. The following

issues have been examined in the literature: The experiences and needs of nurse counsellors (Nulty & Edwards, 2005); counsellor perceptions of their role and work (Rohleder & Swartz, 2005; Hendricks, 2008); how the perceptions and experiences of PMTCT participants could be used to improve feeding counselling (Buskens & Jaffe, 2008); assessment of the quality of VCT (Chopra, Doherty, Jackson & Ashworth, 2005); interventions to improve the quality of counselling using motivational interviewing (Baldassini, 2006; Mash et al., 2008; Evangeli et al., 2009) and a description of counselling styles used based on conversational analysis (Rust, 2005).

HIV/AIDS counselling is a relatively new aspect of health care, and it poses new challenges and complexities to the health care system. Lay counsellors have far less formal training than health professionals, they have no formal hierarchy within the workplace, and their position of having no functional referral network and being isolated from mainstream services, is emotionally challenging and stressful (Rohleder & Swartz, 2005). Previous studies have documented how an undefined role is stressful for other ad hoc health care workers such as interpreters (Drennan, 1998). It is well-documented that support is needed for these HIV/AIDS counsellors, but it is unclear about how the health care system should interact in the provision of this support (Rohleder & Swartz, 2005).

Van der Walt and Swartz (2002) caution that counselling as an 'add on' to existing health care structures may be insufficient to meet the emotional needs of patients or have the desired impact of behavioural change. Burnout from staff is evident in nurses who take on counselling duties in addition to an already demanding workload (Seidel, 1996 in Nulty & Edwards, 2005). As many as 19.1% of nurse counsellors in a study reported that they did not feel supported in this role and requested mentorship (Whiteley & Mdzeke, 2002 in Nulty & Edwards, 2005). Considering the recognition that is given to the importance of counselling and the length of time that counsellors have been part of the HIV response, as well as the lessons learnt from community health workers over the last two decades (Schneider et al., 2008) it seems surprising that counsellors remain poorly paid, unappreciated, and hold little status within the health sector. The very labeling of them as 'lay' workers or 'volunteers' given the demands of their job and the length of time that many of them have been working as counsellors, is demotivating. With the exception of Rohleder & Swartz (2005) there has been a notable lack of attention to the organisational and institutional issues which are faced by counsellors and counselling programmes within the HIV/AIDS arena.

Lessons should have been learnt from experiences with other cadres of ‘lay’ workers (e.g. interpreters and community health workers). However, counsellors continue to receive limited training and support and their status in the health care system remains tenuous despite concrete recommendations from the task-shifting literature (Schneider et al., 2008; Zachariah et al., 2008; Philips et al., 2008). As a result, the common counselling discourse in South Africa is centered on the inadequacy of counselling services as expressed by researchers, other health care workers and patients, and this is mirrored in counsellor feelings of dissatisfaction with untenable working conditions.

Significant weaknesses have been identified in counselling services at PMTCT sites (Chopra et al., 2005). Counselling service capacity, infrastructure, referral and support system deficiencies have been identified by managers (Buskens & Jaffe, 2008; Baldassini, 2006). Documented obstacles to effective counselling include a lack of support within the health hierarchy and the low position of counsellors within this hierarchy, leading to a lack of continuity of care resulting in mixed messages being given to patients (Baldassini, 2006). Counsellors felt that they were used by health workers higher up the hierarchy as a way of disposing of HIV related patients who were generally stigmatized within the health care system (Baldassini, 2006). Even when change has been effected with counsellors across a number of indicators, success has been limited with clinic management (Baldassini, 2006).

Lack of knowledge and confidence about risks of vertical transmission could be one cause for the poor performance (Chopra et al., 2005). Counsellors were confused about the key messages they should be conveying (Chopra et al., 2002). Research shows that counsellors suffer from stress, depression and burnout (Buskens & Jaffe, 2008). Counselling has been described as being far more stressful than nursing, and this has been attributed to role overload and conflict (Nulty & Edwards, 2005). Poor continuity of care and once off sessions with no provision for follow-up made it impossible for counsellors to determine the effectiveness of their sessions (Nulty & Edwards, 2005). There is conflicting evidence regarding counsellor motivation. Buskens and Jaffe (2008) like Richter et al., (1999) felt there was every indication that counsellors were motivated to care and succeed despite facing significant challenges.

2.11 COUNSELLOR ROLE CONFLICT

Counsellors experience difficulty in integrating the different demands of the counsellor role. The literature documents two different tensions within the health care system that contribute

to counsellor role conflict and negatively impact on care, namely: A holistic approach within an outcomes-driven health sector, and non-directive client-centered counselling within a health educational model.

2.11.1 A holistic counselling approach vs an outcomes-driven health sector

In reflecting on the many approaches to HIV/AIDS counselling (client-centered techniques, cognitive behavioural therapy, psychoanalysis and health education), Rohleder and Swartz (2005) conclude that regardless of approach, all of these methods emphasise the importance of a trusting, confidential and respectful relationship between counsellor and client and this is reiterated in the literature (Abdullah, 2005; Godin, Cote, Naccache, Lambert & Trotter, 2005). Rohleder & Swartz (2005) found a clash between a holistic counselling approach followed by counsellors working within a task-oriented health system. Their results suggest a need to consider workplace issues in planning and researching volunteer counselling and testing (VCT).

Rohleder and Swartz (2005) found that nurses tended to adopt a task-oriented approach in counselling. This technicist approach to primary health care may be at odds with the goals of patient empowerment and comprehensive care which are central to patient-centered care (Petersen & Swartz, 2002 in Rohleder & Swartz, 2005). There appears to be a discrepancy between nurses prioritising patient education and testing, and counsellors prioritizing the provision of emotional support. Nurse counsellors themselves reported role conflict in balancing a palliative/ curative role pre ARV rollout (Nulty & Edwards, 2005).

There are contradictions in the literature regarding what constitutes good counselling, as *good* counselling is framed in some studies as being successful when women are convinced to do what the counsellor wants, such as consenting to testing and disclosing their status (de Paoli et al., 2002 in Buskens & Jaffe, 2008). In discussing the pressure for counsellors to meet the outcomes challenge driven by the health sector, Buskens and Jaffe (2008) caution that it is problematic for counsellor success to be framed in terms of outcomes that are beyond their control, particularly as mothers' decisions are deeply rooted within their personal context, psyche and identity (Buskens & Jaffe, 2008). As success will inevitably be limited, this will lead to counsellors feeling disheartened. Evidence of this could be found in some counsellors expressing helplessness in awareness of the rift between health care agendas and the realities of mothers' choices (Buskens & Jaffe, 2008).

Researchers have found that it is not just the counselling itself that is at odds with an outcomes-driven approach. Interventions such as Brief Motivational Interviewing (BMI)

which emphasizes empathy, respect and collaboration, were also been viewed by counsellors to be at odds with an outcomes driven health system (Baldassini, 2006).

2.11.2 Non-directive client-centered counselling versus a health educational model

Following on from the finding of Richter et al. (1999) that the non-directive client-centered approach is incompatible with a health education model, numerous researchers have echoed this (Buskens & Jaffe, 2008; Nulty & Edwards, 2005). Unrealistically, counsellors are expected to provide therapeutic personal encounters as well as preventative care and support including welfare services (Buskens & Jaffe, 2008).

The format held as ideal for HIV/AIDs clients is based largely on psychotherapy designed for the process of mental healing over time and later modified to broader applications and should be open-ended, non-directive and client-centered (Egan, 1982; Rogers, 1951). However, the HIV/AIDS counselling literature indicates a predominantly narrow and biomedical orientation. So although it is acknowledged and claimed that counselling is 'client-centered and open-ended', counsellors tend to be directive and health advising (Buskens & Jaffe, 2008). Buskens and Jaffe (2008) propose that such a format can be a powerful spiritual support however caution against its application as it is time consuming and is not designed for significant information transfer. They propose that in contexts other than infant feeding choice, it may be appropriate, as mothers are also grieving the loss of uncontaminated health, identity and status as well as the loss of unconditional acceptance by family and community (Buskens & Jaffe, 2008). In honoring the agendas of both mothers and the health service, Buskens and Jaffe (2008) caution that counsellors and others do not engage in an effective dialogue. Consequently, the counselling format itself impacts negatively on the potential of mothers and counsellors to communicate effectively.

In translating a Rogerian client-centered approach to the South African context, we need massive human resources of skilled counsellors, who have time to counsel; patients that return for follow up appointments, and it presupposes that patients have choice which may have limited application within a patriarchal society. Furthermore, there is the assumption that patients want to change behaviours and that counsellors want to effect this change.

Despite evidence that there is little relationship between acquiring information and behavior change (Miller & Rollnick, 2002), counselling in South Africa has been characterized as ineffective and adopts an informational or directive approach (Chopra et al., 2005, Buskens & Jaffe, 2008 in Mash et al., 2008). An informational approach is defined by Mash et al. (2008,

p. 54) as “the delivery of predetermined packages of information with a belief that educating the client will lead to the desired decisions and behavior change”. A directive approach involves the counsellors using their authority “to tell clients what they should do and what is best for them” (Mash et al., 2008, p. 54).

In the context of infant feeding, Buskens & Jaffe (2008) demonstrated a rift between counsellors and mothers with regards to programme purpose, implications, logic, functioning and content which forms the subtext of what is hidden and not said in infant feeding encounters, but what nonetheless drives the interaction resulting in incompatible counselling formats. Some encounters started out as open-ended and client-centered, however soon reverted to prescriptive health education mode with counsellors directing streams of information to patients with “scant regard to the meaning made of the information or the implications of clients’ interpretations” (Buskens & Jaffe, 2008, p. 342)

Skilled therapists can be effective in encouraging people to do or be better (Ellis, 1994 in Buskens & Jaffe, 2008), and this, when combined with a high expectation that clients will change, can lead to a good impact on behavior outcome (Leake and King, 1977 in Buskens & Jaffe, 2008). Significant behaviour change is unlikely to occur from attempts to persuade mothers and so following a nondirective format in counselling is ineffective to enable mothers to exercise or adhere to their feeding choice (Moore, 2003, 2005 in Buskens & Jaffe, 2008). This is the premise behind a number of studies examining the application of motivational interviewing to HIV counselling. “Confrontation, persuasion or perceived coercion is more likely to demoralize and inhibit change or elicit client withdrawal, reluctance or resistance (Egan, 1982 in Buskens & Jaffe, 2008, p. 343). Mothers’ behaviors are determined by their specific context and challenges, both personal and traditional (Buskens & Jaffe, 2008).

2.12 Types of HIV counselling

A number of recent studies have explored the quality of HIV counselling in Southern Africa. These studies have focused on counselling in PMTCT, feeding options, VCT and adherence counselling.

Within South Africa, two main clusters of studies exist; namely those describing the quality of counselling, and those describing interventions to attempt to improve counselling. The vast majority of these examine the application of MI to HIV counselling. MI is designed for conversations about behavior change specifically. Key components of MI are collaboration,

evocation and respect for autonomy (Miller & Rollnick, 2002). A thorough examination of motivational interviewing is beyond the scope of this dissertation, however numerous resources explore MI in more detail (Rollnick, Miller & Butler, 2008). MI efficacy has been demonstrated in alcohol and drug abuse populations, as well as in smoking, diet and exercise, hypertension, eating disorders and diabetes (Dunn, Deroo & Rovara, 2001, Hettema, Steele & Miller, 2005 in Evangelini et al., 2009). In HIV, the application of MI has been examined for improving patient adherence (Diloriro et al., 2003; Golin, Earp, Tien, Stewart, Porter & Howie, 2006; Parsons, Rosof, Punzalan & Di Maria, 2005), in HIV risk reduction in HIV negative and positive populations (Naar-King et al., 2006); in reduced sexual behavior in clients attending an STI clinic (Simbayi, Kalichman, Cain, Cherry, Jooste & Mathiti, 2006); in examining specific client behaviours and HIV client outcomes (Thrasher, Golin, Earp, Tien, Porter & Howie, 2006) and on the effect of MI training on counsellor behavior (Mash et al., 2006; Baldassini, 2006).

The VCT and PMTCT studies conducted in South Africa are summarized in Table 2.3 and Table 2.5 respectively and then discussed in more detail thereafter.

Table 2.3 A summary of the research aims, sample, context, analysis methods and key findings for South African VCT studies

Research & Aims	Sample & Context	Analysis Methods	Key findings
Richter, Durrheim, Griesel, Solomon & Van Rooyen, 1999 ; Richter, Van Rooyen, Solomon, Griesel & Durrheim, 2001 Audit of counselling	17 sites in 9 provinces of Southern Africa	Desktop review, survey of services, site visits, interviews with managers and counsellors and counselling sessions with simulated clients	SA is under-served by counselling services. High expectations of the role of VCT, however services are thinly stretched. Concept of ‘counselling’ extends far beyond traditional perception of one on one interactions: Counsellors provide welfare services unavailable from other sources. Limited support and mentoring for counsellors. Counsellor training does not prepare them for group and community-based interactions which are needed
Nulty & Edwards (2005) To document the experiences and needs of nurse HIV/AIDS counsellors at a small South African hospital	4 nurse counsellors and the co-ordinator of HIV services at the hospital in 3 semi-structured interviews Eastern Cape, SA	Qualitative, descriptive narratives From successive tape-recorded semi-structured interviews	HIV/AIDS counselling is emotionally demanding and there were a number of significant problems: confidentiality, stigmatisation. Emotional responses to informing clients of their HIV positive status, cultural and contextual factors and situational stressors of the work environment. Counsellors felt insufficiently supported by work infrastructure.
Rohleder (2003); Rohleder and Swartz, (2005) To explore counsellor accounts of their unclear position on their work	29 counsellors at Lifeline, Khayelitsha, Western Cape, SA	Qualitative Individual interviews and focus group discussions	There is a clash between a holistic counselling approach & a task-oriented health system. Workplace issues need to be considered in planning and researching VCT. Workplace problems reported. Distressed clients were passed on to counsellors leading to feelings of inferiority and anger towards those in higher job positions. A lack of designated counselling space and the importance of privacy were highlighted.

2.12.1 Voluntary Counselling and Testing (VCT) research in South Africa

In South Africa, counselling services in the public sector have traditionally been focused on VCT (Van Dyk, 2001) and there is a tendency for counselling to be a once-off pre-test encounter (Nulty & Edwards, 2005). Much of the research into counselling in HIV/AIDS has focused on the efficacy of VCT with mixed results (Higgins et al., 1991; Weinhardt et al., 1999; Allan et al., 1992; Buwalda et al., 1994; Heyward et al., 1993; Kamenga et al., 1991; Meursing & Sibindi, 2000; Muller et al., 1992; The Volunteer HIV-I Counselling and Testing efficacy group, 2000 in Rohleder & Swartz, 2005). VCT programmes are beset by institutional and social barriers (Coovadia, 2000).

In addition to the audit by Richter et al. (1999), Nulty and Edwards (2005) and Rohleder (2003) examined VCT counselling from interviews with counsellors and colleagues as summarized in Table 2.3. Nulty and Edwards (2005) interviewed nurse counsellors and the co-ordinator of HIV services at a hospital in the Eastern Cape province of South Africa, which is one of the most impoverished and under-resourced areas of South Africa. The findings highlighted topics that are difficult for counsellors to discuss, factors contributing to counsellor burnout and cultural issues. Counsellors found it difficult to discuss issues cross generationally. Difficult-to-discuss topics were material poverty, rape, sexual activity in youth, 'negligent' sexual behaviours, disclosing a positive diagnosis to a client, dying, fears of patient suicide and loss to follow up (Nulty & Edwards, 2005).

Factors contributing to counsellor stress and burnout were the discussion of issues about which counsellors held strong feelings and the difficult to discuss topics mentioned above. Confidentiality was contentious and caused counsellors to feel stressed as it posed ethical dilemmas (such as not confiding to a spouse when both were counselled by the counsellor) or if an individual was well-known to counsellors. Counsellors tended to identify with patient feelings and were unable to 'switch off' and kept thinking about patients out of working hours. Severe work overload and poor continuity of care with patients receiving diagnosis and pre-test counselling from different nurses was stressful as were once off sessions with no provision for follow up sessions (Nulty & Edwards, 2005). Cultural factors raised by counsellors include that many people attributed HIV infection to witchcraft and so sought help from traditional healers (Nulty & Edwards, 2005). Recommendations made by Nulty and Edwards are summarized in the Table 2.4. Communication does not feature as a recommendation.

Table 2.4 Recommendations for supporting counsellors made by Nulty and Edwards (2005)

1. Suitably qualified person, independent of the hospitals need to be employed to facilitate regular support meetings (Jenkins, 1997 in Nulty and Edwards, 2005).
2. Counsellors need regular supervision with an experienced counsellor, preferably a psychologist (Bond, 1995; Nulty and Edwards, 2005) in order to manage the balance between prescriptive and client-centered modes and address sensitive issues such as sexual practices and inaccurate beliefs about HIV/AIDS and to enhance counselling skills, improve confidence and diminish job-related stress. Managers are not qualified to provide this supervision (Gerber, 2000 in Nulty and Edwards, 2005).
3. Counsellors need ongoing in-service training (Miller, 1995 in Nulty and Edwards, 2005). Specific areas identified by Nulty and Edwards include: counselling older people without transgressing cultural customs, dealing with explicit sexual matters, interfacing with traditional beliefs with respect to bewitchment and dealing with the ensuing mistrust and suspicion which these beliefs may engender, training in couple and family counselling, addressing clients' fears and concerns around dying, death and bereavement and keeping updated with ongoing developments concerning the medical management of HIV.
4. A forum is needed in which counsellors can air their concerns to managers (Miller, 1995 in Nulty and Edwards, 2005). Nulty and Edwards recommended that interruptions, switching off phones during sessions, not working with clients who counsellors know well, expanding the service to provide ongoing counselling, unbarring counsellor access to phones and formal recognition of the role they play also needed to be addressed in consultation with managers.
5. Implementation of the above for ongoing research into the effectiveness of different interventions and morale of the counsellors. Research needs to address the evaluation of the counselling offered to clients (Richter et al., 2001; Nulty and Edwards, 2005). Call for clients' evaluations of the counselling they received as well as an investigation into the need for follow up counselling.

The study also found that counsellors felt unappreciated by other staff and hospital management. Practical problems such as access to telephones and mail heightened this sense of not being trusted and appreciated and were barriers to following up patients. Interruptions to counselling sessions were frequent and frustrating for counsellors. In their personal lives, counsellors themselves were fearful of becoming HIV positive and were not able to enact the advice they were giving others. Little provision was made by the hospital for support, and meetings and in-service training were infrequent (Nulty & Edwards, 2005).

A similar lack of appreciation and teamwork problems was reported by Rohleder and Swartz (2005) who recommended that workplace issues need to be considered in planning VCT. Managers needed to be aware of the need for ongoing support (facilitated groups, professional supervision, managerial attention to problems in the working environment and regular in-service training) .

In both of the VCT studies mentioned, the sample sizes were small and were drawn from homogenous samples, limiting the generalisability of the findings. However, the findings are supported elsewhere in the literature and despite their small sample size, have relevance across contexts. They demonstrated the value of using semi-structured interviews with counsellors and other role players to identify problems in the workplace and to make recommendations for improving the counselling working environment.

2.12.2 PMTCT (feeding) counselling research in South Africa

HIV positive mothers face many challenges in trying to adhere to safe infant feeding practices. In order to implement safe feeding, many women need to change their behavior, identity, personality and social role as women (Buskens, Jaffe & Mennell, 2007). A number of PMTCT studies form part of the Infant Feeding Research Project (www.ifrpafrica.org) and examined different aspects of infant feeding counselling within PMTCT. The IFRP aims to improve the woman-counsellor relationship in order to promote safer feeding practices. A key aspect of the IFRP was the focus on woman-centredness.⁹

⁹ Woman-centredness is an interim term used by the IFRP researchers and is based on Eisler's (1987) call for the acknowledgement that "women are situated in a 'sick' world and that their striving for their health and that of their baby has to be understood against this background" (Buskens, 2006, p. 1). The IFRP interprets woman centredness as the acknowledgement that HIV is a scourge as well as an opportunity to call for woman's power and strength for true transformation and health despite the context.

Table 2.5 A summary of the research aims, sample, context, analysis methods and key findings for South African PMTCT counselling studies

Research & Aims	Sample & Context	Analysis Methods	Key findings
Chopra, Doherty, Jackson & Ashworth (2005) To assess the quality of VCT counselling in PMCT	22 PMTCT counsellors with 4 VCT observations per counsellor (mix of pre-test, post-test and follow up counselling): 14 lay staff & 8 nurses across 3 sites in SA	Descriptive qualitative and quantitative. Structured observations of counselling sessions using a checklist: Observations by 2 experienced raters & exit interviews	Communication skills ‘good’ across all three sites on the basis of ‘<i>warm tone of voice</i>’ and accessible language that ‘<i>the mothers understood</i>’. In 80% interactions, mothers had time to respond to and ask questions. In 32% of cases, inaccurate beliefs were not corrected. Infant feeding counselling, disclosure & ARV counselling quality was poor. Mothers’ knowledge remained poor at the end. Mothers given incomplete information on NVP & side-effects. Only 13/34 interactions asked about disclosure to partners. Counsellors lacked confidence to logically process home circumstances and prevent risks. Gaps in the content of VCT has serious implications for the effectiveness of PMTCT.
Buskens & Jaffe (2008) To explore how the perceptions and experiences of PMTCT participants could be used to improve infant feeding counselling	11 varied low-resource settings across Swaziland, Namibia and SA Counselling HCWs, pregnant women and recent mothers in PMTCT context	Ethnography over seven months using participant observation, formal and informal interviews and focus groups. Conceptual framework analysis, analytic retroduction thematic analysis.	Counselling is demotivating. Caregivers felt judged. Counsellors were frustrated by poor compliance. Mothers and counsellors were frustrated by mixed messages. Opposing agendas grounded in conflicting realities of health education vs consultation expectation. Two communication modes prevailed (in theory: non-directive and client-centered; In practice, information –based health education). Counsellors felt compelled to be prescriptive and authoritative in order to achieve the desired outcome of persuading mothers to test and to disclose.
Baldassini (2006) To improve the quality of PMTCT & reduce vertical transmission through exploring approaches to promote improved infant feeding choices	Eshowe, rural KZN, SA 8 lay counsellors working in PMTCT	Intervention study. Participatory Action Research (PAR), Six month Appreciative Inquiry (AI) method & Outcome Mapping	Improved confidence in their ability to effect change on mothers. Counselling environment within health care system is not favourable for counselling. Stigma, lack of continuity to care, a strong hierarchical structure, and poor mentoring and support of lay counsellors prevails.
Mash, Baldassini, Mkhathshwa, Sayeed and Ndapeua (2008) To develop more effective PMTCT counselling incorporating MI and woman centredness, to determine how successful PMTCT counsellors were in incorporating MI skills & lessons learnt from training	4 Southern African sites, 2 in SA and 1 in Namibia and Swaziland 38 PMTCT counsellors consisting of lay counsellors and nurses	Intervention study looking at MI (collaboration, evocation and respect for autonomy)	SA counsellors (in contrast to Swazi and Namibian nurses) had no beginning proficiency in MI. This study examined reflection to question ratio and open question score. Guidelines developed for training.

¹ Appreciative inquiry (AI) is ‘*an approach to organizational change that seeks to enhance the best of what exists by focusing on the positives present in any situation and seeking ways to achieve more of what is good*’ (Baldassini, 2007:11). In Baldassini’s (2006) research, this meant asking the counsellors to reflect on how MI and woman-centeredness were helping them in their counselling and how they believed it could help them even more.

The relatively poor completion of VCT motivated Chopra et al. (2005) to assess the quality of VCT counselling in PMTCT. VCT is a critical component of PMTCT and infant feeding counselling and good quality VCT is essential for success (Chopra et al., 2005). “Done well, it will result in significant reductions in child mortality through decreased postnatal HIV transmission and improved feeding practices; done badly, it could lead to deaths from diarrhoea and other infections, increased drug resistance, and the spread of poor infant feeding practices into the general population.” Given this critical role of VCT in PMTCT, there is surprisingly little published on measuring the quality of counselling and on factors that influence this quality (Chopra et al., 2005).

In 2002, PMTCT was introduced at 18 pilot sites across South Africa (Chopra et al., 2005). Initial evaluations resulted in sites being given extra resources to employ lay counsellors, conduct rapid tests and dispense free formula to those choosing not to breast feed (Chopra et al., 2005). Counsellors received two weeks of VCT training and counselling for infant feeding (Chopra et al., 2005). Chopra et al.’s (2005) study demonstrated that traditional indicators of VCT quality are insufficient measures of the quality of counselling. Sites that rated well in terms of acceptability and uptake, nonetheless rated poorly in terms of the quality of the session. The quality of the counselling and lack of encouragement to disclose, could impact on adherence to infant feeding advice and to medications, thereby compromising the effectiveness of PMTCT (Chopra et al., 2005). Chopra et al. (2005) stated that the general quality of the communication was good, but that the content being communicated within these sessions would have serious implications for the effectiveness of this programme. One difficulty with this statement is that the content of the sessions is a component of communication.

The poor quality of the infant feeding counselling and, once decision was made, the minimal specific advice and support to promote adherence to the chosen method, is an important finding. Poor counselling and a lack of subsequent support for the infant feeding decision almost inevitably leads to mixed feeding which has been shown to increase the risk of MTCT. Poor infant feeding counselling is a finding across many PMTCT programmes.

(Chopra et al., 2005, p. 62)

The focus of Chopra et al.’s (2005) study was on the content of counselling sessions, drawn up from ATICC, Lifeline and PMTCT protocol reviews. Their findings suggested that the gaps in the content of VCT covered in the counselling sessions, could have serious implications for the effectiveness of PMTCT. Similar findings were reported in a study in Kenya by Delva, Mutunga, Quaghebeur and Temmerman (2006) which examined

counsellors' social and communicative skills, duration and topics covered during pre- and post-test counselling sessions by means of the UNAIDS assessment tools. The frequency and duration of the counselling in this study were low, and important topics such as the window period, partner involvement and follow-up support were dealt with haphazardly. Counsellor communication skills were highly rated, however information was rarely repeated or summarized. The limited time set aside for antenatal VCT was incompatible with the large amount of treatment literacy that needed to be covered. In both these studies, global communication ratings did not correlate with more detailed observations of communication. For example, it seems contradictory to claim that communication was good but that information was rarely repeated or summarized (Delva et al., 2006). This raises questions about the usefulness of rating systems and checklists in analyzing communication skills and suggests a need to move beyond global ratings for more in-depth analysis.

The poor quality of counselling in these two studies provides strong motivation for the research conducted in the other three studies summarized above, which all fall within the Infant Feeding Research Project. Buskens and Jaffe's study used ethnography in 11 varied low-resource settings in Swaziland, Namibia and South Africa to provide rich detail of the context of infant feeding counselling. In contrast, the studies by Baldassini (2006) and Mash et al. (2008) were intervention studies that examined the application of BMI infant feeding counselling.

In their study, Buskens and Jaffe (2008) found that poor continuity of care was a contributing factor to mixed messages, with mothers receiving different messages from consultations with different health care workers. Counsellors expressed anger and frustration at mothers not following instructions, that mothers did not tell them the truth about infant feeding habits and did not take their health education seriously (Buskens & Jaffe, 2008). By involving counselling CHWs, pregnant women and recent mothers in the PMTCT context, they demonstrated the usefulness of collating the views of a variety of different stakeholders and the value of an ethnographic approach in providing rich detail.

Buskens and Jaffe (2008) called for a different format of counselling in Southern Africa in order to manage the opposing agendas and conflicting realities in infant feeding counselling to sensitize counsellors to the behaviour change required of mothers and to enable counsellors to guide conversations that motivate and empower mothers to make changes. The study recommended that counsellors need to be provided with the tools to acknowledge and manage

these two opposing agendas and to provide tools to share health information in ways that enable mothers to make meaning and construct knowledge from it.

Responding to the reported failure of non-directive client-centered counselling in effecting behavioural change in mothers' feeding practices, Baldassini (2006) and Mash et al. (2008) implemented BMI interventions within the PMTCT context.

Baldassini hoped to create a woman-centered ethic about the needs and status of women in order to lift barriers, resulting in improved care and consciousness. "We need counsellors sensitive to the challenges women face in this era of HIV/AIDS" (Baldassini, 2006, p.4). One aspect that was emphasised was the unconditional positive regard (Carl Rogers) which required developing a genuine belief by the counsellors that mothers are capable of change (Baldassini, 2006). In his study, counsellors were trained to become aware of their boundaries and roles as rescuers or victims in order to prevent burnout and frustration occurring (Baldassini, 2006). Counsellors expressed the view that patients were resistant to counselling because other health professionals off-loaded patients on to counsellors without telling them why they were being sent to counsellors (Baldassini, 2006). Attendance at training proved problematic and Baldissini reflected that counsellors "appeared reluctant to commit to the process". Despite this, counsellors reported increased confidence in the ability to counsel mothers burdened by HIV after training in BMI. Baldassini concluded that the study succeeded in providing counsellors with strategies to cope with resistant clients and assisted counsellors in maintaining health boundaries (Baldassini, 2006). Prior to training, counsellors followed an educational approach and spent much of their sessions talking. After training counsellors reported an awareness of how much they were talking relative to the client (Baldassini, 2006).

In general, the perception from this study was that BMI is helpful for counsellors to understand their patients and to try and walk in their shoes, which would be a first stage, from which improving their skills could follow. Of particular significance, is that counsellors were liberated by the insight that the responsibility for change lay with the client, and that they were merely facilitators for this change (Baldassini, 2006). Baldassini cautioned that the application of BMI within an androcratic¹⁰ society was limiting. Within the research context in which there is diminished autonomy due to the junior status of women, BMI may be

¹⁰ Androcracy is defined by Baldassini (2007, p.24) as "a social system dominated by men with a strict hierarchical structure that uses the 'power over' rather than a partnership model".

insufficient to affect change. Certainly, issues such as negotiating condom use within a relationship would be equally difficult for many women to discuss with partners as affecting feeding choices. Campbell, Gibbs, Nair and Maimane (2009) reported similar findings in their study aiming to increase empowerment and participation amongst female health volunteers. Their results indicated that empowerment did not extend beyond womens' project-related roles, and more specifically did not impact on their ability to negotiate condom use, to assert themselves to male leaders and to become more involved in wider community decision-making (Campbell et al., 2009).

Baldassini's study suggests partial success as counsellors struggled with a number of aspects of BMI, namely agenda setting and scaling questions. Similarly, in Mash et al.'s study, MI training was shown to have only limited success in some contexts. Nurse counsellors in Namibia and Swaziland demonstrated beginning proficiency in MI, whereas lay counsellors from South Africa did not. There were marked differences between the South African counsellors in Eshowe and Stellenbosch, with the nurse counsellors in Namibia and Swaziland. On average, the lay counsellors scored below beginning level proficiency in all scores. They also had lower basic communication skills and relevant medical knowledge at the baseline level than the nurses did, so additional time was spent in their training to focus on basic communication skills which form the foundation of MI. Examples of these skills included how to organize the room, or how to formulate an open question.

2.13 ADHERENCE COUNSELLING

2.13.1 Adherence counsellor job description in the Western Cape, South Africa

Within the Western Cape, a number of different models of psychosocial support are offered depending on the health care location (rural/ urban), level of care (primary/ tertiary etc) and role players in that community (Abdullah, 2005). At a community-based level within Khayelitsha for example, patients at government roll-out sites select a coach who becomes the main individual in the psychosocial support component. The patient is also supported by site-based counsellors and support groups. However, in Gugulethu, the model differs in that counsellors who are community-based care for up to 40 patients, doing home visits and unannounced pill counts. These counsellors are the patients' first port of call if they experience any difficulties. Counsellors spend time at the site and are involved in the clinic-based management of the patient within a multidisciplinary team comprising a doctor and nurse. More counsellors are needed within this model in comparison to that used by

Khayelitsha. To date, good adherence has been shown with both of these models (Abdulla, 2005).

In contrast to the above two models, at a secondary hospital site for example, patients are counselled by site-based counsellors and then referred to home-based care organizations in the community (Abdullah, 2005). These models are currently being evaluated so that decisions regarding the optimal model at best cost for strong systems can be built at the community level (Abdullah, 2005).

In the Western Cape, the DOH requirements for adherence counselling, require a senior certificate or equivalent, three years experience as a VCT or PMTCT lay counsellor, emotional stability, good interpersonal communication skills and basic administrative and time managements skills (DOH, 2006). In-service training and learning on a continuous basis is the recommended learning field, with no career path specified as this is a contract post (DOH, 2006).

The purpose of an adherence counsellor is “to be part of the broader comprehensive care and treatment counselling initiatives of National, Provincial, Regional/ District AIDS Plan as it is implemented” (DOH, 2006, p. 1). Seven key performance areas have been identified for adherence counsellors in the *Adherence Counsellor Job Description* (C1 – C7, Appendix III). Although a discussion about communication skills is relevant to all seven of these key performance areas, C1, C2, C4 and C7 in particular require strong communication skills. In adherence counselling sessions, a large amount of content information has to be shared with clients, and has to be collected from them through strategic questioning. The seven key performance indicators are summarised and discussed in Appendix III. Table 2.6 lists topics that must be covered in adherence counselling sessions based on the DOH job description, as well as the knowledge that is presupposed to enable discussion of these topics, and the communication skills that are specified.

Table 2.6 A summary of the topics that may be discussed within adherence counselling sessions as specified by the DOH counsellor job description (2006)

	Topics that must be covered	Presupposed knowledge base of topics that may be discussed	Communication skills that are specified
Medical	HIV/AIDS, ARVs, Risk factors for adherence including interaction of alcohol, TB, STIs, Compliance (adherence), Pre- and post-test counselling, Reason for VCT, Sex, Side-effects, Drug classes, Resistance	ARVs: How they work, timing, names of ARVs – common names/ generics/ abbreviations; family planning; HIV transmission; first and second line regimens, condom use	Greetings Eye contact Body language Non-judgmental attitude Empathy Active listening Confidentiality
Psychosocial	Client's motivation to be on ARVs, Disclosure, Partner testing, Support systems, Living positively	Poverty, unemployment, family structure, substance abuse, disruptions to routine such as temporary migration to the Eastern Cape, support at home, relationship with sexual partner, cultural practices: circumcision, consulting traditional healers, feelings about death and dying, stress, income generation, social grants, financial situation, women and agency, intimate partner violence, sex within partnerships, transactional sex, risks of disclosure	Ability to: Determine patient level of understanding Comment on patient readiness Detect and report barriers to adherence Provide education and information on a variety of topics
Clinic Procedural / Referral	Consent, Confidentiality, Preparation for a rapid test, How the clinic works	How the clinic works, frequency of appointments, who does what in the clinic, layout of the clinic, location of the pharmacy and the folder/ clinic card system, living circumstance details	
Interpreting	Interpreting: language/ communication mediator	Role of an interpreter, bilingual, knowledge translation to patient's level of understanding	

2.13.2 Adherence counselling research in South Africa

Ensuring adherence is a fundamental activity of an HIV/AIDS treatment programme, and not solely a responsibility of the patient. (Rhatigan et al., 2009, p. 8)

There has been less focus on adherence counselling than on other types of counselling. This may be due to the long-term nature of adherence counselling, that it is ongoing and less focused on a single event, or because it is so variable making it methodologically challenging. Studies that have examined adherence counselling are summarized in Table 2.7 and described thereafter.

Table 2.7 A summary of the research aims, sample, analysis methods and key findings of South African adherence counselling research

Research & Aims	Sample	Analysis Methods	Key findings
Evangeli, Engelbrecht, Swartz, Turner, Forsberg & Soka (2009) To evaluate a six-session (12 hour) course of MI	17 lay adherence counsellors Peri-urban, Western Cape Training + two individual feedback sessions	Intervention study. MITI coding of audio-recorded role-plays. Questionnaires Training included modeling, role play, small group discussions. Experiential learning, written handouts and didactic presentations.	Counsellors reported using MI both pre- and post- training. Difference between reporting and actual. Changes were evident in MI non-adherence (advice giving, directiveness, control, confrontation) to asking for permission, emphasizing client autonomy, affirming client's response to change. Only a small proportion of counsellors attained beginning level proficiency in MI. Marginal improvement in rate of reflections to questions and % of open questions but to levels below beginning proficiency. No change in global therapy ratings (empathy and spirit of MI collaboration, evocation and autonomy or % complex reflections)
Rust (2005)	2 counsellors across 3 interactions at a secondary/tertiary public sector hospital in the Western Cape	Qualitative description of communication using conversational analysis and semi-structured interviews	Two different counselling styles (paternalistic and mutuality) identified.
Cilliers (2008)	11 caregivers, 4 counsellors & 4 doctors at an outpatient clinic in a tertiary hospital in isiXhosa	Qualitative description of communication using semi-structured interviews and thematic analysis	Recognition of the impact of context is needed. A facilitative conversational style was identified.

Evangeli et al. (2009) found that factors relating to the health system, counsellors, the intervention and the patients constituted both barriers and facilitators to MI implementation. Within the health system itself, the degree of organizational support, time and space to conduct the training, session timing, health system targets and directives impacted on the effectiveness of the intervention. Counsellor factors such as confidence in one's ability to carry out the approach and intervention and patient factors such as the perceived impact of MI and the ease of using the approach, all impacted on the success of MI.

Similarly to the results of Baldassini (2006) and Mash et al. (2008), some improvements on MI skills with training were noted, but not in all skills (Evangeli et al., 2009). Factors that did improve in MI non-adherent practice with training, were advice giving, directiveness, control

and confrontation which became more adherent post-training (Evangeli et al., 2009). Despite some changes, only 3/14 counsellors reached beginning level proficiency in MI. Qualitative descriptions indicated a number of counsellors still follow MI adherent responses with direction and advice. There was no evidence of improvement in global therapist ratings or empathy with training, and significantly, there is no evidence in the effectiveness of counselling in effecting client change for counsellors operating at below the level of beginning proficiency (Evangeli et al., 2009). Individual variations suggest that some counsellors may be more able to develop MI skills than others, which will impact on training selection criteria (Evangeli et al., 2009). Teaching MI skills and demonstrating the resulting counsellor changes does not necessarily mean the use of MI in practice (Evangeli, Engelbrecht, Swartz & Turner, in preparation).

2.14 LESSONS LEARNT FROM INTERVENTION STUDIES

A number of lessons learnt from counselling intervention studies are applicable to planning interventions in adherence counselling. Counselling intervention studies using MI have demonstrated that counsellors are able to shift their beliefs about client behaviours and adopt new skills to challenging situations. In particular, reflective practice and self-awareness appear to have been enhanced with training, and boosted their confidence in their own ability. Furthermore, counsellors believed that their boosted increased confidence would assist them in improving mothers' confidence (Baldassini, 2006). Whilst this is important in boosting counsellor morale and self-confidence, unfortunately, as the results demonstrated, self-reports and actual skills demonstration are not always matched (Evangeli et al., 2009), necessitating examination of actual counselling sessions in order to evaluate the influence of training.

Studies that have examined counselling have not always employed methodological rigour in the form of inter-rater correlations to validate findings (Baldassini, 2006). However, through triangulation within the larger IFRP, cross study substantiation is possible.

There is a paucity of studies that examine communication as a dynamic process between two partners, and that examine the contribution of each partner relative to the other. The MITI coding system, is a useful research and assessment tool for measuring counsellor ability in pre-selected items, so serves a useful means of evaluating counselling skills on training in the MI approach, however does not allow for interpretation based on the conversational context or contribution of the patient. Furthermore it passes a judgment on items that may not be appropriate without consideration for context.

2.15 ATTENTION TO COMMUNICATION ISSUES IN COUNSELLING RESEARCH

The counselling studies described above were reviewed to see what attention was paid to language and communication issues in their research design, and to see what communication-specific findings were reported.

2.15.1 Communication-sensitivity in the study design

In most of the studies, attention has been paid to the language of the trainers and research assistants conducting the research, however others made no mention of this making it difficult to comment on measures that had been taken (e.g. Richter et al., 1999). Buskens' and Jaffe's (2008) study for example mentioned that the researchers were all female indigenous language speakers representing a variety of disciplines. Some studies failed to describe the language of the interactions and whether or not the observers were matched to the languages of the participants (Chopra et al., 2005). Other researchers acknowledged the limitation of the discrepancy between researchers and participants in the South African context in making it difficult for trainers to monitor and feedback on role play performances (Evangeli et al., 2009). In one study, a lack of proficiency in English was an exclusion criterion that was acknowledged (Nulty and Edwards, 2005) as it could have skewed findings because issues might differ for counsellors with different English proficiency levels. There was acknowledgement of the role of the language and cultural background of the researchers in Mash et al.'s (2008) study, in which it was felt that the shared language between the action researchers and the participants in Swaziland and Namibia may have contributed to better MI performance in those settings. Interestingly, the gender of the action researchers was not identified as a factor, although at the Swazi and Namibian sites, the action researcher was female (as were the participants) whereas the action researchers were male at the South African sites. Possibly the female action researchers were able to build a stronger personal relationship with the female participants.

Studies lacked explicit descriptions of the transcription and translation process and which measures were in place to ensure stringent reliability of these aspects. In Baldassini's (2006) study for example, no details were provided on language of interactions, actual transcripts or whether or not these were transcribed and translated. It can be assumed that depending on the language of the interactions and whether the counsellor was working in their first or second language, findings might differ. Similarly, if a researcher is working from data that is in its original form or translated, there may be different interpretation of findings.

Most studies recognized the need to examine actual counselling sessions rather than simulated encounters, as well as the value in video-taping sessions so that they could be reviewed (Baldassini, 2006). However, some studies were limited by not video-recording sessions, which meant that they were reliant on real-time analysis (Chopra et al., 2005).

Studies also recognized the importance of context-specificity and the potential difference created by different cadres of health workers performing counselling duties. This was evident from the studies specifying the site and level of care, as well as which professions were involved. Interesting differences in counselling proficiency were noted across professions and sites as demonstrated by Mash et al. (2008). The application of some of the findings with nurse-counsellors (e.g. Buskens & Jaffe, 2008) may have limited applicability to CHW counsellors. However they provide a useful comparative measure. The fact that communication is variable and is dependent on which patient is being seen and their particular needs, was acknowledged in studies in which multiple episodes were examined for each counsellor (Chopra et al., 2005). This was not a feature of all studies.

There was some acknowledgement of the need for a process approach through inclusion of inquiry groups (e.g. in Baldassini, 2006) and ethnography (Buskens & Jaffe, 2008). However a number of studies used outcomes measures such as checklists which did not acknowledge communication as a two way interaction that is dependent on the dynamics of both counsellor and patient. Evangeli et al. (2009) for example examined only the communication of the counsellor. There was no examination of the patients' utterances as providing a conversational context within which counsellor communication was framed. Because the applicability of prescriptive checklists designed within Western models is not actually known within an African context, such checklists when used without regard for conversational context may not be linguistically or culturally appropriate. Techniques such as MITI (Evangeli et al., 2009) were useful for cross-sample comparisons, however are limited to pre-determined categories. Without describing the communicative context, one risks assuming that all non-reflective statements are bad; and that all questions should be open. Furthermore, it makes a judgment on *information-giving* which appears to always be perceived as bad. Across studies, the potentially positive contribution of counsellors remains largely unexplored despite Richter et al.'s (1999) reference to the social welfare contribution of counsellors.

The study methodologies meant that the non-verbal communication tended not to be systematically examined and was not specifically addressed in some of the research (e.g.

Baldassini, 2006). In some studies, as the focus was on the content of communication, the interactional elements were not discussed (e.g. Chopra et al., 2005). Studies tended to fall into the categories of examining either content (e.g. Chopra et al., 2005) or specific counselling skills such as those used in MI, however not on the interactional elements. No research systematically documents the interactional elements, non-verbal behaviours or the patient's communication in counsellor-patient interactions. The communication context of paediatric HIV counselling has not been explored. Furthermore, a process approach that examines not just if a patient asked a question or initiated a new topic, but why and when they do so, has not been followed. Attention to inter-rater reliability varied between studies, with Baldassini (2006) using only one rater whereas Chopra et al. (2005) used more than one. As Baldassini's study included multiple measures (inquiry groups, reflective notes and videos) this could have diminished the need for inter-rating.

2.15.2 Communication findings in the counselling studies

Some of the studies made vague references to communication generally, rather than to specific communication skills; some paid attention to some skills but not to others. For example, in Chopra et al. (2005), rater perceptions of tone of voice and giving a patient time to respond, are described but no attention is paid to non-verbals. In some studies, this may be due to the data collection methods (audio-taping) which does not allow for such an analysis, or use of simulated patients in which non-verbals may not be successfully acted. Studies did not define what constituted 'good' communication despite making a judgment on it. For example, Chopra et al. (2005, p. 359) commented that "The communication skills of the counsellors were **good** across all three sites. They used a warm tone of voice and language that the mother understood. In over 80% of observations, the mother was given time to respond and an opportunity to ask questions." This was relatively unusual as very few of the studies commented on communication or language issues at all. There appears to be unsaid expectation that communication skills would already be in place to enable counsellors to develop more complex skills. Despite these raters concluding that general communication was 'good', more in-depth discussion of feeding counselling which was described as 'poor' suggests a different conceptualization between those researchers about what communication is. Communication in Chopra et al.'s study appears to consist of tone of voice, level of language and giving patients time to respond. The message factors appear to have been separated out from this, however were also commented on. This is interesting as it shows not only a split in counsellor training focus as incorporating client-centered and educational components, but a split in the research too, showing either a focus on the educational

component or on the client-centredness of the interaction. No studies have examined the interaction of these two components on each other.

One communication difficulty that was mentioned, was counsellors not correcting inaccurate patient beliefs, “however in only a third (32%) of cases were inaccurate beliefs of the mother corrected” (Chopra et al., 2005, p. 359). Within different counselling approaches, the correction of inaccuracies may be controversial. Without in-depth analysis of how beliefs were dealt with, one is not able to determine *how* inaccurate beliefs were managed. As the studies described above used checklist rather than discourse analysis methods, actual examples of quotes from counselling interactions were not presented in the data to back up findings. Within the studies, however, a number of specific communication findings were identified which provide a useful comparative measure for this research. These findings are summarized in Table 2.8.

Table 2.8 Communication-specific findings from counselling studies in Southern Africa

Category	Finding
Topics discussed and information giving	Some topics are seldom discussed. In Chopra et al.’s (2005) study, expressing breastmilk was only explored with 3 mothers. Non-discussion of certain topics; None of the others were asked if they had considered contraception or were provided with any advice on contraceptive options (Chopra et al., 2005). 13/ 34 HIV positive mothers were asked if they had a partner and if they knew their partner’s status, and only in 7 of these, did the discussion progress to disclosure. In Zambia: 10/ 42 providers inquired whether the mother had money to buy formula; 6/42 asked whether the client had access to adequate supplies of water (Rutenburg and Kabila, 2003 in Chopra et al., 2005). This might suggest that money is difficult to discuss. Some topics are complex to discuss: Transmission of risk was seldom discussed (Chopra et al., 2005). Not only are there different stages in which risk may differ (HIV transmission in the womb, during delivery and by breastfeeding), but also the <i>concept</i> of risk – i.e. ‘<i>mathematical chance</i>’ might be difficult to explain. Poor application of breastfeeding to the patient’s lifeworld (i.e. on return to work or school) was only explored in 1 of Chopra et al.’s (2005) cases. Procedural aspects such as when and how to collect further supplies of formula were given to fewer than half of mothers (Chopra et al., 2005). Trouble-shooting: No discussions involving trouble-shooting on how mothers would explain the lack of breastfeeding to others or what she would do if the baby cried at night (Chopra et al., 2005). Counsellors were aware of cultural practices which could have potentially

	dangerous consequences but felt unable to engage with mothers on these topics (Buskens & Jaffe, 2008). Mash et al. (2008) reported that counsellors who scored higher on the MITI gave less information, which was reflected as a shift from being educators to counsellor. One difficulty with this, is that it does not allow for a comparison to studies such as Chopra et al. (2005). It also means that even though less information was given, maybe there were also less reflections.
Instruction giving	Sparse instructions were given to mothers who had chosen to formula feed on how to prepare the formula (Chopra et al., 2005).
Questioning	Few mothers were questioned about whether or not they had previously prepared formula (Chopra et al., 2005).
Caregiver understanding	Caregiver understanding of concepts was seldom explored, with only 2/12 mothers on Chopra's study being asked if they understood the concept of early breastfeeding. Counsellors tended not to correct misbeliefs. Caregiver understanding about infant feeding remained poor at the end of the counselling sessions (Chopra et al., 2005). There is too little 'shared understanding' for the parties to truly connect (Buskens & Jaffe, 2008).
Practical demonstrations	Practical demonstration such as how to mix the formula, or how to position the child on the breast, did not occur at all (Chopra et al., 2005).
Institutional factors impacting on communication	Fear of LTFU leads to counsellors attempting to cram too much into one session Poor continuity of care leads to conflicting messages from different health care workers (Buskens & Jaffe, 2008)
Interaction	As a product of the rift between counsellors and patients, each party talks past each other. There is no real meeting of minds, and so dialogue became ritualistic. Rapport is not well established (Buskens & Jaffe, 2008).
Medical vs lifeworld	There is an assumption that counsellors are experts in health matters, whereas the mother is an expert in her needs and circumstances. Perception of the counselling as a 'consultation' by mothers, contrasted with counsellors framing it as 'advising and giving information' (Buskens & Jaffe, 2008).
Discrepancy between global ratings and individual skills	"The global ratings of competence appeared higher than the ratings for some of the specific skills. In particular the counsellors struggled to move beyond open questions to complex reflections. Simple reflections were often formulated as questions and not as statements."

2.16 COUNSELLOR TRAINING

A number of factors related to counsellor training have been identified as obstacles to effective care. Counsellor training has been criticized for being too information-based with insufficient focus on counselling skills (Baldassini, 2006). The newer DOH format is characterized by more open ended questions however still operates in a fairly rigid structure

(Baldassini, 2006). Significant changes are needed to the definition of the counselling role (Baldassini, 2006). Counsellors require both more and different training in order to assist mothers with making behavioural changes (Buskens & Jaffe, 2008, p. 68):

“a prerequisite for such training is for health services and for individual counsellors to acknowledge the existence of the subtexts, the rift between these agendas, the use of demotivating frames and modes of communication and, most critically, the reality of the possibility of change.”

There has been a general call for health care worker training in communication, particularly in response to the needs of HIV positive women (Lazarus et al., 2009). Findings suggest that health care workers need improved counselling training to account for the complex factors affecting family planning decisions of HIV positive women (Lazarus et al., 2009). Health care workers need to have greater sensitivity to how their messages interact with community views and may undermine appropriate care for babies (Lazarus et al., 2009).

However, despite researcher assertions to the contrary, counsellors in Nulty and Edwards's (2005) study reported that the training provided a good basis for their work. Through sharing their experiences, they understood themselves and others better. The practical skills that they developed increased their confidence in their ability to respond to the wide variety of emotions that clients have (Nulty & Edwards, 2005). It is likely that counsellors working and trained in different parts of the country feel differently about their training and level of confidence in their work.

Skills in which health care workers have been shown to be lacking in communicating with caregivers of HIV positive children include condom use (usually referred to only with regards to transmission and not contraception), sensitivity to community views and feeding preferences (Lazarus et al., 2009). Lazarus et al. (2009) have made a call for supportive networks of caregivers to have a good understanding of how to care for babies, especially with regard to feeding or using medication.

In the Western Cape, there is a great deal of variation in terms of counsellor training. This variation is due in part to the broad group that 'counsellors' encompasses. Numerous NGOs employ and train counsellors. The DOH was faced with the challenge of providing rapid scale-up of ARVs in a short period of time. One way of meeting this challenge was to outsource training in HIV to existing NGOs and to support organisations that had already developed models of training counsellors.

In addition, to ATICC, a number of different NGOs provide counsellor training. At ATICC, training is usually a series of add on courses (ATICC, 2008a; 2008b; 2008c; 2008d). These consist of a basic HIV counselling course (a ten day HIV & AIDS/STI and TB information training), followed by a twenty day basic VCT/PMTCT counselling training and more specialized courses which build on the skills and knowledge already learnt (a ten ARV Adherence counselling course, introduced in 2004; and a five day Paediatric ARV counselling course to counsel caregivers of children on ARVs which was added in 2008). The first three courses mentioned are accredited with the Health and Welfare Sector Education and Training Authority (SETA).

Once learners have been found competent to counsel, they are employed by the NGOs who referred them and are funded by the DOH. Learners who are deemed to be 'Not yet competent' are required to complete the course/ aspects of the course which includes role play and individual training (C. Jacobs, personal communication, 1 March 2009). Assessment of counsellors passing through ATICC is conducted by accredited ATICC trainers, who are registered psychologists and social workers in accordance with SETA requirements.

Training methods include a combination of didactic input, group work (goals, expectations, group contracts), reflection, poster presentations, demonstrations and role play. A summary of the topics covered in the ATICC counsellor training is included Appendix IV.

A comparison between the topics covered in the ATICC training curriculum and the DOH adherence counsellor job descriptions indicates that the counsellor training is aligned with the requirements for the job. It is worth noting that the counselling curricula themselves are a work in progress and are constantly being updated as the need arises. As the cadre of 'HIV counsellor' is a new one in the last decade, development of training guidelines and job descriptions remain a work in progress. Recently a number of protocols and guidelines for counsellors have been developed.

Inadequate counsellor training for breastfeeding has been specifically targeted as a critical prevention strategy. Despite counsellors receiving '*intensive training on HIV and infant feeding*' and receiving ongoing support from a dedicated mentor and supervisor (Chopra et al., 2005), the quality of infant feeding counselling is documented as poor. Recommendations to assist counsellors are: counselling cards to remind them of key issues to cover, prioritizing the topics covered as there is a large amount of info that needs to be covered (Chopra et al., 2005), and a checklist in each client's folder so that HCWs can indicate which topics have been covered, with space for notes (Chopra et al., 2005). The results from Chopra et al.'s

(2005) study indicated a need to develop appropriate training materials and improve training courses to achieve proficient support for infant feeding choices.

Research suggests that counsellor receptiveness to in-service training interventions varies, with some counsellors not being motivated to improve their counselling as their job was just a stepping stone to earning better pay (Mash et al., 2008). The negativity of some of the counsellors was felt to be a hindrance to the process overall and wasted a lot of time and energy. Some counsellors regarded MI as just another set of external guidelines (Mash et al., 2008). A number of studies have shown the value of an inquiry group to counter initial resistance to intervention measures. Counsellors may have been relatively less committed to their profession and to their professional development than their nursing counterparts. Table 2.9 summarises recommendations for in-service counsellor training from Mash et al. (2008).

Table 2.9 Recommendations for in-service training from Mash et al. (2008)

- | |
|---|
| <ul style="list-style-type: none"> • Assess baseline skills prior to training so that progress can be monitored and in order to determine learning needs • Counsellor readiness to change needs to be explored at the beginning of training and periodically thereafter • A combination of initial training workshops, ongoing action reflection and small group meetings as well as individual mentoring is effective • After initial training, learning should be based as much as possible on audio or video tapes of actual counselling sessions • Facilitators should ideally be able to speak the same language as the participants and should understand their working environment • A group process that is characterised by listening, inquiry, curiosity, reflection, experimentation, openness and collaboration in learning creates an environment for change that is also coherent with MI • Training that focuses on achieving understanding of and alignment with the spirit of MI may be more successful than training with a focus on specific techniques as a starting point • The support of facility management is important in enabling the implementation of new counselling styles • Training should be appreciative of the counsellor's successes and build confidence |
|---|

2.17 SUMMARY

Published literature on HIV counselling in SA, shows a shift with the progression of the ARV rollout, from an initial focus on VCT (Richter et al., 1999; Coovadia, 2000) to counselling for the prevention of vertical transmission (e.g. the Infant Feeding Research Project studies). This shift mirrors the progression of the response to the pandemic within the country, both politically and with the growing sophistication of knowledge about HIV treatment. This section described the strong emphasis on counselling in the national ART guidelines for children. However it also recognizes that the importance of communication in interactions is implied rather than being explicitly stated in these guidelines. By tracing the history of HIV counselling research in South Africa, there is evidence that the stop-gap solution of 'lay' counsellors in response to the human resource shortage appears to have compromised the quality of counselling. Models of counselling point to a mismatch between non-directive client-centered models versus health educational models. The job requirements of adherence counsellors specify a large health educational component to be covered in interactions with patients. The training of adherence counsellors is of limited duration and may not equip counsellors sufficiently for managing the tension between client-centered and health educational models given the treatment literacy and task-focused emphasis in the health sector.

This section describes how HIV counselling research appears to have focused primarily on counselling skills, and has largely ignored the core communication skills which form the foundation of interactions, despite an established need for communication skills training in this group. The methodologies used in the published counselling research do not acknowledge the patient's contribution to the interactive process, the conversational context of the counsellor's communication or the cultural and linguistic challenges of the South African context. Taxonomic 'checklist' approaches have been useful in measuring the relative merits of different counselling interventions, but have failed to examine communication as a process or to recognize the contributions of counsellors that fall outside of prescriptive models. Further exploration is required to establish the transferability of counselling interventions within the HIV-disease context and the counsellor-patient 'shared context' of women living in poverty in the South African pandemic.

There is a need to explore communication in the field of adherence counselling, within the paediatric context in particular, using data led, non-taxonomic research methods that are sensitive to the importance of process. Such research would be helpful in determining the nature of communication in paediatric HIV counselling interactions. Chapter Three that follows outlines a health communication framework and analysis methods that are suited to such an approach.

CHAPTER THREE

HEALTH COMMUNICATION AND HIV: PROCESS AND CONTEXT

3.1 INTRODUCTION

This chapter provides an overview of some key theories relevant to examining communication in medical interactions within the multilingual, multicultural South African context. Critical to this discussion is an understanding of communication as a dynamic two way process, dependent on the contribution of both health professional and patient. Within a patient-centered model of care, effective communication needs to elicit the patient's explanatory model and lead to accurate patient understanding.

This chapter presents an overview of linguistic methods of inquiry as tools for analyzing communication in interactions with consideration for both situational and conversational context. The impact of the disease-context of HIV on communication in interactions remains largely unexplored. It is well-established that good health professional communication is essential to ensure quality interactions. Given the challenges posed by the cultural and linguistic environment in South Africa and the HIV disease context, exploration of the communication process in HIV interactions using culturally sensitive analysis methods, is needed.

3.2 AN OVERVIEW OF RELEVANT HEALTH COMMUNICATION THEORIES

Health communication has its origins in the field of sociology. Researchers such as Drew and Heritage (1992) examined institutional interactions rather than ordinary conversations in recognition of the influence of interaction, context and social structure on communication. Central to the exploration of communication in interactions, is an understanding of patient-centered care (Kleinman, 1988); social constructionism (Bruner, 1991; Crossley, 2000), Mishler's theory of the lifeworld (1984) and ecological models of care (Street, 2002, 2003; Street, Gordon & Haidet, 2007).

Emerging from the work of Kleinman, there is an interest in illness (the disease-experience of the patient). In what was to be termed 'patient-centered care', acknowledgement of the importance of the lived experience of the patient was realized. Health professionals became viewed as experts on the biomedical aspects of disease, and patients as experts on their own illness. Explanatory models are defined as the notions that patients, families and practitioners have about a specific illness episode (Kleinman, 1988). The health professional-patient relationship is conceptualized as a dynamic transaction between explanatory models

(Baarnhielm, 2004). Patient-centered interactions aim to achieve concordance between health professional and patient by respecting the patient's agenda and right to be the decision-maker, and by creating openness in the therapeutic relationship to allow for negotiation between equals (Bissell, May & Noyce, 2004; Vermeire et al., 2001; Weiss & Britten, 2003).

Providing patient-centered care is a cornerstone of modern medicine and the call for a system “that allows physicians to refocus on the patient-centered, personal and unique experience of ‘illness’ is an imperative of our time” (Green, Carrillo & Betancourt, 2002, p. 141). When health professionals explore patient models of causation, treatment is likely to be more effective because patients believe that providers are addressing their concerns (Mullin et al., 1998). Increased patient satisfaction can lead to improved health-seeking behavior by patients, more appropriate testing and screening, fewer diagnostic errors, avoidance of treatment complications and better adherence (Vanderpool, 2005). However, managing care constraints, litigation and regulatory pressures often results in medicine approaching a ‘disease-based’ model and results in a failure to emphasise the ‘art of healing’ (Green et al., 2002:141).

Parallel to the emphasis on patient-centeredness, there has been a shift in health communication research from examining the communication of the health professional only, to examining the process of communicating between both the patient and the health professional, and the mutual influence of both members of this dyad (Hall & Visser, 2000). Traditional models of health communication pay limited attention to the more subtle aspects of social interactions (Pope, 2004). *Process* studies address issues of ‘How does it work?’ in contrast to *outcomes* studies that address the issue of ‘Does it work?’ (Burck, 2005). The development of outcomes studies has been driven by the emphasis on evidence-based practice, in which quantitative analysis that uses manualised, replicable methods is favoured. Recently however, researchers have argued for systemic practice-based evidence (Larner, 2004 in Burck, 2005). Quantitative research methods tend to lack the variability and richness of data that can be generated in qualitative methodologies (Burck, 2005). Complex interactions between health professionals and patients are difficult to measure, and qualitative research methods are the best way to explore subtle differences across contexts and individuals (Daniels & Swartz, 2009).

It is important to gain insight into how individuals and different social and cultural groups make sense of their interaction with caregivers and local health care services (Baarnhielm, 2004). Examining the language used in interactions can provide this insight. Both the words

used and the manner in which words are communicated, contribute to the meaning and the characteristics of any interaction. In a social constructionist approach to language, our feelings are affected and shaped by our word-selection and sentence structures (Swartz, 1998). There are many ways patients express and give meaning to illness, suffering and emotional distress, and there are many ways patients and caregivers understand each other and their treatment (Baarnhielm, 2004). According to theories of social constructionism, language and discourse construct external reality and one's own identity (Bruner, 1991; Crossley, 2000 in Rohleder & Gibson, 2006). By examining the talk and non-verbal behaviours in actual interactions, researchers are able to interpret the feelings and experiences of the participants in an interaction. Culturally-sensitive analysis techniques and adapted research methodologies are required to examine communication in interactions because experimental research does not allow for analysis of communication processes and interactive behaviours (Ong, de Haes, Hoos & Lammes, 1995).

According to Habermasian Theory of Communicative Action, all speech acts have the intrinsic goal of mutual understanding, and humans have the capacity to achieve this understanding (Habermas, 1984 in Habermas, 1987). A breakdown in communication in interactions can arise from confusion between '*communicative action*' (interaction that is linguistically mediated and in which the speaker performs actions) and '*strategic action*' (when a speaker produces an effect on the listener to manipulate an outcome to achieve success). Within medical interactions, two voices, namely that of medicine and the patient's lifeworld, predominate (Mishler, 1984). These voices coexist but can lead to health professionals dominating interactions, resulting in ineffective medical care because the patient's lived experience is not heard (Mishler, 1984).

An ecological approach acknowledges the individual as part of a broader social context and contends that individuals are predisposed to communicate according to a pattern that is dependent on each participant's individual communication style (Street, 2002). Contextual and environmental factors, including culture, economy, media, politics and organization influence communication (Street, 2002, 2003). Individual communication style is influenced by identity, personality, linguistic attitude and skills of socialization. Interactions are embedded within an interpersonal context that includes the goals, skills, perceptions and emotions of both participants (Street, 2002). The communication style of a health professional subsequently affects the style of patient communication, and vice versa. The health professional's communication is influenced by past experience of patient interactions, philosophy of care, medical training and socialization (Street et al., 2007).

Within this ecological framework, the interaction between both communication partners in the dyad impacts on the quality of the interaction. Patient demographic characteristics (race, age, gender, education level) may influence health professional communication as the health professional may be biased as a result of perceptions of these characteristics (Street et al., 2007). In the South African medical context, patients are considered to be relatively disempowered by virtue of their race and past inequalities from apartheid. This adds to the traditionally passive patient 'sick role' which is attributed to the information gap between patients and clinicians, and the intimidating medical environment (Allshouse, 1993). From an ecological perspective, these patient characteristics shape the physician's communication, along with the physician communication style (influenced by race, age, gender, orientation to the relationship), physician-patient concordance (influenced by race, age and gender) and physician-patient communication (asking questions, being assertive and expressing concerns).

Implicit in Street et al.'s (2007) model, is that modification of communication style may result in changes to both the patient's communication and physician-patient concordance. Studies from interactions within which one communication partner is impaired, support the influence of modifying the communication of one partner relative to the other. Within the field of aphasia for example, training the non-impaired participant to be a 'communication ramp' to support the relatively disempowered partner to reveal their competence, has been found to facilitate more effective communication (Kagan, Black, Duchan, Simmons-Mackie & Square, 2001). Without pathologising patient communication and regarding it as being impaired, by training health professionals to be the 'communication ramp' in medical interactions, we are afforded the opportunity to improve the quality of communication in interactions. Watermeyer (2008) has called for a modification of Street et al.'s (2007) ecological model in recognition of disease-specific characteristics that impact on communication. Consideration of historical and contemporary perceptions of HIV, culture and language are recommended to acknowledge the influence of the macro-context on concordance and attunement between health professionals and patients (Watermeyer, 2008). This is aligned within Chick's (1995) belief that communication breakdown can be traced to social relations within communities that are constrained by ideologies and values of broader society (illustrated in Figure 3.1).

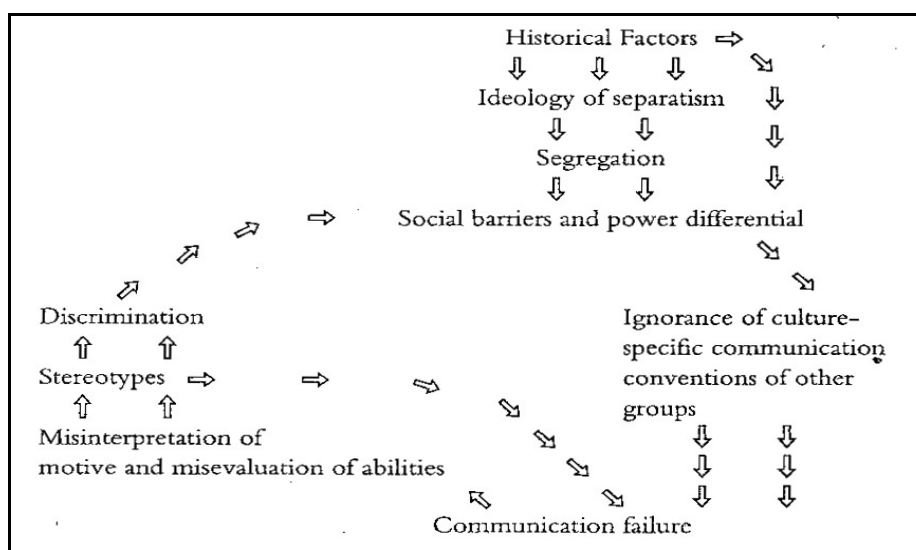


Figure 3.1 Chick's (1990) model illustrating the role of language in maintaining relations of power in interactions and in the wider context of society (Chick, 1995)

3.3 DEFINING 'GOOD' COMMUNICATION IN HEALTHCARE INTERACTIONS

Despite advances in medical technology, communication is often regarded as being the primary diagnostic tool for health professionals (Engel, 1977; Street, 1991 in Ong et al., 1995). Furthermore, communication shapes clinician–patient relationships and the needs of both parties are met through the alternating exchange of information (Ong et al., 1995). Interaction impacts on the quality, quantity and accuracy of data elicited by health professionals; this impacts on the accuracy of diagnosis (Kalet et al., 2004). The need for clear and effective health-professional patient communication is an issue of clinical importance and good communication is associated with improved treatment adherence (Ihler, 2003).

Through good communication, a therapeutic alliance is formed between patients and health professionals that will impact on the patient's adherence to treatment plans, to medication regimens and lifestyle changes (Kalet et al., 2004). Communication involves both an exchange of information (transaction), and the manner in which this information is exchanged (interaction). Some researchers refer to communication skills more narrowly (i.e. equated to transaction) and distinguish them from interpersonal skills (i.e. interaction) (Duffy et al., 2004). However, it is well-established that the two form an integrated whole and that information exchange alone is insufficient to sustain personal relationships (Duffy et al., 2004). Throughout this study, a broader definition of communication as encompassing both interpersonal and the narrower transactional dimension of communication, has been applied.

Communication in interactions is usually described in terms of both verbal and non-verbal¹¹ behaviours and less often, includes a comment on the less tangible *atmosphere* of an interaction best described as:

An unequivocal sense of the right moment to be silent or to continue giving information, of the length of a pause or a gaze cannot be located in a 'hot spot' in our body, but it is a typical phenomenon of the lived body. (Langewitz, 2007, p. 322)

It is insufficient to examine verbal communication alone, as the non-verbal behaviours contribute considerably to the meaning of the interaction. Failure to examine non-verbals, could lead to meaning being misinterpreted in a research context. Within the medical context, it is often assumed that the information flowing from the health professional to the patient has a predominantly biomedical orientation, and that the information flowing from the patient to the health professional, is primarily centered on the patient's lived experience of the illness and relevant life events. However this is a generalization as both biomedical and lifeworld information can be communicated by either communication partner.

In what Mishler (1984) refers to as the 'unremarkable interview', a pattern of the doctor issuing requests followed by the patient responding, is repeated. Although this structured format appears coherent, it is actually fragmented due to a lack of acknowledgement of patient responses, topic shifting and interruptions (Mishler, 1984). To assume that the medical voice dominates the patient's world in all interactions is to oversimplify a number of different possibilities: both the doctor and patient can use the voice of the lifeworld (i.e. 'mutual understanding'), the doctor can ignore the patient's lifeworld voice (i.e. 'lifeworld ignored'), the voice of medicine is used exclusively by both doctor and patient (i.e. 'strictly medicine') and the patient uses the voice of the lifeworld but this is blocked by the doctor (i.e. 'lifeworld blocked') (Barry, Stevenson, Britten, Barber & Bradley, 2001).

Defining what constitutes *good* communication, is subjective and depends on the paradigm of the person interpreting the data. From the perspective of communication as a process of *information exchange*, good communication can be conceptualized as a message which is presented in a way that is accessible to the listener (simple in terms of language choice, level of difficulty and practical application), clear (unambiguous and non-mitigating) and structured (logically presented) and was considered to facilitate understanding. Evidence of the communication being understood can be shown in listener demonstrations of understanding (verbally and non-verbally),

¹¹ Verbal behaviours refers to the spoken language used as well as the manner (e.g. tone, loudness level, intonation) in which utterances were expressed. Non-verbal behaviours include all body movements and positioning of the participants during the interaction.

a lack of confusion in their responses, a lack of breakdown in communication, and in the thread of meaning being comprehensible and logical. From a patient-centered paradigm, good communication would also need to facilitate the expression of empathy and lead to an atmosphere of collaboration. In keeping with both a patient-centered approach and Mishler's theory of the patient's lifeworld, good communication is that which is shaped by the health professional to elicit the patient's explanatory model or to explore the patient's lifeworld. Information exchange is a necessary component of this. The issue of empathy is contentious as some researchers have questioned whether or not empathy can be systematically taught and whether or not empathy is a skill or an attitude (Pellegrino, 1999 in Klitzman, 2006) whereas others propose that it may be more beneficial to teach specific skills concerning content and process factors rather than trying to instill empathy (Klitzman, 2006). In being culturally-sensitive, cultural attunement to the customs, beliefs and rituals of the patient and an awareness of cultural and linguistic barriers is necessary (Hoskins, 1999). This is also referred to as cultural safety, defined as:

A situation in which a client feels that their cultural, social and human values are respected, and that an organization providing services to that client re-orient its institutional practices, values, resource and governance arrangements accordingly. (Phillips 2007, p. 67 in McGrath & Philips, 2008)

Cultural safety extends beyond cultural awareness and cultural sensitivity, which assist practitioners in recognizing their personal attitudes and prejudices; cultural safety explicitly acknowledges the experience of the recipient of care (Nguyen, 2008) and thus fits well within a patient-centered paradigm. The clinician's use of narratives has been explored within multilingual encounters as a culturally appropriate method to obtain the patient's story (Penn, 2000; Evans, 2001).

Recently there have been moves to standardize definitions of the components of communication and to recommend best practices for teaching communication skills. In America, two conferences held in Kalamazoo, Michigan, have attempted to define the content of communication (Duffy et al., 2004). Table 3.1 is a compilation of factors considered to result in 'good' communication, taken from a variety of sources. It needs to be acknowledged from the outset that numerous published recommendations for improving communication exist. In addition to the Kalamazoo II report recommendations (Duffy et al., 2004), the studies selected for inclusion in the table relate particularly to the multilingual South African context (Penn, 2007), to the disease-context of HIV (Watermeyer, 2008), recognize the importance of cultural sensitivity and communicating about sensitive topics (Klitzman, 2006) or emphasise patient-centeredness (Mishler, 1984).

Table 3.1 demonstrates the many recommendations for facilitating 'good' communication in the literature. Some authors, notably Klitzman (2006), are a particularly useful resource for

discussing traditionally sensitive topics such as sex which are applicable *within* interactions. Other authors have extended their recommendations about communication beyond the boundaries of just the clinician-patient encounter; Penn (2007) has made recommendations for communication facilitators immediately prior to and after interpreted interactions, and Duffy et al. (2004) have made recommendations on communication facilitators within the health care team because clinical work with peers and colleagues is equally important to ensure good communication and this has been confirmed in numerous other studies (Lipkin, Putnam & Lazare, 1995; Kalet et al., 2004). Competence in teamwork requires speaking up against an authority gradient, clarity in assuring the sequence of messages-sent-message-received, attentiveness to roles and relationships, monitoring and backup (Duffy et al., 2004).

Penn (2007)'s recommendations relate particularly to multilingual interactions in which an interpreter is present. Given the multilingualism of the South African context, it is likely that these recommendations hold merit in same-language and cross-language interactions in health care. Prior to an interaction, the setting needs to be prepared by checking the seating arrangements and that provisions have been made to limit the impact of potential noise, interruptions, or a lack of privacy (Penn, 2007). After the enrolment session, the participants' comprehension should be checked through culturally relevant methods including narrative or open-ended questions and suitably adapted materials should be sent home (Penn, 2007; Canadian HIV Legal Network, 2002). Pope (2004) cautions against exclusive use of checklists to check patient understanding in multilingual encounters, because they may result in decreased opportunities for participation and fewer open-ended questions. Instead, working with other bilingual health professionals and asking interpreters for feedback after interpretive sessions is recommended (Pope, 2004).

Table 3.1 Some recommendations for achieving ‘good’ communication in medical interactions from Duffy et al., 2004 (1), Houts et al., 1999, (2) Klitzman, 2006 (3), Mishler, 1984 (4), Penn, 2007 (5), Watermeyer, 2008 (6), Watermeyer & Penn, 2009a, 2009b, 2009c (7)

Category	Specific facilitators
Simplification of complex information	Spoken language: Simplification of spoken language by presentation in short, manageable chunks, avoiding embedded sentences (5). Monitor the length of sentences & the consistency of the terminology used (5). Repetition, rephrasing, slower speech, cross checks, literal language, analogies & examples (5). Highlight topic changes (5). Bring important aspects to the fore (5). Provide direct/ concrete information without euphemisms (3, 4). Use language the patient can understand (1). When discussing ‘taboo topics’, be blunt but do not use technical terms (3). Written materials: Simplification of language in patient written materials (2). A level of Grade 6-8 is recommended in consent materials (5). Check cultural meanings of critical items (5).
To help patients remember information	Provide small chunks of information: The more information given, the less patients recall: Only 29-72% is remembered (2). Use of pictographs (6). Dual use of written information and pictographs (2, 6). Use supports, such as props, videotapes, printed material with a large type face, or pictorial representations (5, 6, 7). Check patient understanding through questioning, self-report or recall (1)
Exploration of the patient’s lifeworld and perspective	Appropriate use of open and closed ended questions (1). Open-ended questions allow patient responses to be unconstrained (4); Make explicit connections between the health professional’s lifeworld and that of the patient (4). Explore contextual factors (family, culture, gender, age) (1, 3). Ensure enough time/opportunity for a person’s story to emerge (5). Provide talk that flows and which is social and not just linked to the aims of the enrolment session (5). Explore beliefs concerns and expectations (1). Encourage questions (1). Emphasise the patient’s experience of the illness (1). Ask questions that are easier to understand and are non-judgmental (3). Pinpoint specifics about what is happening with non-adherence (3).
Listening to the patient	Not interrupting (4); Allow the patient to complete his/ her opening statement (1). Active listening (4). Elicit the patient’s full set of concerns (1). Stop and ask if clarification is needed (5).
Expression of empathy	Use of statements that affirm common humanity (1). More sensitivity when discussing bad news, adherence and non-medical concerns (3). Respond to patient feelings (1) and Express own feelings (4). Establish/ maintain a personal connection (4). Awareness of the influence of the patient and clinician’s feelings on the relationship (1). Be sensitive to non-verbal aspects of the session, such as seating and individuals’ gaze, body posture, head movements and gestures (3, 5). Encourage through acknowledgement of small successes (3).
Working towards collaboration	Encourage the patient to participate in decisions to the extent that they desire, and check the patient’s willingness and ability to follow the plan (1). Identify and enlist resources/ supports (1). Acknowledge process factors e.g. having kept patients waiting (3). Charting at the bedside increases patient perception of contact time (3).
Provide closure	Ask whether or not the patient has other issues/ concerns (1, 3). Summarise and affirm with the plan of action (1). Discuss follow up, next visit and plan for unexpected outcomes (1). Follow up with more details about what to expect and when (3).

3.4 COMMUNICATION BREAKDOWN

Communication breakdown is assumed to have occurred when the information transferred results in misunderstandings on the part of either participant, and/ or poor clinician-patient rapport. Evidence of communication breakdown is well-documented in interaction analyses. However this may not necessarily be apparent to participants at the time of the interaction. A number of situations contributing to communication breakdown are summarised in Table 3.2.

Table 3.2 A summary of situations identified by Fallowfield et al. (1998) that contribute to communication breakdown

• Communicating complex information • Informed consent • Giving information to relatives (Relatives withhold truths, angry relatives, conflicting views over management of the child) • Emotional or personal information • Coping with motion in a busy clinic • Breaking bad news to young parents • Discussing recurrence with patients who have had a toxic treatment to no benefit	• Communicating with colleagues when another colleague has given an unrealistic hope or colleagues with different philosophies • Changing treatment conditions (e.g. from curative therapy to symptomatic control) • Practice constraints (privacy, time, conflicts between academia and patient care) • Trust, hope and truth: Being truthful and maintaining hope, challenging denial • Discussing difficult topics: eg. Sex or giving negative feedback to juniors
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Fallowfield et al. (1998) reviewed documented consequences of communication breakdown, and reported that the following resulted: distress and uncertainty regarding diagnosis, prognosis and treatment, increased stress, lack of job satisfaction, burnout, faulty clinical data and worsened clinical and psychosocial outcomes. Other studies indicate confusion regarding the participants' roles and obligations in clinical trials (Watermeyer, 2004) and poor adherence (Silverman, 1997). Research shows that although there are individualized variations in communication style between health professionals, communication patterns within interactions do not vary across patient characteristics (Piccolo et al., 2002 in Ellington et al., 2006). Health professionals vary in the amount of biomedical information they provide, the use of emotionally-centered comments, psychosocial discussions, partnership-building statements, facilitation of patient involvement and understanding and addressing client distress (Ford et al., 1996, Lobb et al., 2005 in Ellington et al., 2006).

Maguire and Pitceathly (2002) provide a comprehensive review of health professional behaviours leading to breakdowns in communication. The literature suggests that it is both the topic (i.e. the type of information) asked for by clinicians, as well as the manner in which

it was asked, that contributes to communication breakdown. Patient perceptions and the psychosocial impact of illness are seldom asked about (Stewart & Roter, 1989 in Maguire & Pitceathly, 2002). In providing information to patients, information is often provided in an inflexible way that is inadequate and incomprehensible to the patient. Patient information needs are ignored and little attention is paid to checking patient understanding (Maguire & Pitceathly, 2002; Fallowfield & Jenkins, 1999). Furthermore, not all health professionals feel instinctively communicative all of the time (Klitzman, 2006). In analyzing the communication in interactions, it is necessary to document not only the topics discussed, but also by whom they were initiated, and to establish which topics and how they were addressed, contribute to communication breakdown.

The use of jargon (e.g. biomedical language and terminology) can lead to misunderstandings in interactions. The use of biomedical language extends beyond just the traditional medical practitioner to complementary and alternative practitioners too (Hollenberg, 2006). Hollenberg (2006) suggested that for the alternative medicine practitioners, this served to increase their professional status and that dominant biomedical patterns exist even when attempts are made to integrate biomedicine within alternative medicine. A reluctance to depart from the traditional medical model due to fears of increasing patient distress, taking up too much time and placing a greater emotional burden on themselves, as a potential reason for deficiencies in doctor communication skills was also found by Silverman et al. (1989 in Maguire & Pitceathly, 2002). Although what actually constitutes jargon in different contexts is subjective, common sense dictates that any terminology used within a specific context that is likely to be difficult for someone unfamiliar with that context to understand, may be considered to be jargon. Examining what jargon is used and who it is used by in interactions, can contribute to our understanding of the degree to which the participants have mutual understanding.

Doctor-awareness of the frequency with which patients withhold information and why this is done, is poor (Maguire & Pitceathly, 2002). Patient reasons include the belief that nothing can be done anyway, a reluctance to burden the doctor, the desire not to seem ungrateful or pathetic, concern that their problems are not legitimate enough, doctors' blocking behaviour and worry that their fears of what they think is wrong will be confirmed by the doctor (Maguire et al., 1996 in Maguire & Pitceathly, 2002). Blocking behaviours that inhibit effective communication include: offering advice and reassurance before the patient has the chance to express their main difficulties, explaining away stress as 'normal', attending solely

to physical ailments, topic switching and ‘jollyng’ patients along (Maguire & Pitceathly, 2002).

Within the context of HIV/AIDS, additional communication barriers have been noted (Fallowfield & Jenkins, 1999). Some of these may be attributed to the disease-context of HIV (Watermeyer, 2008). A lack of time, limited expertise in the HIV field, inability to see the patient’s perspective and strong emotions towards the disease are attributed to interfering with the health professional’s ability to communicate effectively with patients (Fallowfield & Jenkins, 1999). As there are many issues which are difficult to discuss in HIV care, professionals detach and distance themselves from patients (Fallowfield & Jenkins, 1999). They tend to intuitively censor information and use euphemisms rather than talking openly and honestly and feel embarrassment in discussing certain issues (Fallowfield & Jenkins, 1999). Several studies have documented health professional difficulties in discussing ‘taboo topics’ (Klitzman, 2006). In one study, respondents reported that condom use was widely discussed with clients by health care providers. However the dual use of condoms and another contraception method to prevent infection and pregnancy was not reportedly discussed with health care providers (Cooper et al., 2007). In most cases, contraception services were accessed outside of the HIV care and treatment setting, and women participants reported that this constrained their contraception use (Cooper et al., 2007). Perceived attitudes of health care workers towards reproductive choice in HIV positive women and men are important in that health carers views can influence clients’ reproductive decision-making as not encouraging open, non-judgmental, non-directive discussions impacts on individual and public health (Cooper et al., 2007).

Much of the health communication literature focuses on doctors specifically, but many of the communication characteristics are evidenced in other health professionals too (e.g. in alternative medical practitioners (Hollenberg 2006)). However, evidence from the field of pharmacy (Watermeyer, 2004, 2008; Pilnick, 1998, 1999, 2003) and genetic counselling (Ellington, 2006) suggests that there may be unique characteristics in interactions involving different professions.

From Ellington et al.’s (2006) study in genetic counselling sessions, communication was regarded as being predominantly educational in nature with the counsellors and clients devoting the majority of their dialogue to providing biomedical information. A range in usage was found reflecting content (biomedical and psychosocial) and process (teaching and counselling) when mapped onto current models of counselling, suggesting that counsellors have unique styles in which they combined educational and counselling approaches

(Ellington et al., 2006). In Ellington et al.'s (2006) study, four communication patterns were identified; Two indicated a focus on psychosocial content, namely the counsellor driven psychosocial pattern (in which the counsellor dominates with a discussion of issues and the client's voice is largely absent, suggesting the counsellor is exercising verbal control and presenting or teaching information) and the client-focused psychosocial encounters (genetic counsellors facilitate the client opening up and sharing psychosocial information). The other two patterns are consistent with a biomedical focus, namely the biomedical question and answer pattern (the client actively asks questions and listens to the counsellor providing biomedical information which is also referred to by some authors as the consumerist pattern) and the most common of the four patterns which is the client-focused biomedical pattern in which both the counsellor and the client are involved in exchanging biomedical information (equal proportion of counsellor: client discussion).

In contrast to physician-patient interactions, genetic counselling clients do not have common social interaction templates for encounters with genetic counselling (Bernhardt et al., 2000 in Ellington et al., 2006). Furthermore, clients typically do not develop an ongoing relationship of care with genetic counsellors as that same client might with a primary care physician (Ellington et al., 2006). Ellington et al. (2006) concluded that it is important to be sensitive to the fact that there are a variety of effective communication patterns and that counsellors may vary in their ability to use different patterns. These findings support the need to examine communication behaviours for different professions as communication patterns may vary.

Communication breakdown occurs commonly and has consequences on the outcome of medical interactions. Characteristics of different professions and in different fields may contribute to a greater or lesser extent to communication breakdown. In South Africa and other resource-constrained settings, counsellors differ in job description and length of training markedly from countries such as the UK. This suggests that even within professions, variations are also likely to be apparent.

3.5 MODIFYING COMMUNICATION IN INTERACTIONS

The consequences of communication breakdown provide motivation for modifying communication in interactions through training to improve the quality of interactions. Further support for improving the communication in interactions comes from professional bodies, patients' efforts to play a greater role in their own care, educators who now understand more effective instructional methods for teaching communication skills and market forces that now recognize the role of communication in impacting on the perceived quality of doctor-patient

interactions, and the recruitment and retention of patients (Aspergern1999; Kalet et al., 2004). Communication skills teaching and assessment has become more visible in medical education where it is recognized as a measurable clinical skill (Makoul, 2003).

Research indicates that communication skills can be taught and that changes are maintained and expanded when taught well (Gordon & Rost, 1995). Numerous studies have found communication skills training to be effective with medical doctors, nurses and students, dispelling the myth that communication skills reflect personality and talent which cannot be improved (Fallowfield, Lipkin & Hall, 1998). Results from studies indicate that those with the lowest pre-course results improve the most (Chan et al., 2003).

Within anxiety/ uncertainty management theory (AUM), the effectiveness of communication across relationships and cultures is attributed to individuals' abilities to manage anxiety and uncertainty (Gudyknst & Nishida, 2001). By training health professionals and decreasing their anxiety, communication can be improved. Certainly, the results from numerous health professional communication interventions support this. After training, doctors' attitudes seemed more centered on the patient, and less on the disease (Fallowfield et al., 2002). Furthermore, more accurate identification of patient problems has been reported (Maguire et al., 1986 in Maguire & Pitceathly, 2002). Better patient satisfaction and understanding of diagnoses, investigations and treatment options and better patient psychologic adjustment have been reported (Maguire & Pitceathly, 2002). Better patient adherence, a decrease in patient distress, vulnerability and depression and improved physician-patient relationship results (Bull, 2002; Silverman et al., 1998 in Maguire & Pitceathly, 2002). Improvement in doctors' well-being due to greater job satisfaction and less work stress has also been reported (Maguire & Pitceathly, 2002).

Some studies, such as that by Epstein, Morse, Frankel, Frarey, Anderson & Beckman (1998), have noted that there are still significant barriers between patients and health professionals who have received advanced training in doctor-patient communication. The manner in which topics are introduced and the doctor's handling of awkward moments and problematic language as well as the extent to which the health professional attempts to understand the patient's perspective all impact upon the outcome and success of HIV-related discussions with patients (Epstein et al., 1998).

Difficulties have been experienced in implementing communication training in some studies. In the university context, factors contributing to this are competing curricular priorities, decreased faculty time for teaching, and students' resistance to change in general and the

content in particular (Kalet et al., 2004). Factors that have been shown to facilitate the implementation of communication skills training include support from oversight bodies and accreditation standards, establishing an evidence-based outcome, institutional flexibility and choice in curriculum content (Kalet et al., 2004). Motivation for in-service training can be found in studies that show that communication skills which are taught in preclinical years to medical students, often decline by the time of graduation as there is insufficient reinforcement (Scott, Donnelly & Hess, 1975 in Kalet et al., 2004). Time and clinical experience have not been shown to resolve communication problems (Fallowfield et al., 2002).

In the field of HIV, it remains unclear to what extent communication and medical interactions can be modified given the existence of societal beliefs about disease and the prevailing discourse of stigma, poverty and both historical and current health care inequalities in South Africa.

3.6 METHODOLOGIES USED IN HEALTH COMMUNICATION RESEARCH

Interactive communication in healthcare settings has particular methodological challenges (Hall, 2003). Experimental research is insufficient to investigate the influence of communication on patient outcomes, or to gain insight into how contextual variables (patient background, disease and site) influence communication in interactions (Ong et al., 1995). In studying communication in health care, it is necessary to examine both the interactive processes as well as factors influencing these processes (Pilnick & Dingwall, 2001). Finely-tuned qualitative research methods are needed in order to understand medical interactions (Daniels & Swartz, 2007).

Patient-centeredness is relevant in selecting communication methodologies as it emerged from a paradigm of relativism rather than universalism. By looking for a limited range of signs and symptoms, universalists are unable to enter the emotional worlds of the people they are studying (Swartz, 1998). Checklist ‘taxonomic’ approaches that are commonly used as communication methodologies appear to do just that in that they impose a predetermined list of criteria onto a situation, thereby failing to recognize a relativist (patient-centered) approach.

The fields of applied linguistics and health communication can offer much to general medical research in terms of theoretical frameworks and culturally sensitive methodologies. Techniques such as Conversational Analysis have proved to be effective in examining issues such as the detailed understanding of interpreting dynamics, power relations and gender

issues and are useful in determining the manner in which information is shared with patients, and how it is understood (Pilnick & Dingwall, 2001). In addition, the qualitative research methodologies of narratives, and discourse analysis have the potential as excellent research methodologies in the field of HIV/AIDS (Burck, 2005).

3.6.1 Conversational analysis and discourse analysis

In the field of ethnomethodology, Sacks developed theories of behavior patterns of interactions based on analyses and observations of conversations which resulted in the identification of conversational patterns and rules within conversations (ten Have, 2000). In what has become known as Conversational Analysis (CA), researchers base their analyses on this premise that interactions are made up of predictable sequences between speaker and respondent. CA is a data driven approach that emphasizes the value of descriptions of observable behaviour. The success or breakdown of communication is analysed within the context of the conversation and the responses of each conversation partner.

Conversational analysts view communication as a collaborative achievement by partners who engage in turn-taking (Schlegoff, 1982 in Perkins, 1995). Turn-taking repair and topic management can be examined to yield evidence of communication breakdown as well as the strategies employed to deal with problems (Perkins, 1995). Turn-taking and the specific sequences that occur in a conversation are regarded as being the basic foundation of CA (Jones, 2003).

CA has been employed in numerous studies on institutional interactions examining how participants construct and orientate themselves to institutional norms (Drew & Heritage, 1992; Heritage & Maynard, 2006). Microanalysis of interactions provides evidence of how power relations in interactions are played out (Nettleton, 2006).

CA allows for the careful scrutiny of the conversational participants within a naturalistic interaction that is not artificially staged by the researcher (ten Have, 2000). It provides the researcher with a valuable method of identifying linguistic, cultural and social themes and dynamics that facilitate or inhibit communication. The potential of CA as a research tool has been criticized for its lack of structure and definition in comparison to quantitative research. Ten Have (2000) puts a strong case forward in favour of CA stating that studies using the technique of CA do not usually have rigorously pre-defined frameworks but do follow a degree of structure as the researcher follows a protocol of systematic analysis and the extraction of themes and patterns across the domains of conversation. Triangulation of data

through interviews, ethnographic observations and the use of invented examples based on the researcher's observations and intuitions (ten Have, 2000) can be used to strengthen the validity and reliability of CA results.

Research into the use of CA within health care contexts is beginning to gain recognition. It has been used to investigate nurse-patient communication (Jones, 2003), dietician-patient interviews (Tapsell, Brenninger & Barnard, 2000), in Alzheimer's disease (Muller & Guendouzi, 2002) and in many studies within the clinical speech therapy setting (Tetnowski & Franklin, 2002). In the field of HIV, CA has been used in studies by Watermeyer (2004) and Rust (2005). In her exploratory case-study of the communication and potential use of pictographs during the informed consent process in an HIV/AIDS vaccine trial, Watermeyer (2004) aimed to make recommendations regarding the potential use of pictographs to assist health professionals in communicating vital information to potential trial participants. An essentially qualitative paradigm was employed throughout and data was analysed using CA in conjunction with ethnographic observations of the research process. Turn-taking, repair and the roles of interlocutors were examined. Results indicated an awareness by health professionals of some communication barriers and the need to ensure understanding of key concepts within the protocol. Watermeyer (2004)'s study was limited by its small number of participants and the presence of the researcher during interviews which could have impacted on the reliability of the data. However, it highlighted a number of avenues for further research including the potential to analyse and to compare the same process at other sites, as well as examining other variables such as gender, education, age and language upon the informed consent process. Likewise, Rust's (2005) study was limited by its small sample size. Rust (2005) interpreted the results as the counsellors operating from two different communication styles of mutuality and paternalism.

Discourse analysis involves similar close scrutiny of language and the patterns of talking from which discourse analysts believe people construct an understanding of their world (Burck, 2005). Discourse is therefore a set of meanings, metaphors and representations which produce versions of events and the social world and is located within a social constructionist paradigm. Discourse analysis typically involves careful examination of language transcripts to see how themes and topics are discussed. In addition to looking for how language constructs ideas or information, variability and inconsistencies are sought to see what assumptions they reveal and what the implications of this are (Burck, 2005). It is common practice to involve a group of researchers to analyse transcripts so that multiple perspectives can be pooled and to judge the persuasiveness of the analysis (Burck, 2005). Many different

types of discourse analysis exist and many forms of analysis fall within the umbrella term of 'discourse analysis'. My study borrows elements of CA and discourse analysis methodologies in a hybridized linguistics method of analysis, as described in Chapter Five.

3.6.2 Ethnography

There is a need to find out more about what health workers in a range of contexts experience and how they do their work (Kai, Beavan, Faull, Dodson, Gill & Beighton, 2007). Ethnography, which emerged from the field of social-anthropology, is a method that allows for detailed examination of context (Button, 2000). Through immersion in the study population, ethnography aims to provide an understanding of the social world and behavior (Galanti, 1999). This is achieved through detailed descriptions of the population group, their beliefs and culture (Snape & Spencer, 2003). The analysis calls for the interpretation of meanings of certain actions in striving towards understanding people and in the development of new theoretical ideas (Hammersly, 1998). Virtually any ethnographic model must take language into account (Saville-Troike, 2003). *"It is well-established that there is a correlation between the form and content of a language and the beliefs, values, and needs present in the culture of its speakers"* (Saville-Troike, 2003, p. 28).

The application of ethnography to the social and health sciences and to clinical encounters is strongly supported (Flick, 2002; Harrison, 2002; Lincoln, 1992; Scheper-Hughes, 1990; Simmons-Mackie et al., 1999). Particularly in the South African HIV/AIDS context with the added complexities of multilingualism and multiculturalism, ethnographic research can be used to complement other quantitative and qualitative methods in which more structured research methodologies can have limited application (Geertz, 1996 in Flick, 2002).

Naturalism, understanding and discovery are three guiding principles of ethnographic research. Naturalism requires that the everyday context of people's lives forms the backdrop to the research stage as opposed to contrived experimental conditions (Hammersly, 1998). Artificial settings where speech acts need to be performed on demand are unlikely to generate the subtleties in selection of speech forms, shifts in formality and intimacy by which speakers categorize each other in every day interactions (Gumperz, 1972).

"Since language choice is largely subconscious, and since the signaling of social information is crucially dependent on context, the study of social meaning requires fieldwork techniques capable of challenging the verbal skills employed by speakers in everyday interactions". (Gumperz, 1972, p. 23)

Observing people's behaviour, studying what they think, do and believe, and interpreting what they actually think and believe are the core features of ethnographic research (Galanti, 1999). To this end, patient-observation is critical during data collection as a means of allowing the researcher to learn the cultural rules of behaviour governing the research population (Galanti, 1999). The researcher can consequently study phenomena as they occur and acquire additional insights through self-experience. The ethnographer should strive to recreate an authentic picture so that the reader can identify with the situations, sites and sounds that are described. These descriptions need to be rich in detail, meaning and interpretation (Kovarsky & Crago, 1991).

The ethnography of communication has been influenced by Functionalism, Interactionalism and Marxism (Saville-Troike, 2003). From a Functionalist approach, language is one of the integrated systems of society and culture, and it reflects and functions in relation to social categories. An Interactionalist approach emphasizes the variations in language which need to be accounted for, such as establishing and expressing role relations. Within this approach, language is regarded as a dynamic factor in an individual's construction and realization of their social identity. From Marxist theory, language is considered to replicate fundamental differences and inequalities between social groups, enabling discussions of power in communication through critical approaches to discourse analysis and ethnography.

Examples of how ethnography has been effective in examining HIV-related issues in sub-Saharan Africa can be found in the ethnographies of counselling health workers and mothers in the context of PMTCT counselling (Buskens, Jaffe & Mkhathshwa, 2007) and in explaining adherence success in sub-Saharan Africa (Ware et al., 2009).

3.7 THE SOUTH AFRICAN CONTEXT: A CHALLENGE FOR INTERACTIONAL RESEARCH

South Africa's history of segregation has heightened traditional doctor-patient divides. Evidence of this can be found in the majority of health professionals in South Africa not speaking the same language as their patients, with less than 5% of doctors having the ability to conduct consultations in the first language of their patients (Levin, 2006a, 2006b). Even when linguistically matched, some interactions still take place in a language other than the first language of the patients (Schwartz, 2004; Levin, 2006b). From studies of immigrants in other countries, particular difficulties are encountered by patients who do not speak the same language as service-providers. Health professional feelings of uncertainty, inconvenience and fear of stigma may contribute to nurses not checking patient understanding for patients with limited English proficiency (Pope, 2004). A lack of understanding of how to take medicines,

the purpose of medicines and their common side-effects, were identified as the primary reason for non-English speaking patients making errors with medicine administration (Fejzic & Tett, 2004). Semantics, the meaning attached to words, can also be lost in translation (Fejzic & Tett, 2004).

For communication to be effective in intercultural interactions, an awareness of many complex dimensions is required; mindfulness and a critical perspective about identity and relational meanings within the intercultural setting are among these (Ting-Toomey, 1999). Additionally, awareness of how to practically apply knowledge about intercultural diversity, is needed (Kai et al., 2007).

Patients who do not speak English are relatively disempowered because packaging inserts and treatment literacy materials are usually only available in English (Odegard, Lam, Chun, Blough, Li, & Wu, 2000) and have poorer adherence (Orrell et al., 2003). In every day communication within a multilingual context, many strategies are employed for more effective interactions such as code-switching and code-mixing. The extent to which these facilitate or hinder communication in a medical context, has received limited attention. In one study in the pharmacy context, Watermeyer (2008) found that a group of pharmacists adapted their communication strategies to facilitate patient understanding within a multilingual hospital context in South Africa. Pharmacists in this study stipulated the agenda for the session and used repetition, reinforcement, summation, code-switching and repair strategies to facilitate effective communication (Watermeyer & Penn, 2009a, 2009b, 2009c). As code-switching and code-mixing are a product of the pattern of social relationships (McCormick, 1995) and as they occur commonly in Cape Town speech communities, examining code-switching and code-mixing in interactions can tell us about the relative status of the speakers and their rapport.

Given the linguistic diversity of the South African population, both translation and interpreting are necessary in healthcare. There is a shortage of trained interpreters and translators in the health sector with very few professionals interpreters being employed in public hospitals. Government policy makes provision for interpreters and recommends their employment to enable patients to be consulted in their home language (PANSALB Act 1995; LANTAG, 1996). However, in reality, few trained interpreters are employed. Instead, ad hoc interpreting by nurses, counsellors, other clinic staff or family members, is the norm (Crawford, 1994; Flores et al., 2003; Penn, 2007; Anthonissen, 2008).

In interpreted consultations, intercultural translation may be challenging as there is not always a translation equivalent and words hold different meanings across cultures (Schaafsma et al., 2003; Levin, 2006a, 2006b). From research into the use of medical terminology in informed consent, Woodsong and Karim (2005) have recommended specific guidelines for inclusion of both individual and community resources in developing local and dialectal interpretations of terminology. Interpreting has often been criticised for a lack of accuracy, but some errors in translation are beneficial in aiding patient understanding and contribute to interpreters playing a cultural mediating role (Evans, 2000).

Studies show that interpreters are seldom neutral in interactions and tend to side with clinicians rather than the patient in conflict situations (Bolden, 2000, Cambridge, 1999 in Hsieh, 2006). Interpreters may attempt to resolve conflicts in their performances and role expectations of the other participants (Hsieh, 2006). There are vast cultural differences, expectations and diverse goals between doctor and patient which cause interpreters to mediate this conflict (Hsieh, 2006).

Within the South African context, conversational analysis has provided insights into interpreting in cross-lingual interactions with evidence of mistranslations and the identification of factors facilitating or preventing effective communication (Penn, 2007). The call for the merging of scientific rigour and artistic sensibilities in examining the rich and diverse South African context (Penn, 2007) fits well with the call for *process* rather than *outcomes* research to examine interactions in healthcare.

3.8 THE CONTEXTUAL DEBATE: THE MEANING OF ‘CONTEXT’ IN ANALYSING COMMUNICATION IN INTERACTIONS

Context in health communication is specified in many ways. Kleinman (1988) emphasized the importance of the institutional context on communication in interactions; Street (2002) refers to the importance of both the interpersonal context, and the environmental/ situational context; Chick (1995) traces communication breakdowns to the wider historical and societal context, and Lupton (2003) and Watermeyer (2008) add the disease-context to the aforementioned models. In contrast, within the literature on the analysis of communication through techniques such as conversational analysis, context has a far more specific meaning relating to the position of an utterance within a sequence of turns. In fact, CA purists believe that the only relevant context for analyzing interactions, is how each turn is contextualized within a script, and that the background or situational context is irrelevant (ten Have, 2000).

Sometimes factors within an interaction are referred to as the ‘micro’-context (specified as including language use, discourse, verbal interaction and communication by Van Dijk, 2001), and those external to the interaction such as the system of health care (specified as including power, dominance and inequality in social groups by Van Dijk, 2001) are regarded as the ‘macro’-context. The institution (referred to as the ‘Meso context’ by Mishler, 1984) is conceptualized as a pivot between social structuring and the interaction which is the social action.

There is recognition that these layers overlap and are indivisible and that creating a distinction between these layers creates a rift between the interaction, the institution and society (Fine, 1993). With this in mind, it may be helpful to conceptualise context as comprising of many layers, like an onion. Towards the outside, broad socio-political factors constitute the context within which culture, environment and disease contexts are embedded. Deeper within, lies the interpersonal context, and deeper still, the conversational context referred to in conversational analysis theories.

The significance of what Hilbert (1990) refers to as the ‘micro-macro debate’, lies not so much in which factors constitute which layers of context, but in the relevance of context in the interpretation of data. Working from a bottom up approach, conversational analysts believe that the truth lies in the data itself, and that utterances are shaped by the conversational activity in which they occur (Sacks, Schlegoff & Jefferson, 1974). Within a CA approach, researchers need not know anything of the background of an interaction as the evidence is in the data itself (ten Have, 2000). Talk is therefore analysed with an understanding of how it is normally organized (Pilnick, 1999).

Other researchers (Salter, 2005) have strayed from this narrow CA approach, and have incorporated other methodologies such as ethnographic observations to provide situational context to their studies. Lazarus (1988) supports the inclusion of context in interpreting interactional data, as interactions are integral to the health professional-patient relationship. CA can be conceptualized as providing evidence for the manner in which talk is organized, whereas visiting the situational context provides the justification for why talk is presented in such a way (Silverman, 1999). Observations from Salter’s (2005) study for example, allowed for specific practical recommendations to be made. Watermeyer (2008) followed a similar approach, and contends that it is impossible not to consider the situational context of interactions, particularly within a multilingual and multicultural environment. This is in line with the aim of analyzing talk in order to develop more effective tools for the analysis of distributional, institutional and social structural problems (Schlegoff, 1997).

Watermeyer (2008) draws our attention to the narrowness of CA in identifying site-, disease- and context- specific influences on medical interactions, and questions its practical application in informing models of best practice. In her study on pharmacy interactions in HIV/AIDs, she used a hybridized approach informed by theories of discourse analysis, critical discourse analysis, Foucauldian analysis and methods proposed by Potter and Wetherell (1987) and Roberts and Sarangi (2005) which acknowledge contextual influences on interactions. This approach effectively demonstrated the value of combining qualitative methodologies to demonstrate the influence of disease-context.

3.9 THE HIV DISEASE CONTEXT

Lupton (2003) contends that the degree to which patients are empowered to take control of their own health, is impacted on by the nature of their health problem as each disease has different emotional and physical dimensions. Watermeyer (2008) emphasizes the significance of stigma, discrimination and fear of death, and the way in which the physical manifestations of the disease and treatment side-effects, are experienced by patients with HIV/AIDS. Researchers have cautioned that stigma is by no means unique to people affected by HIV (Klitzman, 2006). Given that HIV is a socially constructed illness, it is important to consider the social, political, economic, linguistic and cultural factors impacting on health care interactions (Watermeyer, 2008).

A new democracy is an era of resurging life. Sex is the most life-giving of activities. That a new nation's citizens are dying from sex seems to be an attack both on ordinary people's and a nation's generative capacities, an insult too ghastly to stomach. (Steinberg, 2008, p. 6)

As discussed in Chapter 2, in South Africa particularly, HIV appears to be shaped by discourses of metaphor, secrecy and the overturning of traditionally held perceptions. Through AIDS, sex (traditionally associated with creation), has become linked to death. Women, givers of life, have become vessels perpetuating a deadly disease through vertical transmission to children. In the context of the newfound freedom of post-apartheid South Africa, in which Posel (2005) argues that liberation became sexualized (as it was *the* sphere within which newfound freedoms from apartheid were asserted), because of HIV, even this sphere needs to be curtailed. Through HIV, the natural order is disrupted as grandparents watch their children and grandchildren die before they do. For many South Africans, optimism about equality has been dashed as it has been shown that in HIV, not everyone is equal: Women, children, black people and poor people are the least equal of all. And, for

many, post-apartheid political optimism in South Africa gave way to a lack of trust and faith in political leaders due to AIDS denialism.

In addition to the over-turning of traditional beliefs described above, HIV has necessitated a shift in perspective on medicine. With the advent of ARVs, traditional perceptions of Western medicine providing a cure for disease with pills and injections had to be tempered with acceptance that all that Western medicine can provide at present is the complex management of a chronic illness. In Africa generally, the duality of perspectives and worldviews (African versus Western) may further complicate perceptions of HIV (Nettleton, 2006) and may add to the confusion and development of myths around the HIV disease, particularly in light of this adjustment needed in our perception of 'treatment'. Given the overturning of traditional perceptions described, it is unsurprising that HIV is considered, more than any other disease, to be stigmatized (Sontag, 1991). Evidence of stigma has been found in the narratives of women (Rohleder & Gibson, 2006) and as surveys of stigma do not measure actual incidents of stigma (Stein, 2003), examining the communication in HIV interactions may provide insight into stigma in the lives of people living with HIV and how it impacts on communication in interactions. As the HIV disease context is shared by both health professionals and patients alike, the discourses on HIV from both health professionals and patients may be valuable in aiding our understanding of health professionals and patients interact within this shared context.

3.10 SUMMARY

This chapter positions communication as critical to determining the quality of health professional-patient interactions within a patient-centered paradigm. Strategies such as training interventions for improving health professional communication are well established. However the degree to which these strategies can be successful in the disease context of HIV remain largely unexplored. There is evidence to suggest that communication may be disease- and context- specific, and that it may vary across different professions. Linguistic-based process methodologies are likely to be well-suited to examining both healthcare interactions, and the diversity of the multilingual, multicultural South African context. Furthermore, when used to analyse verbal behaviours (including topics, code-switching and jargon) and non-verbal features (such as body position and movement), they may be of value in providing rich detail about communication, and may provide insight into how the language used by participants, their self-perceptions and constructs can be interpreted within the disease context of HIV.

In Chapter Two it was established that the ‘disease-context’ of HIV is shaped by our notions of HIV the-disease, constraints within the health care system and a feminized pandemic, which all contribute to the creation of many sub-contexts that may impact on the communication in interactions. Despite this, communication as an interactive process remains largely unexplored. Chapter Three has proposed using linguistic methods of analyses for examining the communication process in interactions within the HIV disease-context which are linguistically and culturally sensitive to the South African context. A number of methodological considerations relating to both the implementation and evaluation of a communication intervention within such contexts, are described in the next Chapter.

In order to examine these issues using a process approach whilst providing a convincing evaluation framework, a number of methodological complexities arising from conducting an intervention study need to be addressed. These complexities are discussed in Chapter 4 that follows.

CHAPTER FOUR

METHODOLOGICAL CONSIDERATIONS

4.1 INTRODUCTION

This chapter will explore the methodological alternatives which exist for evaluating interactional processes and intervention studies in health care contexts.

Based on my evaluation of prior health research in Chapters 2 and 3, as well as the contextual and disease challenges of the topic, a number of important features for assessing and evaluating research are summarized below and justified in the discussion that follows.

Table 4.1 Features selected by the researcher to guide the qualitative communication assessment

- The analysis needs to be data-led and by allowing data to ‘star’ so that the data in all its richness and breadth become the main focus.
- In order to be data led, a turn by turn discourse analysis approach influenced by CA can provide a framework for analysis which will create a degree of standardisation across raters without imposing pre-determined categories for analysis
- The use of real-life data is necessary as it is more naturalistic and is less of a ‘testing’ environment; Furthermore, it is a more powerful learning tool for participants.
- Recordings of real-life data rather than real-time analysis are necessary, to allow for repeated reviews of the data for more detailed analysis, review by multiple raters without intruding on the consultation and participants self-reflection on observation of the recordings
- Interpretation from multiple perspectives is needed particularly as validation by consensus or repeatability is seldom adequate in qualitative research

Table 4.2 A proposed evaluation framework for this study based on the researcher’s review of the literature in Chapter 4

- Flexibility in design: The research design needs to be continually renegotiated with participants by incorporating participant reflections
- Control groups do not serve the purpose of providing rich site-specific information with practical applications and are not necessary for validity as this can be gained through triangulation and respondent validation.
- The use of a pre-/ post- design, establishing baseline measures, rater blinding, participant -reflection, triangulation and respondent validation are all critical
- The participatory nature of the research necessitates evaluation by criteria that differ from other methods. Specifically, alignment with purpose, ownership of the process, development of reflexivity, democratic and collaborative group dynamics, commitment to action and experience, documentation of the process, transferability and construction of practical knowledge need to be commented on.

Qualitative research has been shown to be particularly beneficial in HIV research as the most appropriate method of examining the ‘art’ of healing (Green et al., 2002). However, this can be odds with the call for evidence-based medicine. Particularly as this research is an intervention study and one of the aims is to evaluate the intervention, this chapter discussed the relative merits of assessment and evaluation approaches within a qualitative paradigm. In keeping with the relativist¹² approach described in Chapter 3, these methods need to be data-led, able to generate new information, applicable in linguistically and culturally diverse settings, acknowledge the process of communication and the process of implementing change, and need to recognize context-specificity.

4.2 DIFFERENTIATING BETWEEN ASSESSMENT AND EVALUATION: A NOTE ON TERMINOLOGY

A distinction needs to be drawn between the assessment of an individual counsellor’s communication skills, and the evaluation of an intervention such as a training programme. In this research, in order to distinguish between these, the term ‘assessment’ will be applied to individual participant communication skills, and ‘evaluation’ when discussing the merits of the intervention programme. Evaluation implies a measure of comparison between two different assessments as a means of establishing whether or not the training was successful. In evaluating communication interventions, a discussion of methods of analysis are important as a comparison of the pre- and post- assessment of communication skills contributes to the overall programme evaluation.

4.3 A REVIEW OF TRADITIONAL COMMUNICATION ASSESSMENT METHODS

In an educational context, the outcomes of assessment should promote learning, inspire confidence in the learner, enhance the learner’s ability to self-monitor and drive institutional assessment and curricular change and should include a strong mentoring programme (Epstein & Hundert, 2002). Epstein and Hundert (2002) have identified personal, institutional and societal goals that assessment should serve: for the trainee, assessment should provide useful feedback about individual strengths and weaknesses that guides future learning, fosters habits of self-reflection and self-remediation, and promotes access to advanced training; for the curriculum, assessment can respond to lack of demonstrated competence, certify achievements of curricular goals, foster course or curricular change, create curricular

¹² In a *universalist paradigm*, findings can be discovered objectively and apply to all situations and cultures. In contrast, from a *relativist paradigm*, some elements of a culture are relative to / dependent on other aspects (Swartz, 1998).

coherence, cross-validate other forms of assessment and establish standards of competence for trainees at different levels; for the institution, assessment is useful in guiding a process of institutional self-reflection and remediation, discriminating among candidates for further training or promotion, expressing institutional values by determining what is assessed and how assessment is conducted, developing shared educational values among a diverse community of educators, promoting faculty development and in providing data for educational research.

Traditional communication assessment methods tend to be limited as they appear to be grounded in a reductionist approach. The main methods of assessing communication skills in a medical education setting identified by the Kalamazoo II report (Duffy et al., 2004), were checklists of observed behaviours, surveys of patients' experience in interactions, examinations using oral, essay or multiple choice responses, checklists/ rating systems of observed behaviours and linguistic-based analysis methods, which are discussed below.

4.3.1 Participant interviews about communication

Interviews or 'surveys' of participant perceptions are widely used. They are an indirect measure of what actually occurs within consultations and are quick and easy to administer which is advantageous in the real-life context of a busy clinic. Patient surveys are often used to assess interpersonal skills as patients are often considered to be the best judge of the effectiveness of a physician's interpersonal skills. However, because being rated may influence performance, those being observed should be told which behaviours are being rated (Duffy et al., 2004).

Surveys among American medical schools indicate a variety of methods for assessment in this area, namely: a combination of discussion, observation and practice; small-group discussions and seminars; lectures and presentations; student interviews with simulated patients; student observation of faculty with real patients; and student interviews with patients (Makoul, 2003).

Some researchers have recognized that patient assessment of communication overcomes the limitation of using an observer's rating of the potential inability of a third party to infer patient feelings (Duffy et al., 2004). A problem with using patient perceptions in analyzing communication in South Africa, is that given the history of disempowerment in this country, patients are traditionally not demanding and may not be equipped to assess what constitutes

‘quality’ communication in care. Furthermore, there are language and literacy barriers in using such methods cross-culturally.

4.3.2 Examinations

Assessments of knowledge, perception and attitudes about communication have been shown to be helpful in stimulating learning about novel approaches to communication which could be useful as a means of heightening self-awareness and creating interest in the training programme (Duffy et al., 2004). Examinations are an effective means of testing knowledge and the conceptual basis of interpersonal relationships. In an in-service training environment with adult learners, examinations are problematic as they tend to focus on assessing *knowledge* rather than *abilities*. Knowing how to communicate does not necessarily equate to using that skill in practice.

4.3.3 Checklists and rating systems

Checklists remain the most frequently used assessment tool for assessing communication behaviours (Duffy et al., 2004). Checklists usually involve rater observations of several communication behaviours according to a scale (Duffy et al, 2004). An anchoring statement (a written description of poor and ideal behavior) restricts the raters to the items on the checklist.

Rating systems, can be self-assessments, peer assessments or educator assessments. Peer ratings are accurate and reliable measures of physician performance and may be best placed to measure professionalism (Epstein & Hundert, 2002). Self-assessments with standardized patients are effective when used in programmes that include explicit training in the use of self-assessment instruments (Gordon, 1991 in Epstein & Hundert, 2002). However they have been shown to be invalid and inaccurate when trainees had no training in the use of self-assessment instruments in which case it is more closely related to the trainees’ self-confidence (Epstein & Hundert, 2002).

Ratings can be direct observations of real-patient consultations, simulated encounters with standardized patients or video- and audiotape interactions (Duffy et al., 2004). Objective Structured Clinical Examinations (OSCEs) are useful for formative and summative evaluation in a formal teaching environment but are high in cost (Duffy et al., 2004). A disadvantage to using an OSCE is that it creates the atmosphere of a ‘testing’ environment. Within the context of in-service training in a fragile work environment with limited job security (such as that experienced by counsellors and described in Chapter 2 Part 1), this might be inappropriate as

participants might feel that their jobs are at stake. Standardized patients are often used in educational contexts to provide a uniform experience across many learners (Duffy et al., 2004), but lack the richness and variety of naturalistic encounters as well as the reality of the institutional context.

Traditional checklist methods have high inter-rater reliability (Makoul, 2001). The SEGUE framework is an example of a research-based checklist of medical communication tasks that is the most widely used framework for teaching communication skills in America (Makoul, 2001). Data from clinical skills and assessments with standardized patients provide evidence of concurrent and construct validity (Makoul, 2001). Inter-rater reliability with standardized patients was high when recording performances immediately after a live encounter and when coders were evaluating videotaped and audiotaped encounters. Analysis of recordings is advantageous in a research context as it allows for detailed analysis that can be used comparatively to other encounters (Duffy et al., 2004) and the data can be reviewed and revisited by numerous raters or using different checklists. Checklists scores show improvement with expertise of examiners and the reputation of the training programme, but global rating scales of interpersonal skills may be more valid than behavioural checklists (Epstein & Hundert, 2002). Global rating scales are less helpful in pinpointing areas of relative strength and weakness, and as such are less useful as a teaching tool.

In addition to checklists, a number of researchers have used classification systems which have also been shown to have good inter-rater reliability (Ellington et al., 2006). For example, the widely-used MIPS involves classification of all utterances by participants into content categories (side-effects/ socio-demographic information) and modes of exchange (closed / open questions, expressions of sympathy) (Fallowfield et al., 2002). Similarly, the Roter Interaction Analysis System (RIAS) has been used effectively in research in which sessions were coded according to process (e.g. passive listening) and content (e.g. biomedical focus) to explore whether or not genetic counselling approaches were consistent with the educational or counselling models (Ellington et al., 2006). The RIAS coding system is a method of coding medical dialogue which uses a complete thought expressed as a statement, phrase or single word as a unit of analysis. Each thought is assigned to a mutually exclusive and exhaustive code (Ellington et al., 2006). This framework differentiates between the level of assessment (knows, knows how, shows how, does) and context of care (new problem, chronic illness, emergency, preventative and acute hospital). This framework is plotted onto a grid which is then completed according to the type of assessment conducted (Standardised Patient, video etc) and each category can be combined with a number designating a category such as the

name of a patient, type of exercise or team exercise. An advantage to coding systems such as the RIAS, is that, unlike interviews or checklists, they differentiate between knowledge and demonstration of skill. However, they are similarly reductionist in design as the assessor is restricted to the items on the list.

Further advantages to using a checklist, categorizing or rating system are that they are replicable, reliable and allow for standardized comparison over time. Such systems involve the analysis of recordings of actual communicative behaviours in interactions that are assessed first hand rather than the perceptions of such behaviours. However, checklists and rating systems are limited in terms of construct validity as they limit the assessor to a prescribed set of behaviours. This can fail to generate new information and runs the risk of not necessarily being culturally or linguistically appropriate across contexts as it involves imposing a preconceived framework on a situation. Particularly given the linguistic and cultural diversity in South Africa, the use of ‘Western’ checklists of what constitutes ‘good’ communication behavior, is questionable.

4.3.4 Linguistic-based analysis methods

There is a need to embrace analysis methods that are not limited to predetermined categories in order to stay true to the qualitative ideal of open-ended exploration. In this research, to meet the challenge of assessing communication in a way that it can be compared to existing research without being limited to predetermined data categories and staying true to the qualitative ideal of open-ended exploration without predefined criteria, an alternative assessment approach is needed to traditional communication training assessment approaches.

Duffy et al. (2004) contend that linguistic-based communication analyses are useful in programme evaluations, but are often not feasible within time-constrained settings. Whilst the argument against using linguistic-based analyses due to time constraints may be valid in educational contexts, within a research context, linguistic-based analysis provides a far more accurate and holistic assessment of communication. Methods such as CA are constructionist in design and are not restricted to predetermined items on a list. As it is data-led, CA allows for the generation of novel information and is applicable across languages and in multilingual and multicultural contexts. As it is not context-bound, recommendations can be made that are practical and have foundation in real-life data, which provide for a more powerful learning experience.

However, as discussed in Chapter 3, CA purists do not recognize the influence of context on communication. An assessment framework that is based on the data-led principles of CA and

which follows a structured turn-taking approach is needed. In acknowledgement of context, raters would not be bound to the communication context of the utterance, but could add interpretation based on their knowledge of the situational and disease context. In order to ensure comparison is possible across raters, a framework within which raters needed to assess the communication is needed. In order to avoid the pitfalls of taxonomic, reductionist approaches, the framework would need to be sufficiently broad to allow for the generation of new ideas. Within this framework, Glaser's (1978) constant comparison method can be applied to allow for comparison within transcripts, across consultations and across participants. A grounded theory approach (Glaser & Strauss, 1967) emphasizes the importance of generating ideas and theory that are grounded in the data. Within this approach, it was contended that it is possible to approach a text without prior hypotheses, but more recent researchers have acknowledged that researchers' implicit hypotheses make this impossible (Burck, 2005). Acknowledgement and awareness of researcher preconceptions through reflective practice is effective to counteract this.

In acknowledgement of the role of the participants in assessing communication skills, inclusion of participant reflections would strengthen the validity of the findings and would serve the purpose of assessment outlined above.

4.4 A REVIEW OF EVALUATION METHODS IN INTERVENTION STUDIES

In this section, evaluation methods in communication training programmes and in counselling interventions, are reviewed.

4.4.1 Evaluations of communication training programmes

In order to determine if training methods impact on clinical practice, thorough and objective evaluation is required to meet scientific and economic parameters (Parle, Maguire & Heaven, 1997). Formative evaluation uses checklists to assess learning needs, create learning opportunities and direct feedback and training (Duffy et al., 2004). Summative evaluation is the use of the same assessment tools administered in a standardized way and rated by an evaluator (rather than a teacher) with a predetermined passing score (Duffy et al., 2004). Summative evaluation is a powerful means for driving curricular content and what students learn (Epstein & Hundert, 2002).

As described in Section 4.3 above, in choosing not to follow a checklist approach, the evaluation framework for this research needs to be based on alternative assessment methods. There is criticism for training evaluations which are too narrow, lack structure and neglect

aspects such as attitudes and beliefs (Parle et al., 1997). As a result, multiple methods of assessment are considered to be the most effective means of evaluating communication training programmes (Epstein & Hundert, 2002).

A review of the literature revealed a number of different methods that have been used to evaluate prior communication skills training programmes. Evaluation strategies used in five successful communication skills training programmes, include:

- In the Macy initiative (Kalet et al., 2004), standardised patients, a pre- and post-intervention design, rater blinding and baseline measures were used.
- Baile, Kudelka and Beale (1999) made use of satisfaction questionnaires and self-efficacy measures in their communication skills training for oncologists.
- Fallowfield et al (2002) also trained oncologists but used objective and subjective ratings by all participants, self-confidence and attitude scores, case selection from a larger data sample and control groups.
- Byrne, Watson, Butler & Accoroni (2006) used self-administered questionnaires and qualitative feedback in examining MI in sexual health.
- Parle et al. (1997) used skills analysis of transcripts, pre- and post- intervention, self-efficacy measures, outcome expectancy beliefs and qualitative feedback in evaluating communication with cancer patients.

A common feature of evaluation methods is that pre- and post- measures have been used in the majority of programmes to determine the impact of the intervention. Another common feature was the use of multiple methods of analysis to triangulate findings, and data collection methods that allowed for re-evaluation at a later date through the use of formats such as video- or audio-recordings. More recent evaluations have combined objective and subjective measures to strengthen validity of findings whereas earlier evaluations relied on subjective measures such as self-ratings and attitudinal scales.

Based on the recommendations from the literature, a number of elements needed to be factored into an evaluation framework for the communication training programme in this study, namely a pre-/ post design, establishing baseline measures, the use of blinding, self-reflection, a framework rather than a rating system and triangulation (e.g. inclusion of semi-structured interviews to support findings). These are described below:

- **Pre- and post- design**

Pre- and post- designs are commonly used in programme evaluations as they allow for an evaluation of change in the participant communicative behaviours.

- **Establishing baseline measures**

The Macy Initiative established baseline measures prior to the development of the communication curriculum (Kalet et al., 2004). This involved each university inventoring its baseline communication curriculum, an assessment of institutional characteristics and barriers and promoters for communication change. Semi-structured interviewing of previous communication training and capturing of existing communication practices through video-taping allows for a measure of baseline performance.

- **Use of blinding**

Blinding the researchers to the content of the intervention in a study strengthens the validity and generaliseability of the findings. This can be further strengthened by the researcher not conducting the training, but analyzing it through video recordings and by the communication raters being blinded to both the training content and to which consultations are pre- and post-intervention. Time-point of assessment concealment from raters has been used effectively in other programme evaluations too (Fallowfield et al., 2002).

- **Self-reflection, Reflexivity and Respondent validation**

Reflexivity “the knower’s mirror”(Malterud (2001, p. 484) involves focusing on the context of knowledge construction and the researcher-effect at every step of the process, through conscious awareness by the researcher of this potential for bias by systematically journaling and reflecting on the research experience (Mays & Pope, 2000).

Qualitative research, arose out of the post-positivist rejection of a single, static, objective truth (universalism) and so the search for ‘reality’ in qualitative research involves the negotiation of truths through subjective accounts (Winter, 2000) A researcher’s theoretical framework defines both the recording and interpretation of data and qualitative researchers need to embrace their involvement and role within the research (Winter, 2000). Researcher bias is impossible to eliminate (Luttrell, 2000), so it needs to be acknowledged through researcher reflexivity (Malterud, 2000) in an effort to identify their own biases, expectations and theoretical sensitivity (Galanti, 1999; Gonzalez, 2000).

Qualitative researchers are not good at sharing the choices made in creating research studies and the rationales for the choices in presenting work (Constas, 1993). Constas (1993) advocates for a ‘spirit of openness’ in the presentation of qualitative research methods.

The validity of respondent validation of findings and the involvement of participants in the interpretation of data (Interpretive validity), is controversial. Mays and Pope (2000) emphasize the importance of respondent validation of findings to enhance validity. Some researchers go so far as to say that an account is only valid if the participants are able to confirm or recognize the findings of the research particularly if they are to be disadvantaged by the results (Maxwell, 1992 in Winter, 2000). Others dispute this, on the grounds that an individual may have not have any more ‘valid’ interpretations of his own actions than another observer might make (Winter, 2000).

- **Use of triangulation to strengthen the evaluation**

Triangulation of data through multiple methods of data collection and analysis increases credibility and lends it greater scientific rigour (Mays & Pope, 2000). Credibility is further enhanced by the inclusion of attention to negative cases and fair dealing (Mays & Pope, 2000). Triangulation of data through interviews, ethnographic observations and the use of invented examples based on the researcher’s observations and intuitions can be used to strengthen the validity and reliability of CA results (ten Have, 2000). Triangulation has been shown to be effective in a number of training programme evaluations (Byrne et al., 2006; Parle et al., 1997).

Research needs to take into account the factual accuracy in the informational statements that describe what was observed and experienced as well as in the choice of language and selection of relevant data which can be a threat to validity (Winter, 2000). Using quoted examples from the transcripts in the presentation of findings can minimize potential bias by researcher word-choice. With transcribed and taped data, others involved in the study can audit the data (Miller, 1992).

4.4.2 Evaluations in counselling interventions

Many of the counselling interventions studies described in Chapter 2 Section 2 also used checklist approaches with a pre-/ post design to allow for a summative evaluation (e.g. Evangelini et al., 2009 in which the MITI coding system was used). These studies were strengthened by their attention to the process of intervention and to the formative evaluation of interventions.

a. Participatory Action Research

Participatory Action Research (PAR) is an example that is frequently used in health care intervention research as it lends itself to research that focuses on *process*. This formative style

of research is responsive to events as they naturally unfold and involves collaborative spirals of planning, acting, observing, reflecting and replanning e.g. in design of training programme. Meyer (2000) warns that this process can be threatening because democratic practice is not always a feature of health care settings, so the researcher needs to work across traditional boundaries and juggling competing agendas. Furthermore, as counsellors occupy a fragile position within the health care system, participatory action research can ensure that counsellor voices are heard and that the research process is less threatening.

Participatory research attempts to break down the distinction between the researchers and the researched, the subjects and objects of knowledge production by the participation of the people-for –themselves in the process of gaining and creating knowledge. In the process, research is seen not only as a process of creating knowledge, but simultaneously as education and development of consciousness, and the mobilization for action. (Gaventa 1988, p. 19 in Mordock & Krasney, 2001)

The cyclical design of Participatory Action Research (PAR) makes it an effective methodology for developing and implementing an intervention programme. True PAR involves participants setting the aims of the research themselves; this is not practical in the current study, which does not claim to be true PAR but incorporates elements of PAR. Using a PAR framework, the researcher is able to draw on the expertise of the participants and follow a bottom-up approach. PAR is most widely associated with an educational context in which a team of participants evaluates themselves over time so that they can improve their own practices. From PAR, the principles of revisiting procedures, respondent validation and flexibility of design, are particularly valuable in the development of training programmes. The success of PAR is not judged in the size of change, but rather in relation to what has been learnt from the experience of undertaking the work.

Action research has its own evaluation criteria. Mash et al. (2008) and Buskens and Jaffe (2007) have identified the following evaluation criteria that are applicable to action research: alignment with purpose, ownership of the process, development of reflexivity, democratic and collaborative group dynamics, commitment to action and experience, documentation of the process, transferability and construction of practical knowledge.

4.4.3 Considering the role of control sites in intervention studies

A number of qualitative studies have employed control groups in intervention studies. Fallowfield et al. (2002) used control groups through the distribution of different types of

feedback to different groups of doctors. In this way, they were able to compare the impact of course and written feedback combined with written feedback alone, and with no feedback at all. In the small sample size from within the clinic in which my data was collected, it was not possible to divide the participants into study and control groups as one of the core features of the training is that it is multidisciplinary and whole-clinic.

Multi-site interventions studies (e.g. Mash et al., 2008) demonstrated not only the value of comparison between sites, but also the site-specificity of the quality of counselling with regards to counsellor training, motivation and possibly the ‘culture’ and atmosphere of the clinic. This supports the idea of highly context-specific communication and supports an in-depth analysis at one site, rather than cross site.

Although considered to be an essential part of controlled trials and many intervention studies, the role of control groups in qualitative research is debatable. There is a strong argument to be made against the use of control groups from outside of the research context as context-specificity plays such a substantial role in impacting on communication interventions.

What is certain is that qualitative research sets itself up for failure when it attempts to follow the procedures of quantitative research such as experimentation, efforts of replication, use of control groups, use of standardized formulas or the use of the pre-test/ post-test method. (Winter, 2000, p.8)

Although this is an intervention study, this research did not use a control group as a means of evaluating the impact of the training programme. Traditional scientific knowledge such as that from randomised controlled trials, often does not fit the uniqueness of a situation (Meyer, 2000). Research suggests that the randomized control trial is not necessarily the most appropriate tool for evaluation of socio-behaviour interventions (Power, 1998:4) and it is recommended that as much emphasis is placed on process as on outcome measures.

Buskens and Jaffe (2008), propose that even conclusions that are not drawn from a statistically significant number of encounters, should not be under-estimated or disregarded on the basis of being stereotypical.

A number of factors in qualitative research provide support for not using a control group.

- **The unique institutional context of each clinic**

Even within the context of paediatric HIV, each health care site has unique characteristics, institutional culture and atmosphere. Clinics differ in terms of staffing, models of counselling

and patient demographics making it difficult to match two clinics. Interpretation of the impact of the training programme was necessarily grounded within the clinic context. If different clinics are compared, it would be difficult to separate the impact of the training programme from the impact of the context. Even between participants within a clinic, there are many variables clouding the interpretation of the impact of an intervention.

- **The participatory nature of the intervention design**

If a participatory framework is followed in the development of an intervention programme, this means that the health professionals at a research site contribute to the curriculum development of the training programme which is then tailored to their needs. Each paediatric HIV clinic is likely to share some of these training needs, but is equally likely to differ. In keeping with a participatory framework for the development of the training programme, a different training programme would need to be designed for each clinic if control sites had been used, weakening comparisons.

- **The inclusion of pilot studies**

Through fairly simple and quick analysis methods, pilot studies had already demonstrated the usefulness of a training programme in different HIV counselling contexts (Penn & Evans, 2009, 2010). They suggested that what was needed was a more in-depth examination of the process of implementation and a more detailed analysis of the interactional aspects of counselling which could be achieved within the context of one clinic. A more detailed, in-depth analysis should be prioritized above a larger sample size.

- **Transference and applicability of findings**

Within the qualitative literature, there is debate about the relevance of the transferability of qualitative findings to other contexts. Findings that have practical application within a research context where a study is conducted are more clinically useful than having general findings with no practical application. Concern that research is not sufficiently influencing practice development is increasing and so action research has gained credibility in health care settings (Walsh et al., 1995 in Meyer, 2000). Findings can thus have practical application to a specific research setting and can be used to generate hypotheses for other contexts.

4.5 MAINTAINING RIGOUR IN QUALITATIVE RESEARCH

Numerous guidelines and recommendations exist for improving the scientific rigour of qualitative data (Guba, 1981; Guba & Lincoln, 1994; Miles & Huberman, 1994; Blaxter,

1996; Elder & Miller, 1995; Mays & Pope, 1995; Giacomini & Cook, 2000) despite the controversy about the applicability of validity to qualitative research (Winter, 2000). Mays and Pope (2000) recommend that the broad concepts of validity and relevance can be assessed but that these need to be operationalised differently in qualitative research. Qualitative research has no standardized and accepted tests, so the nature of the investigation is determined and adapted by the research itself, and the research validity thus lies with the representation of the participants, the research purposes and the appropriateness of the processes involved (Winter, 2000).

Winter (2000) argues that external validity (i.e. in what other contexts can the results be applied?) is not important in qualitative research and that attempts to achieve it can in fact hinder its overall validity, so qualitative findings are best generaliseable to the development of theories rather than to wider populations. However, qualitative research does require some degree of internal validity (i.e. is the study investigating what it is meant to?), but that this is not centrally concerned with issues of cause and effect, and is not as strict as quantitative research in the isolation and categorization of particulars within phenomena. More importantly, qualitative validity is concerned with how representative the description is and how justifiable the findings. This is why many researchers claim that ‘understanding’ is more pertinent to qualitative research than validity (Wolcott, 1992 in Winter, 2000).

Qualitative research validity can be explored further by examining transferability of the findings to other contexts and the replicability of the study methods. Other methods for strengthening qualitative research validity (namely triangulation, reflexivity and participant validation and interpretation) have already been addressed in Section 4.4 above.

4.5.1 Transferability and the importance of context

Malterud (2001) states that although the aim of research is to produce information that can be shared and applied beyond the study setting, no study, irrespective of the method used, can provide findings that are universally transferable. Qualitative findings are not generaliseable to the population at large, but are valuable within an applied setting (Winter, 2000; Malterud, 2001). Generalization itself is neither valid nor accurate, as it is likely that a generalization, although it may relate to all to whom it is applied, may not describe the phenomena of any single case (Winter, 2000).

To enhance transferability, an adequate and sufficiently varied sample is needed as well as consideration for whom and what the findings concern (Malterud, 2001). Important

contextual details need to be included including demographics and a description of the study setting (Hoddinott & Pill, 1997).

To balance the process of data separation and isolation, researchers have to take care to situate their data so that readers have an idea of its context and can begin to evaluate its meaning within this context (Chenail, 1995). For studies to have situational validity when findings are described, researchers need to re-construct the data's setting and allow us "to return to the place where the data once lived" in what Chenail describes as "the artistry that is writing qualitative research" (Chenail, 1995, p.2). When using interviews and transcripts, Chenail (1995) recommends displaying ample pre- and post- talk in dialogues so that conversational context is understandable to the reader. In the presentation of findings, quotes from the data need to be placed in the conversational context to ensure accurate interpretation of findings.

4.5.2 Replicability

Although transferability and replicability are often considered to be interlinked, it is necessary to draw a distinction between the two in this discussion about validity. Transferability applies to whether or not the results would hold true in another context i.e. at another paediatric HIV clinic in another hospital. The use of the term replicability could apply to two things; firstly, in reference to providing the reader with sufficient information so that the study methodology can be repeated; and secondly, to the issue of whether conducting the same analysis on the same data would produce the same results.

To ensure replicability, clear explanation of data collection and analysis methods is necessary (Mays & Pope, 2000) and procedures for analysis and interpretation need to be systematic and transparent (Malterud, 2001).

Regarding whether or not replication of the analysis of the data could achieve the same results, it is worth noting that some qualitative researchers deny that replication is useful or possible in situations concerning highly complex and transient circumstances, particularly those involving the lives, thoughts and behavior of participants (Winter, 2000). Considering the impact of the researcher's background and biases, and those of the other analysts, as well as the transience of participant opinions, it is unlikely that replication of the analysis would yield identical results. In re-visiting and re-analysing data, findings often change and gain more depth with multiple perspectives, and so "validation by consensus or repeatability is seldom adequate in qualitative research" (Malterud, 2000, p. 484).

4.6 SUMMARY

This chapter reviews methods commonly used in assessment and evaluation in communication studies. This chapter points out the potential pitfalls of some established methods when used in multicultural contexts and in HIV/AIDS. A hybridized linguistic analysis based on the turn by turn procedure used in CA which also incorporates participant perceptions throughout, provides an appropriate methodology for use in the South African context.

Chapter 5 that follows builds on the principles established in this Chapter and describes the methods followed in achieve the study's aims of designing, implementing and evaluating a communication training programme for adherence counsellors in the paediatric HIV context.

CHAPTER FIVE

METHODOLOGY

5.1 CHAPTER ORIENTATION

This chapter builds on the previous discussion of methodological considerations in intervention studies and outlines the methods used in study. It consists of two parts:

- Part 1 describes the research methodology;
- Part 2 outlines the design and implementation of the communication skills training programme. As the findings from the pilot studies relate to the design and implementation of the training programme, they are also included within Part 2 of Chapter 5.

Part 1 of this chapter starts with a description of the overall study design based on the guiding principles described in Chapter 4. Within the overall design, there are five sub-studies. Each of the five sub-studies is described separately in the order in which they occurred, as each one can be regarded as a study on its own with its own methodology. These five sub-studies are:

1. Developing a detailed description of the research context (a mini ethnography¹³)
2. Establishing the baseline communication measure from video recordings of the communication in interactions between counsellors and caregivers
3. Designing and implementing the communication skills training programme
4. Evaluating the impact of the training programme by comparing the pre- and post- training communication from video recordings of interactions between counsellors and caregivers
5. An evaluation of the overall study: ‘the study within the study’

Whilst the different sub-studies occurred consecutively, each one was influenced by the results of the sub-study preceding it, and so the overall study should be conceptualized as an integrated whole. Ethical considerations encountered in the process of this research are discussed at the end of Part 1 of this chapter. The description of the research context that is traditionally described within a methodology has been included at the start of Chapter 6, as it is a combination of methodology and results and provides the context for the baseline results also presented in that chapter.

¹³ The term *mini-ethnography* is selected rather than a true ethnography which implies total immersion within the study context. In this research, the researcher was working from the position of a participant observer. The mini-ethnography was based on researcher fieldnotes taken over a three month period prior to other data collection, and then updated throughout the period of the study. Given the limited time-frame of eighteen months of data collection, total immersion in the study context would not have been possible.

CHAPTER 5 PART 1: METHODOLOGY

5.2 THE MAIN STUDY

5.2.1 Main study aims

This study aimed to explore the impact of a communication skills training intervention on counsellor-patient HIV adherence counselling interactions in one paediatric HIV clinic in a public hospital in South Africa. This study aimed to evaluate the effectiveness of the in-service communication intervention in the short- and medium-term, through describing the verbal and non-verbal communication processes in counselling interactions with caregivers. Furthermore, this study aimed to evaluate the implementation of group training for multidisciplinary health care workers, and individual training for adherence counsellors within one site.

More specifically, in order to design and implement a contextually-relevant, in-service communication training programme, this study aimed:

- To describe adherence counselling within the day-to-day functioning of the paediatric HIV clinic.
- To describe the counselling communication needs from the perspectives of the multi-disciplinary health care team including the counsellors themselves
- To identify what information the multi-disciplinary team felt needed to be communicated within adherence counselling consultations
- To identify what adherence-related information patients within the clinic could recall and understand, and their perceptions of adherence counselling

In addressing the above, this research aimed to establish what the communication training needs of the participant counsellors were in their specific clinic context.

In order to evaluate the impact of this training programme on communication, this study sought to describe the following features of communication within counsellor-patient interactions:

- Verbal and non-verbal communication that characterized counsellor-patient interactions
- Verbal and non-verbal counsellor communication that either facilitated or inhibited patient understanding of adherence

- Interactional elements contributing to the success or failure of the communication training programme

In doing so, this study aimed to establish how communication skills training impacts on counsellor- patient interactions, and to identify which aspects of communication are or are not impacted on by training.

5.2.2 Main study design

A qualitative paradigm was used in this intervention study to examine the process aspects of communication, and to allow for the exploration of complex socio-behavioural and cultural aspects of HIV (Power, 1998). In recognition of the importance of context on communication, ethnography was incorporated into the overall design. As this research was committed to describing and interpreting the participants' viewpoints, participant reflections were included throughout. As outlined in the introductory chapters, qualitative research methods have been successfully utilized in studying both communication and counselling and are particularly suited to the South African multicultural, multilingual healthcare context.

Ethical approval for this study was obtained from the University of Cape Town, the University of the Witwatersrand and the relevant research site. Data collection took place over an eighteen month period between June 2006 and December 2007. The timeline for this study is illustrated in Figure 5.1.

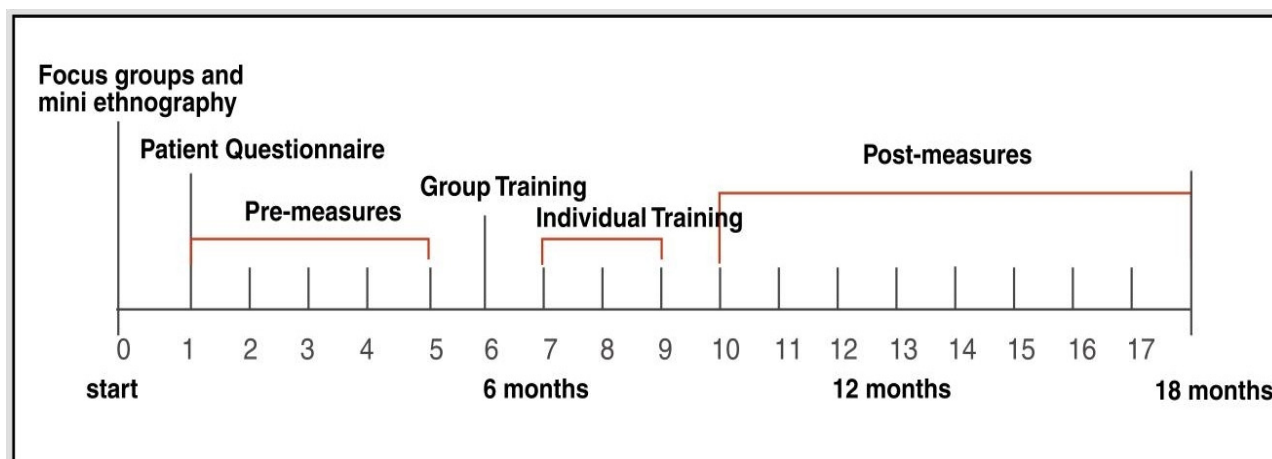


Figure 5.1 Study timeline

In this research, data collection and analysis methods were interpretive, observational and descriptive in nature. Triangulation of types of data and analysis methods was used to gain in-depth opinions and multiple perspectives (Katzenellenbogen, Joubert & Yach, 1991) in order to produce rich contextual data through which social phenomena and behavior could be

interpreted (Power, 2002). The following were triangulated and collated to form the data corpus:

- Ethnographic field notes and researcher process reflections
- Individual semi-structured interviews and focus groups with doctors, nurses and counsellors within the multi-disciplinary team on communication practices within the clinic
- Patient interviews and questionnaires to measure patient understanding and recall
- Video recordings of consultations between counsellors and caregivers of children with HIV
- Video recordings of group and individual training sessions
- Training participant questionnaires and interviews on their perceptions of the training
- Training facilitator questionnaires on their perceptions of the training

Analysis methods varied for each type of data collected, but included thematic analysis of interviews, content analysis of questionnaires and detailed observational analysis of video-recordings and hybrid sociolinguistic analysis of transcriptions. These are described in more detail later in this chapter. The constant comparison method (Glaser, 1978) allowed the researcher to compare findings from within each data type, and within the data corpus, to identify resonating themes and patterns (Mays & Pope, 2000).

Figure 5.2 illustrates the stage design of this intervention study and the data that was collected at each stage.

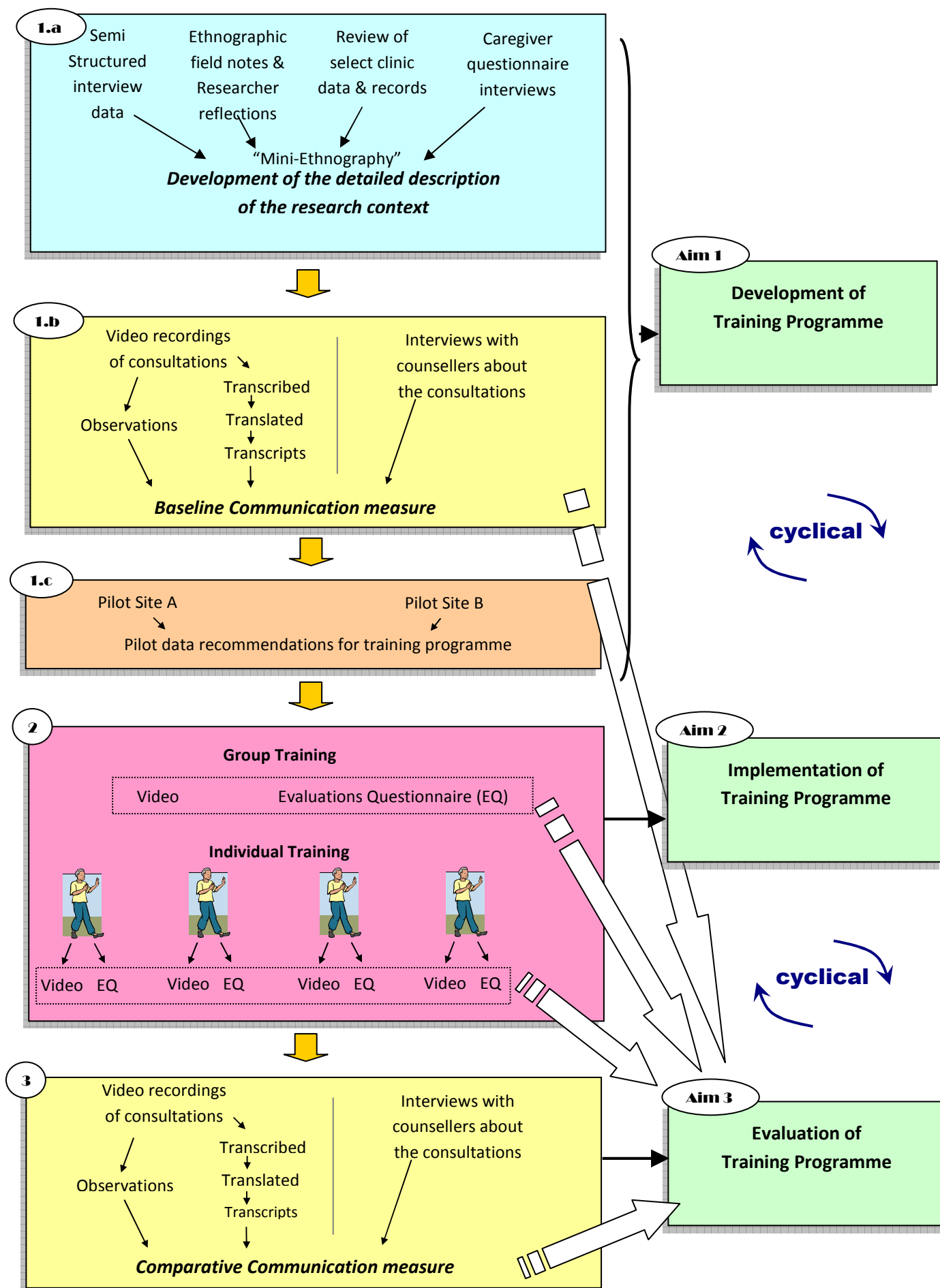


Figure 5.2 The stage design of the intervention study

In order to realise the three main aims of the study, this research involved a number of sequential stages in the research process.

Aim 1: To design a communication skills training programme for use in a paediatric ARV clinic

In order to realise the first aim of designing a training programme, the following sub-studies occurred:

1a) The mini-ethnography of the research setting

1b) The collection of baseline measures at the study site. Consultations were video-recorded as baseline measures for comparison with the consultations post-training. The video-recordings were transcribed verbatim, translated and back-translated.

Based on the above, as well as recommendations from the piloting of the training programme at two sites (Penn & Evans, 2009, 2010), a communication skills training programme was developed and modified for use within the specific research setting. The development and piloting of this programme is described in Part 2 of this chapter. Participant feedback was helpful in determining appropriateness of material and to allow for adaptations to the material before testing. During this stage, semi-structured interview data and focus groups were conducted and the results were thematically analysed.

Aim 2: To implement the training programme

The training module was implemented by two experienced health professionals who had worked extensively in the field of communication generally and health communication specifically. It was necessary for the training to be implemented by someone other than the researcher in order to prevent researcher bias from impacting on the results as discussed in Chapter 4. The health professionals were trained in facilitating the intervention programme by the researcher. The training module was interactive and consisted of a combination of small group exercises; a short didactic training video on the content aspects of communication, culture and language issues, role play and analysis of individualized video footage of the counsellors themselves taken from the baseline measures. A brief summary of the training programme itself can be found in Appendix V.

The group training programme was attended by thirteen multidisciplinary team members, and four of these counsellors subsequently participated in the individual training. The facilitators kept detailed notes on the implementation process, and all of the participants completed questionnaires evaluating the training.

Aim 3: To evaluate the training programme, the data from before and after the implementation of the training programme were compared.

Post-training, counselling consultations were video-recorded for comparison with the baseline measures. Consultations were recorded over a period of 6 months post-training to allow for an analysis of whether the impact of the training diminished over time. The training programme was evaluated by comparing the pre- and post- intervention consultation data as well as analysing the implementation process from the video footage of the implementation of the training programme.

In order to evaluate the overall process of designing, implementing and evaluating the communication skills training programme, attention to this process was employed throughout the research through researcher reflections and triangulation of all of the different data types.

5.2.3 Research setting

This study was conducted in the Cape Metropole which is one of four health regions of the Western Cape Province in South Africa. Although physically situated within a secondary/tertiary level facility, the clinic has been providing care from a primary level upwards for HIV positive children and their caregivers. At the time of data collection, the clinic was staffed by 21 multidisciplinary team-members (including non-medical staff) and excluding students and registrars. Chapter 6 provides a detailed description of the clinic counselling and communication practices.

a. Selection of research site

The chief medical officer at the research site expressed an interest in improving the communication between health professionals and patients, and in addressing the multilingual and multicultural complexities at the clinic through communication training. The researcher was invited to attend a weekly staff meeting to explain the nature of the proposed training programme and to arrange for individual follow up discussions with multidisciplinary team members.

Informal discussions between the researcher and a cross-section of different health professionals working at the clinic indicated that there were communication issues on which they wanted training, particularly with regards to interpreting and improving patient understanding.

5.2.4 Participant selection criteria

There were four groups of participants in this research:

1. The multidisciplinary team members¹⁴ participating in the training programme
2. The counsellors at the clinic
3. The caregivers of paediatric HIV patients participating in consultations with the counsellors mentioned above
4. The researcher, facilitators and research assistants

All of the participants were required to speak one of the official languages of the Western Cape (English, Afrikaans or isiXhosa) as their first language. Furthermore, all of the participants needed to be above the age of 18 years.

a. Selection criteria for participation in the group training programme

After ethical approval had been obtained from the necessary hospital and research authorities, informed consent was obtained individually from each member of the multi-disciplinary team to participate in focus groups, individual interviews and the group training programme. A detailed consideration of ethical aspects is provided later in this chapter.

To participate in the group training programme, participants needed to:

- Be employed or volunteering at the clinic as part of the multidisciplinary team
- Have regular contact with the caregivers of the paediatric patients, but not necessarily in the capacity of clinician or health care worker (e.g. the secretary, data capturer and other ‘non-medical’ staff were also invited to participate)
- Be available for the full duration of the training programme (2 x half day sessions)

¹⁴ The term *multi-disciplinary team members* is used here in a loose sense to include any doctors, nurses, psychologists, specialists or even the administrative staff who are regularly engaged in activities within the clinic.

b. Selection criteria for the counsellors participating in the individual training programme

Separate consent was sought from the counsellors working at the clinic for participation in this research because their involvement needed to be more long-term (over 12-18 months) and rendered them more vulnerable (as they would be videotaped in their working environment).

The counsellors were required to:

- Be employed at the HIV clinic on a regular basis (either part-time or full-time)
- Counsel patients as their primary function within the multi-disciplinary team
- Be proficient in the language of the patients and the caregivers with whom they were working (i.e. Predominantly isiXhosa or Afrikaans)

No training requirements or experience was specified as these varied considerably between counsellors. All of the counsellors and the majority of the caregivers at the clinic were female.

c. Selection criteria for the caregivers

It was anticipated that this particular subgroup of caregivers of HIV positive children, would have particular needs and common experiences in the counselling setting.

Caregivers of the paediatric HIV patients needed to be:

- The primary caregiver(s) of an HIV positive child who fit the age criteria for the clinic
- Residing in the Western Cape and regularly involved in the treatment programme for the paediatric patient

d. Selection criteria for the research assistants and facilitators

The research assistant who obtained informed consent from the participants was required to:

- Be first-language isiXhosa-speaking
- Have obtained a minimum of matric-level English and isiXhosa

- Be trained in individual sessions with the researcher on the study aims, questioning techniques, role playing question-answer scenarios, trouble-shooting potential problems, ethical concerns and obtaining informed consent, and accessing debriefing
- Be culturally similar¹⁵ to the patients at the clinic

The research assistants who transcribed and translated the data were required to be:

- First-language isiXhosa/ Afrikaans-speaking
- Enrolled at a University in South Africa and competent in written isiXhosa/ Afrikaans, and English
- Computer literate
- Trained in transcription and translation by the researcher
- Culturally similar to the patients at the clinic

The research assistants who analysed the consultation data were required to:

- Be experienced in analysing conversation transcripts.
- Have obtained a minimum of a masters level degree in communication sciences/ linguistics or an appropriate degree
- Be familiar with research procedures necessary for conducting research in a multilingual context

All of the research assistants were trained by the researcher in the following:

- The aims of the research and the research methodology
- Issues of confidentiality and informed consent
- Interviewing strategies
- Where to access emotional support and debriefing during and after the course of the research
- Use of the technical equipment including recording devices
- Field note-taking and journaling of their experiences

The training programme facilitators were required to be:

¹⁵ Participants from the same communities and who spoke the same language as the patients were regarded as being culturally similar.

- Experienced clinicians working within a health care context
- Trained in the field of health communication and counselling
- Experienced facilitators
- Familiar with working in the South African cultural and linguistic context

5.2.5 Participant description

a) The multidisciplinary team participants

13 participants and two facilitators attended the multidisciplinary communication skills training and participated in interviews and the evaluation of the training programme.

Table 5.1 Group training participants described by gender, age, race, language and length of involvement in the clinic

Participants	Gender	Age range	Race	Languages	Length of involvement in clinic	Attended individual training
Doctor 1	M	45+	White	English/ Afrikaans	5+ years	Not applicable
Doctor 2	M	30 – 45	Black	English/ French	1 - 2 years	Not applicable
Doctor 3	F	30 – 45	White	English/ Afrikaans	1- 2 years	Not applicable
Doctor 4	F	30 - 45	White	English/ Afrikaans	0 - 1 year	Not applicable
Nurse	F	30 - 45	Black	isiXhosa/ English	0 - 1 year	Not applicable
Non-clinical 1	F	30 - 45	Black	isiXhosa/ English	2 - 5 years	Not applicable
Non-clinical 2	F	30 - 45	Coloured	English/ Afrikaans	0 - 1 year	Not applicable
Counsellor 1 (Agnes)	F	30 - 45	Black	isiXhosa/ English	2 - 5 years	NO
Counsellor 2 (Beatrice)	F	30 - 45	Black	isiXhosa/ English	2 - 5 years	NO
Counsellor 3 (Nokuzola)	F	30 – 45	Black	isiXhosa/ English	2 - 5 years	YES
Counsellor 4 (Elsie)	F	30 - 45	Coloured	Afrikaans/ isiXhosa/ English	2 - 5 years	YES
Counsellor 5 (Babalwa)	F	18 - 30	Black	isiXhosa/ English	0 - 1 year	YES
Counsellor 6 (Lindiwe)	F	45 +	Black	isiXhosa/ English	2 - 5 years	YES
Facilitator 1	F	30 - 45	White	English/ Afrikaans	Not involved	YES
Facilitator 2	F	45+	White	English/ Afrikaans	Not involved	Not applicable

b) The Counsellors

Four of the six counsellors opted to participate in the research involving individual training and analysis of their video-recorded counselling sessions. These four counsellors are highlighted in the table above.

c) The Caregivers

77 caregivers participated in this research. Of these 77 caregivers, 45 participated in the first phase of the research where site variables were being examined to develop the description of the research context. These 45 caregivers completed questionnaires measuring their understanding of concepts relating to HIV, ARVs and adherence. All of these caregivers were black isiXhosa-speaking women aged between 18 and 45 years. 22 caregivers participated in the main study in which counsellor-caregiver interactions were examined. These 22 caregivers participated in consultations which were video-recorded. Their relevant biographical details are summarized below.

Table 5.2 Caregiver biographical and consultation details described by age, race, relationship to child, who counselled them, the language of their interaction and whether the interaction was recorded pre - or post - training

Caregiver	Age range	Race	Relationship to child patient	Counsellor	Language of the interaction	Pre/ Post training
A	18 - 30	Black	Mother	Nokuzola	isiXhosa	Pre
B	18 - 30	Black	Mother	Nokuzola	isiXhosa	Pre
C	18 - 30	Black	Mother	Nokuzola	isiXhosa	Pre
D	18 - 30	Black	Mother	Nokuzola	isiXhosa	Pre
E	18 - 30	Black	Mother	Nokuzola & doctor	isiXhosa	Pre
F	18 - 30	Black	Mother	Nokuzola	isiXhosa	Pre
G	18 - 30	Black	Mother	Nokuzola	isiXhosa	Post
H	18 - 30	Black	Mother	Nokuzola	isiXhosa	Post
I	18 - 30	Black	Mother	Nokuzola	isiXhosa	Post
J	18 - 30	Black	Mother	Nokuzola	isiXhosa	Post
K	18 - 30 & 45+	Coloured	Mother & Grandmother	Elsie	Afrikaans/ English	Pre
L	18 - 30	Black	Mother	Babalwa	isiXhosa	Pre
M	18 - 30	Black	Mother	Babalwa	isiXhosa	Pre
N	45+	Black	Grandmother	Babalwa	isiXhosa	Post
O	18 - 30	Black	Mother	Babalwa	isiXhosa	Post
P	18 - 30	Black	Mother	Lindiwe	isiXhosa	Pre
Q	18 - 30	Black	Mother	Lindiwe	isiXhosa	Pre
R	18 - 30	Black	Father & Girlfriend	Lindiwe	isiXhosa	Pre
S	18 - 30	Black	Mother	Lindiwe	English	Post
T	18 - 30	Black	Mother	Lindiwe	isiXhosa	Post
U	18 - 30	Black	Mother	Lindiwe	isiXhosa	Post
V	18 - 30	Coloured	Mother	Elsie	Afrikaans/ English	Post

d) The training programme facilitators

Facilitator 1 is a PhD student who holds a masters degree in Speech Pathology and has 5 years experience lecturing, facilitating and in clinical supervision of university students. She has had specific training in facilitation and has lectured and conducted research in the field of

health communication. From her own PhD research and through her clinical work, she is familiar with the complexities of working in a multilingual and multicultural research context.

Facilitator 2, the researcher's PhD supervisor, is an experienced clinician and researcher with a particular interest in multilingual interactions.

e) The research assistants

The two research assistants involved in the transcription and translation of the isiXhosa data were postgraduate university students who were busy completing their honours degrees, one in Psychology and one in Marketing. Both were from the Eastern Cape and were first language isiXhosa speakers with excellent spoken and written English. Neither of them had experience with transcription of data, although both had completed courses in research methods. The research assistant who transcribed and translated the Afrikaans data is a first language Afrikaans speaker who was completing a postgraduate degree in translation studies.

The three research assistants who analysed the data were postgraduate students at the University of the Witwatersrand in the Department of Speech Pathology and Audiology in the School of Human and Community Development. Two of them have doctorates in this field and one holds a masters degree and is working towards her doctorate. All three of them were experienced at analysing transcripts and interactions from their own qualitative research and from clinical supervision of Speech Therapy and Audiology students.

5.2.6 The role of the researcher

In this research, as a female, white, English-speaking South African with a university degree in the health sciences, I differed from the majority of the participants by virtue of my race, language, cultural, educational background and socio-economic status. That I was female and had experience working within a health care context, made me similar to the counsellors and most of the participating health care workers as well as the caregivers.

Some social scientists recommend that researchers should be part of the same social group that they research in order to understand the participants' experiences, particularly in the case of disadvantaged or disempowered communities (Tinker & Armstrong, 2008). Recent literature, however, in favour of the researcher being an outsider to the study population,

proposes that this is advantageous as the researcher can gain detailed and comprehensive accounts from interviewees, whilst still maintaining a critical distance needed for rigorous and detailed analysis and for gaining perspective on the research question (Bridges, 2001 in Tinker & Armstrong, 2008).

Qualitative researchers accept that all research has a subjective bias that adds to the richness of data collection and analysis (Silverman, 1993). The researcher's background was important as the researcher's subjective experience as participant-observer formed the basis of some of the data through systematic journaling and detailed field notes. In this research, observation and interviewing were the predominant activities of the researcher. The researcher did not facilitate the training programme as this might skew the validity of the training programme evaluation.

Considering the politics and the existing dynamics between the clinic where the counsellors were working and the institution employing them (another NGO), it was probably only by being an outsider that I was able to access the range of participants and for them to speak openly in the interviews without perceiving any institutional affiliation or bias.

However, despite these advantages, an awareness of my limitations within the multilingual research context needed to be maintained at all stages of the research process, and a number of methodological contingencies were planned to bridge the challenges presented.

a. In the research planning process:

All written material used in this study, including consent forms, information sheets for participants and data transcripts, was translated from English to isiXhosa and back-translated to ensure accuracy and appropriateness for all of the participants in their first language. Once the forms were translated, they were shown to the counsellors at the clinic site so that they could be checked for accuracy and level of language so that appropriate modifications could be made.

b. In the data collection process:

A trained research assistant who was black, isiXhosa-speaking and female (i.e. matched in race and gender to the patient and counsellor participants), obtained informed consent from all of the caregivers and counsellors, and conducted all caregiver interviews and questionnaires. This research assistant also acted as an interpreter for the researcher in instances when queries arose from participants.

c. In the implementation of the training programme:

The group training was conducted in English despite the fact that the first language of some of the participants, was not English (isiXhosa, Afrikaans and French). English was the lingua franca between staff members of the clinic site (e.g. Used routinely in interactions and in weekly staff meetings and in correspondence). The language diversity of the training group was acknowledged by the facilitators at the start of the training in one of the intervention programme activities, and in all other activities, the trainers steered away from medical jargon. The use of brainstorming activities in which the words of the participants themselves were written up, allowed for the language of the participants to be used.

Training a language-diverse group presented challenges (discussed in the implementation of the training programme, Chapter 5 Part 2) but also added to the richness of discussions for the particular topic of this training programme. In the individualized training with the counsellors, for the sake of continuity, the same facilitator who had run the group training, conducted the individualized sessions. At the start of this research, the counsellors had all demonstrated a good command of the English language and it was not anticipated that running the training in English would be problematic, particularly as the facilitator herself is skilled in working in cross-lingual encounters. Analysis of the implementation process of the individual training sessions highlighted how critical it was for the facilitator to be experienced, as it presented a challenging training context (See Chapter 5 Part 2).

d. In the treatment of data process:

Two first language, isiXhosa-speaking assistants were trained to transcribe and to translate the video data. To increase the accuracy of transcriptions, each video was transcribed by one assistant (Initial transcript) and checked for accuracy by a second transcriber (Checked transcript). Where dialogue had been omitted or incorrectly transcribed, the second assistant made note of this on the transcript and this checked transcript was then re-considered independently by the first transcriber and re-checked (Final transcript). It was necessary for very stringent measures to be put in place as, despite training, the research assistant initially responsible for transcribing the data, made numerous omissions and all of the data was omitted from this research and needed to be re-transcribed by the two new isiXhosa research assistants.

In the translation stage, all of the transcripts were translated from isiXhosa to English by one assistant (Initial translation), checked by a second translator who also added additional input

in the form of her own comments especially where opinions differed or alternative word choices were offered (Checked translation), and then watched with the video tape and re-checked by both research assistants (Final translation). At all stages of the transcription and the translation, the research assistants were encouraged to make notes in the margins of the scripts with their own comments that might explain colloquialisms/ slang/ contextual references that would enhance the meaning of the transcript. By encouraging both of the research assistants to type comments in the margins, multiple potential meanings of certain words and phrases were acknowledged. The researcher then went through the transcripts with the translators to clarify any uncertainties. This transcription and translation process is summarized in Figure 5.3. The same process was followed for the Afrikaans transcripts.

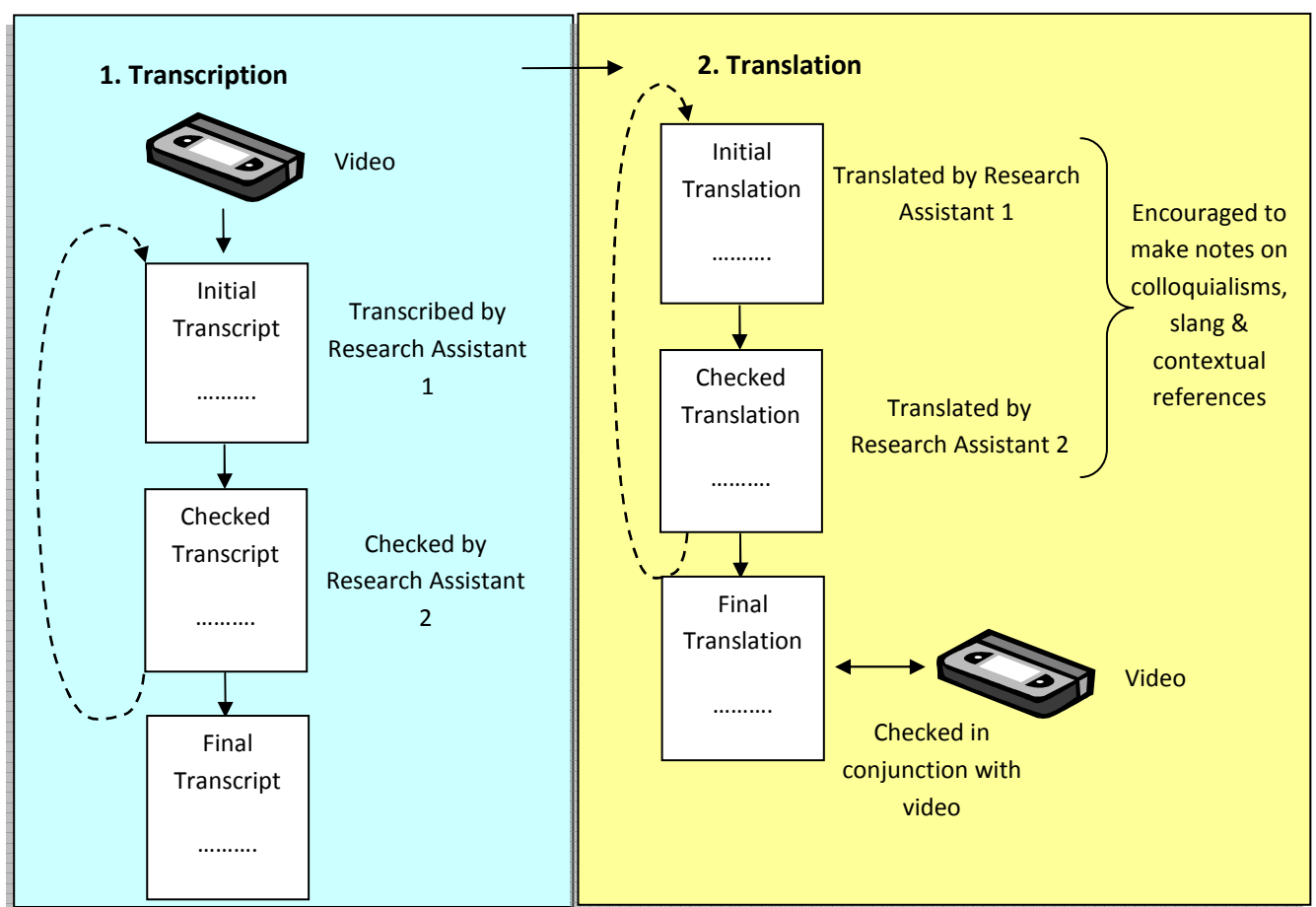


Figure 5.3 The transcription and translation process

5.2.7 Overall sampling strategy

Throughout this research, convenience sampling was used. Prior to commencing the data collection, the interview sample size was not pre-specified and the selection was sequential with a rolling process, inter-leafed with coding and analysis. Sampling evolved in a stepwise

way, including more data from one group or less from another depending on what extra material was needed to answer the research question effectively (Malterud, 2001; Curtis, Gesler, Smith, & Washburn, 2000). Qualitative research usually involves small samples that are studied intensely, with each case typically generating a large amount of information (Curtis et al., 2000). There is no consensus on how large a qualitative sample needs to be, but it is generally accepted that there is a trade-off between the size of the sample and the depth of the analysis (Malterud, 2001).

5.2.8 Triangulation

The types of data triangulation identified by Denzin (1984) and that were used in this research, are summarised in Table 5.3

Table 5.3 Triangulation used in this study

Types of triangulation as identified by Denzin (1984)	Triangulation in this study
Data source triangulation	Patient questionnaires, participant interviews, ethnographic field notes, consultation recording & transcripts, training recordings, transcripts and questionnaires
Investigator triangulation	Analysis of data by the researcher, team of three consultation analysts, facilitator analysis and participant self-analysis
Methodological triangulation	Thematic analysis and discourse analysis

5.2.9 Data collection

The data collection and analysis is described within each of the five sub-studies in the sections that follow.

5.3 DEVELOPING A DETAILED DESCRIPTION OF THE RESEARCH CONTEXT

5.3.1 Data collection to develop a detailed description of the research context

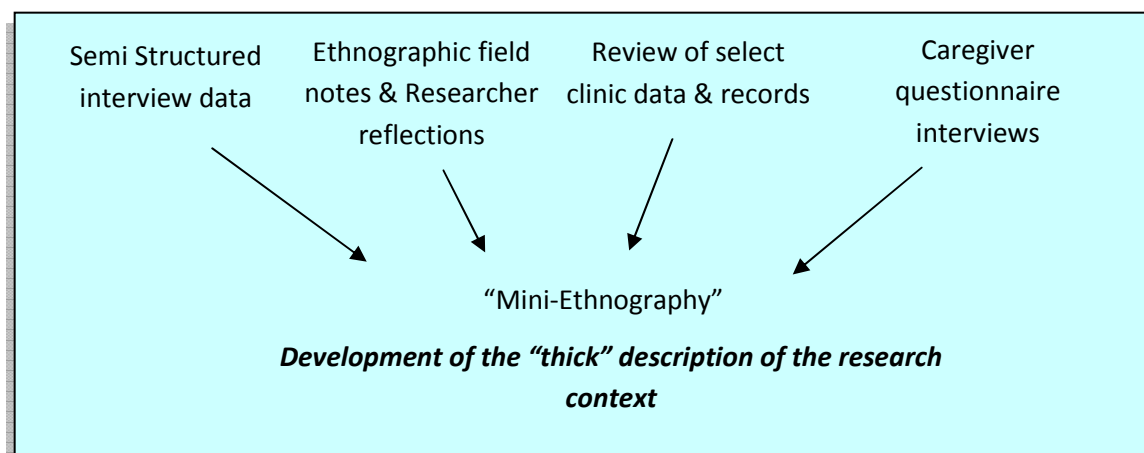


Figure 5.4 Developing the detailed description of the research context

a. Semi-structured interview data from counsellors and health professionals

Semi-structured interviews and focus groups about adherence counselling and communication were held with the participants. Questions were guided by the following topics:

- Counsellor training
- Experiences of counselling in the clinic and prior counselling experience
- Uptake of counselling
- Communication skills of staff
- Interpreting
- Adherence counselling needs
- Patient recall and understanding
- Role of counsellors
- Recommendations to improve counselling

In addition, the counsellors and other staff members were asked to comment on participation in the multi-disciplinary team, counselling challenges and successes, and counsellor training

These interviews were video-recorded and transcribed verbatim. When necessary, a first language isiXhosa-speaking research assistant conducted the interviews in the home language of the interviewee. This method was chosen over the use of an interpreter working with the researcher, to avoid the complication of interpreting as this is known to add complexity to the interview process (Swartz, 1998; Drennan, 1999; Evans, 2000; Fisch, 2001). The research

assistant was trained in interviewing skills by the researcher herself. In all of the interviews, open-ended questions were chosen as they allowed the participants to share their stories in their own words. The interviews were a crucial means of trying to discover the *emic* view, the insider's perspective of what it is like to be a participant (Silverman, 1993).

b. Ethnographic field notes and researcher reflections

This study employed an ethnographic approach in order to understand the model and framework of the counselling services at the clinic from an observational perspective. Detailed field notes taken during the data collection by the researcher were a critical component of the data collection and involved *bracketing* (Silverman, 1993), the cognitive process of putting aside one's own beliefs and not making judgements. Field notes included the goals and feelings of the population group, dimensions such as the physical space under investigation, objects in the environment, activities and actions of the people therein and the timing of events (Byrne, 2001).

In order to standardize the format of researcher reflections, the researcher followed a six-step format recommended by Christodoulou (2005) within which she had been trained and felt comfortable using as she had experience in training medical students in the same reflective process. These steps involved identifying the data, feelings, meaning, impact, need and the learning at each stage of reflection.

c. Review of select clinic data and records

In addition to the ethnographic field notes, the researcher collected information from clinic records such as appointment books, statistics submissions and time sheets to establish counselling patterns and uptake in the clinic. Table 5.4 summarises the information reviewed.

Table 5.4 Types of clinic information reviewed

	Specific information sought from each source:
Clinic	Days of operation, outreach clinics, services offered, routine procedures, referral process and interaction with other divisions in the hospital, length of operation, contact personnel, funding sources, lines of reporting
Counsellors	Number, names, positions held, job description, employee status, level of training, hierarchies within the clinic system, support provided
Counsellor training facilities	Where they are positioned, how they are financed, intake, approach / model which they follow, qualifications of the trainers, content of training programmes, level of ongoing support

Table 5.4 continued

Model of counselling	What counselling model the clinic followed, the theoretical basis for this, review systems of this process, counselling options, type of counselling (group / individual, home-based / clinic-based)
Patients	Number of patients requiring counselling, number of patients attending counselling, regularity of attendance, language needs, financial costs to patients, attendance, adherence
Clinic personnel	Who is providing the counselling, level of qualification, facilities available to them, work load / burden

d. Caregiver questionnaire interviews

45 caregivers attending the clinic volunteered to complete a questionnaire with a counsellor designed to gauge caregiver recall of essential clinic and adherence information. This was done to establish which of the adherence information that was routinely covered in adherence counselling sessions was accurately recalled by caregivers, and which information caregivers had difficulty in recalling or understanding. Selection for participation in the questionnaire interviews was based on convenience sampling over two consecutive clinic days.

The researcher drew up the questionnaire in consultation with three of the medical officers, the nurse, and the counsellors at the research site. The questions were predominantly open-ended, requiring caregivers to recall factors relating to clinic procedures and their ARV regimen. Whilst patient recall is not necessarily the same as patient understanding (recall can be lower than understanding), an open-ended method was selected as it eliminated the chance of ‘guessing’ which can occur with yes/ no questions. Furthermore, it allowed for variations in patient regimens. An interview method was chosen over a written questionnaire as it prevented patient literacy levels from impacting on the findings. All participants were given the option of completing the questionnaire in isiXhosa, English or Afrikaans.

The caregiver questionnaire interviews were conducted by a research assistant who was a volunteer at the clinic site. All patient responses were written verbatim on the questionnaire, and were scored by the researcher, the research assistant and the counsellor in conjunction with each patient’s clinic folder and the answer schedule drawn up by the medical officers at the clinic site. Table 5.5 below lists the questions included in the caregiver questionnaire interviews.

Table 5.5 Questions to establish caregiver recall of their child's treatment regimen

1. What is the name of your child's medication?
2. How much medicine must your child take and when must they take it?
3. Why is it important to stick to taking the medicine at the right time?
4. What must you do if you forget to give your child their treatment?
5. What must you do if your child experiences side effects such as diarrhoea and vomiting?
6. If you are going to the Eastern Cape for a holiday, what must you do about your medication?
7. What is a CD4 count?
8. What is viral load?
9. How do ARVs work in the blood?
10. Why do you need to practice safe sex?
11. What must you do if you fall pregnant / if you want to fall pregnant?

5.3.2 Sampling of data to develop the description of the research context

Table 5.6 Inventory of Interview data

Data type	Comments	Total number
Transcripts from focus groups	Counsellors: 2 groups of 5 participants	2x Transcripts
	Medical officers: 1 group of 3 participants	1x Transcript
Transcripts from individual interviews	Counsellors: 5 x 1 hour interviews	5x Transcripts
	Nurse: 1 x interview	1x Transcript
	Chief Medical officer: 1 x interview	1x Transcript
Caregiver questionnaires		45 questionnaires

In total, 10 interview transcripts and 45 questionnaires were analysed in this sub-study

5.4 ESTABLISHING THE BASELINE COMMUNICATION MEASURE

5.4.1 Data collection in establishing the baseline communication measure

In order to establish the baseline communication measure, consultations involving counsellors and caregivers were video-recorded. Consultations were conducted in the language of the

counsellor and patient with no interpreter. Data was transcribed verbatim and then translated and back-translated where appropriate for analysis in English. This is illustrated in Figure 5.5.

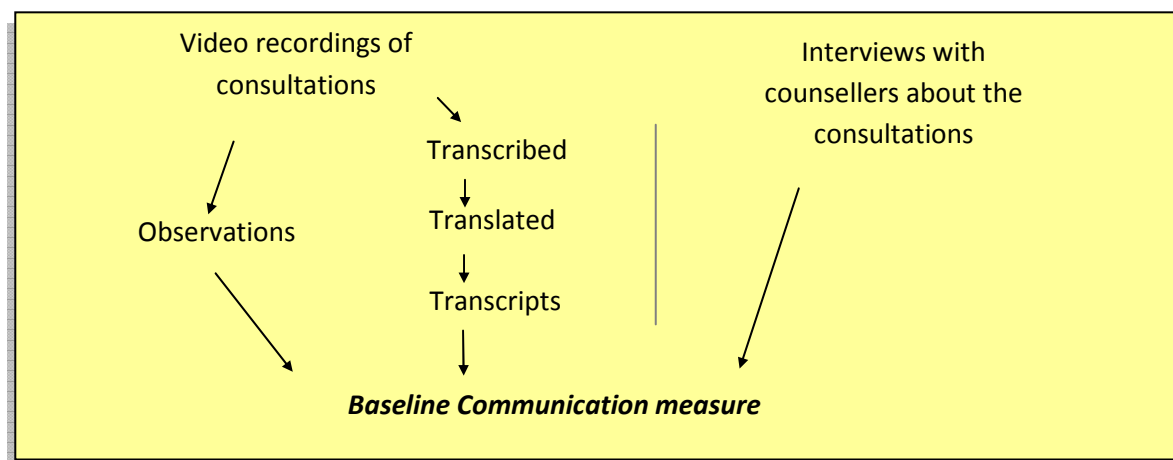


Figure 5.5 Data collection to establish the baseline communication measure

Naturalism, understanding and discovery are three guiding principles of ethnographic research. Naturalism requires that the everyday context of people's lives forms the backdrop to the research stage as opposed to contrived experimental conditions (Hammersley, 1998) and is considered a prerequisite for attempting to understand people in their own context (Galanti, 1999). In order to achieve as naturalistic an environment as possible, counsellor patient interactions were recorded in the existing counselling facilities at the clinic. After each consultation, caregivers were given a snack for them and their child. Counsellors spent a few minutes with the researcher after each consultation, reflecting on how they felt that the communication in the consultation had gone. This allowed the researcher to jot down pointers for items to follow up on when analysing the data.

5.4.2 Sampling strategy in establishing the baseline communication level

Convenience sampling was used in the process of collecting the consultation data. The researcher made the video equipment available in the clinic so that any counselling consultations between a counsellor and caregiver could be video-recorded if the caregiver was willing to participate in the research. The advantage to this was that a wide variety of different types of counselling sessions (e.g. first consultations, follow-up consultations, referrals from doctors for non-adherence, self-referrals) were recorded providing a naturalistic and representative sample of the types of counselling cases seen in an HIV clinic. A disadvantage to this was that some of the cases were not appropriate for analysis, as they were too short, did not involve counselling or the video quality was too poor for detailed analysis.

Twelve consultations comprised the baseline sample of consultation data. The intention had been to collect a minimum of three consultations for each counsellor, but this proved challenging as some counsellors rarely saw patients at the time of data collection or the language of the patient did not match the language of the counsellor. This skewed distribution is a significant drawback, however does portray the disparity in amount of counselling being done by different counsellors within a single clinic. The distribution of baseline recordings is illustrated in Table 5.7.

Table 5.7 Distribution of baseline recordings according to counsellor

Counsellor	Nokuzola (C3)	Elsie (C4)	Babalwa (C5)	Lindiwe (C6)
Pre-consultations	6	1	2	3

5.5 THE DESIGN AND IMPLEMENTATION OF THE TRAINING PROGRAMME

5.5.1 Data collection in the design and implementation of the training programme

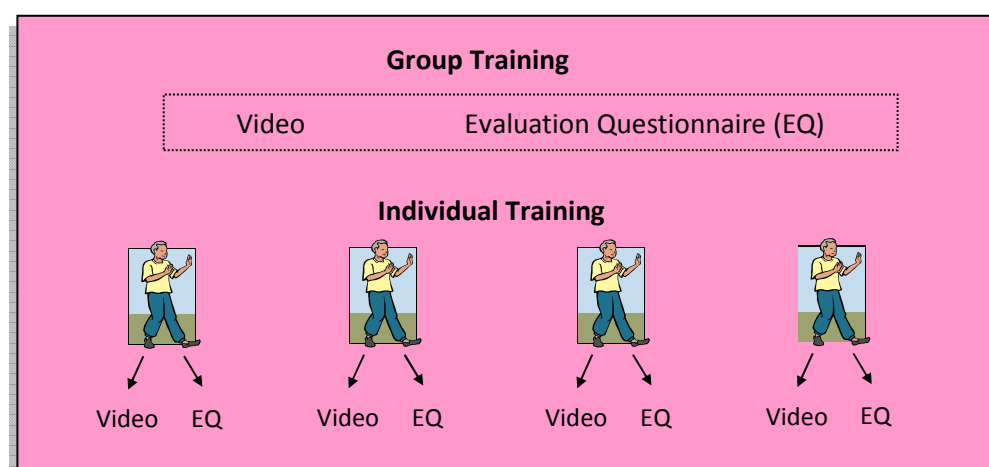


Figure 5.6 Data collected in the process of implementing the training programme

5.5.2 Sampling strategy in collecting data during the implementation of the training programme

As the researcher did not participate in the training programme itself, both the group and the individual training sessions were video-recorded for analysis. All of the participants and the facilitators were asked to complete written evaluations of the training programme. This evaluation was written in English and consisted of predominantly open-ended questions. In addition to this, the facilitator who implemented the individual training made extensive notes

following the same six step method used by the researcher throughout this study (Christodoulou, 2005).

Table 5.8 Data collected in the implementation of the training programme

Data type	Comments	Total time
Transcripts and video footage from group training	2 x 5 hours sessions	10 hours
Transcripts and video footage from individual training	4 counsellors x 6 hours each	24 hours

Table 5.9 Participant evaluations of the training programme

Data type	Comments	Quantity
Evaluation questionnaires/ interviews	Facilitators Group training programme participants Individual training programme participants	12 questionnaires 20 questionnaires 4 questionnaires
Fieldnotes	Facilitator reflections	Notes on each of the 9 individual feedback sessions

5.6 THE EVALUATION OF THE TRAINING PROGRAMME

5.6.1 Data collection in the evaluation of the training programme

In addition to the formative evaluation data described in the previous section, the evaluation of the training programme also depended on a comparison of the baseline measure with the comparative communication measure to constitute the summative evaluation. For this reason, exactly the same procedure that was followed in collecting and analysing the baseline communication measure, was followed with the comparative measure.

5.6.2 Sampling strategy in the evaluation of the training programme

All of the consultations that were analysed contributed to the evaluation of the training programme. Unfortunately as the collection of recorded consultations depended on counsellor and patient willingness to be recorded, an unequal distribution resulted. This was disadvantageous because it meant that for counsellor 4 (Elsie) in particular, both the evaluation and the assessment were only based on 1 pre- and 1 post-consultation, diminishing the strength of the findings. This was counteracted in part by triangulating the consultation

data with the researcher notes on the interaction of the counsellor and facilitator in the individual feedback sessions (described in Chapter 5 Part 2).

Table 5.10 Number of pre- and post- consultations recorded per counsellor

Counsellor	Pre-consultations recorded	Post-consultations recorded
C3 Nokuzola	6	4
C4 Elsie	1	1
C5 Babalwa	2	2
C6 Lindiwe	3	3

Table 5.11 Inventory of consultation data

Data type	Comments	Total time
Transcripts and video footage of consultations	4 counsellors with a total of 21 consultations One additional consultation in which researcher fieldnotes were made. The total number of consultations analysed was 22.	21 hours

Whenever possible, consultations were video-recorded. However, in order to protect the patients' and counsellors' privacy, in one of the consultations (at the request of the counsellor), the researcher did not video-record the interaction but made observational notes on the interaction instead.

In addition to the 22 consultations described above, seven recorded consultations were discarded as they were not appropriate for analysis:

- Two were discarded because they were too short. Both were under three minutes in duration and involved procedural questions rather than counselling.
- Three were discarded for technical reasons, including poor sound quality due to loud background noise making accurate transcription impossible.
- One was discarded as a doctor was called in a few minutes after the start of the session and the video recording was turned off.
- One was discarded at the counsellor's request because she was not feeling well and so the video recorder was turned off.

5.7 THE EVALUATION OF THE RESEARCH

It takes two studies to present one in qualitative research. One is the ‘official’ research project and the other is the study about that study.

(Gregory Bateson in Chenail, 1995, p.1)

In the story of the research process, Chenail recommends a spirit of ‘openness’ in outlining what choices were made by the researcher in the construction of the study as a process for establishing trust between the researcher and the reader (Chenail, 1995). “Even if what you were doing was intuitive guessing, let the reader in on it” (Chenail, 1995, p. 2). The researcher’s field-notes and annotations comprise the ‘study about the study’, and extracts from these field notes are interspersed amongst other data in the presentation of the results.

In this research, a cyclical approach was followed enabling constant feedback to participants and to allow for their interpretations to be heard and included. Respondent interpretations have been included in the results and discussion in this study. Participant interpretations were incorporated in the following ways:

- Feedback on the semi-structured interview data was given to participants after the interviews had been transcribed and analysed. Participants were then given the opportunity to add comments – some participants opted for additional interviews after this to allow for additional interpretations to be included
- Feedback on the ethnographic and interview results was presented at the group training programme, where participants were able to discuss these. Confidentiality was protected by not revealing participant professions or identifying features. By recording the training programme, the participants’ reactions to these results could also be captured.
- By recording the individual feedback sessions between the facilitator and the four counsellors, the counsellors’ interpretations of their own behavior and their reflections on their own communication, were also captured.
- By presenting the preliminary research findings to the analysts and facilitators and engaging in discussions with them on these findings, an opportunity was created for their additional comments to be incorporated into the final results.

5.8 DATA ANALYSIS

The data analysis in each of the sub-studies is described below.

5.8.1 Data analysis in developing a description of the research context

The semi-structured interviews, ethnographic field notes, researcher reflections and relevant clinic data was thematically analysed and the constant comparison method was applied in order for common themes to be identified across and within the different data. These findings are all summarized in Chapter 6 and contributed to the development of the communication skills training programme.

The data from the interviews and the researcher's ethnographic field notes were analysed thematically using the recommendations made by a number of researchers (Corbin & Strauss, 1990; Patton, 1990; Aronson, 1994; Marshall & Rossman, 1995). Thematic analysis focuses on identifying themes and patterns of behavior (Aronson, 1994). Data were examined to assess factors that shaped the participants' experiences, identifying categories of recurrent themes/patterns of experiences that were subsequently coded as *phenomena* (Klitzman, 2006). These *phenomena* come directly from quotes or the paraphrasing of common ideas (Aronson, 1994).

Data that related to the classified patterns and the identified phenomena were grouped and categorized according to common properties and dimensions (Aronson, 1994) and a coding manual was developed. New phenomena that did not fit into this coding framework were discussed and modifications made according to the manual where appropriate (Klitzman, 2006).

Thereafter, the data were combined and catalogued into sub-themes, which are components of ideas or experiences which are often meaningless when viewed alone (Aronson, 1994). Themes were then pieced together to create a picture of the participants' collective experience. This interpretive approach is necessarily subjective and impacted on by researcher bias. Subsequently, to validate these findings, feedback was obtained from the participants about the themes that were identified by the researcher (Constas, 1992) and additional input was requested from other expert researchers (Klitzman, 2006). To ensure coding reliability, the interviews were analysed by the researcher again (Klitzman, 2006).

5.8.2 Data analysis in the baseline communication measure

The verbal and non-verbal communication in the counselling consultations was analysed by examining both the video and the transcription data from the consultations for evidence of what facilitated or inhibited successful communication. As the researcher had selected not to be limited by a checklist approach, the data were analysed from the proposed assessment framework outlined in Chapter 4.

The analysis of the consultation data comprised of a number of stages represented in Figure 5.7 and described thereafter.

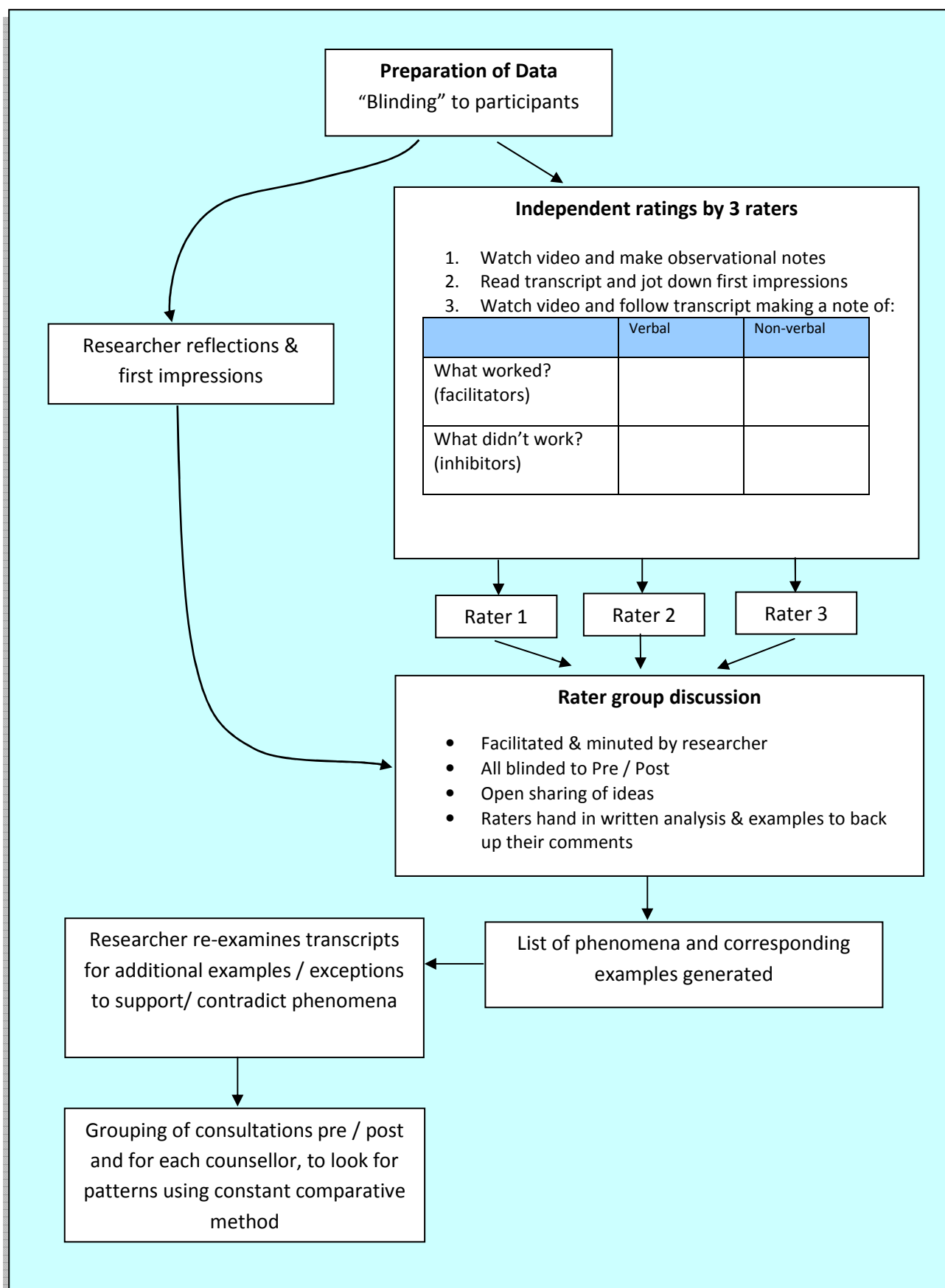


Figure 5.7 Consultation data analysis procedure

a. Preparation of the data for analysis

After the transcription, translation and back-translation of all of the data, the researcher checked the numbering, timing and use of the transcription symbols for continuity. The transcription coding conventions used can be found in Appendix VI. The transcripts were then sorted and labeled in such a way that it was not possible to determine whether they were pre- or post- training to allow for a blind analysis by the team of data analysts.

a. Researcher reflections on the consultation data

In order to familiarize herself with all of the transcripts, the researcher watched each consultation video together with the transcript and jotted down first impressions. These first impressions weren't defined by any specific framework other than whatever stuck out as being 'most memorable' to the researcher and included the researcher's perceptions of the atmosphere of the consultation.

In addition to making unstructured field-notes to capture the atmosphere of each consultation, the researcher also systematically read through each transcript and noted 'features of significance' (Love, 1994). These were defined as features that revealed differences from presuppositions or the literature. Based on the literature reviewed in Chapter 3, the researcher examined the following:

- Ratio of words spoken
- Topic initiation and shifting
- Code-switching
- Cultural language and terms of address
- Jargon
- Questions
- Evidence of patient understanding/ misunderstandings
- Structure of consultations (Introduction, body, ending)
- Non-verbals

Love (1992) outlined a number of features of significance for identifying themes which have been used in thematic analyses. These were a helpful framework for identifying the features of significance in the consultations and the themes in the interview data.

Table 5.12 Features of significance (Love, 1994, p. 2)

- Repetition within and across interviews
- Levels and nature of affect (emotion through non-verbal cues)
- Historical explanations, descriptions and interpretations (stories of the past)
- Explicit and implicit interpretations (connections between thoughts and activities)
- Serendipity (behaviours and expressions that differed from the expected)

The researcher then re-read each transcript and listed the general topics discussed within each consultation. After this, each transcript was given a 'title'. From reading through these informal notes consisting of the annotated first impressions, the list of topics discussed and the title of each consultation, the researcher then compiled a list of questions to ask the team of analysts about particular aspects of each consultation.

b. Independent rating by three raters

Analysis of the transcripts and videos was initially undertaken by the raters independently. Each consultation was analysed by a minimum of the researcher and at least two out of a team of three raters.

For each transcript, raters were requested to:

- Watch the video and make observational notes on first impressions (these were written on the transcripts). Analysts were encouraged to highlight/ underline/ make comments in the margins.
- Read the transcript and make notes on first impressions (also written on the transcript).
- Watch the video and follow the transcript, making note of their impressions of the following:

1) Verbally, a) what worked well (facilitators)? b) What didn't work (inhibitors)?

2) Non-verbally, a) what worked well (facilitators)? b) What didn't work (inhibitors)?

3) a) The reason the patient attended the clinic b) Whether this reason was met?

- 4) a) *Critical moments*¹⁶ ('*Magic*' or '*Wow!*' moments) b) describe these c) justify why?

Table 5.13 Definitions of parameters used in rating the transcripts

Category	In brief	Defined as:
Facilitators	'What worked well'	<i>How</i> the message was conveyed to make it easier for patients to understand. These contributed to the language being accessible (simple in terms of language choice, level of difficulty and practical application), clear (unambiguous and non-mitigating) and structured (logically presented) and were considered a facilitator to patient understanding. Evidence of the communication being more understandable was sought in patient demonstrations of understanding (verbally and non-verbally), a lack of confusion in their responses, a lack of breakdown in communication, and in the analysts being able to trace the thread of meaning and themselves understanding what the counsellors were trying to convey. Communication that facilitated the expression of empathy and added to an atmosphere of collaboration, was considered to be a facilitator.
Inhibitors	'What did not work well'	Factors that contributed to misunderstandings and/ or to patient needs (both interactional and informational) not being met. Communication inhibitors resulted in language that was inaccessible, unclear and unstructured. Evidence of communication breakdown can be found in adjacent pair mismatch, the thread of meaning being lost and the raters themselves not being able to understand what the speaker is saying. Furthermore, non-verbal communication that did not match the corresponding verbal or non-verbal information being shared, was considered to be an inhibitor to establishing rapport between speaker and listener.

¹⁶ *Critical moments* were considered to be moments of greater interaction in which increased emotion or more informal behavior might be exhibited.

c. Rater discussion group

The *rater discussion group* then met to discuss their comments regarding each transcript. All ideas were discussed and no viewpoints were discarded. Instead, ideas were pooled to generate more questions and comments and these were minuted by the researcher. After examining the written comments on the transcripts by each analyst, and bearing in mind the minutes from the team discussion, a list of questions and phenomena from each consultation was compiled by the researcher so that these could be revisited by the researcher within the data. This served the purpose of looking for similar or contrasting occurrences of phenomena within and across transcripts. In addition, each comment required matching to ‘evidence’ in the form of quotes from the actual transcript to substantiate comments. The output from the team discussion was a list of questions and phenomena achieved by consensus which formed the basis for the researcher’s re-examination of the data.

Emerging from the rater discussion group, was a need to examine the following phenomena across consultations for evidence of additional examples to substantiate findings or to contradict them. A list of the phenomena that were generated has been compiled from researcher minutes and is presented in Table 5.14.

Table 5.14 List of verbal and non-verbal phenomena generated by the rater discussion group and examined within consultation transcriptions

General characteristics:

- Transcript dimensions: Participants; reason for referral; key issues; transcript title; time; turns; word count; and ratio of Counsellor: Patient words
- Consultation topics: How they were discussed; Who introduced which topics; What made patients introduce topics
- Code-switching to English in the isiXhosa consultations: Which types of words were code-switched
- Cultural language and terms of address: Which terms of address (names/ titles) counsellors and patients used for each other

Communication facilitators:

- Use of practical examples
- Use of analogies
- Instances of mitigation / non-mitigation
- Open questions
- Evidence of shared moments including humour: What led to instances in which humour was used or emotion was displayed
- Non-judgmentalism
- Non-verbal communication: When was gesture used?
- Patient advocacy: Evidence of counsellors filling a patient advocacy role

Communication inhibitors:

- Introductions: How consultations began; What was included in introductions
- Questioning and verification: Number of questions and question type; the number of counsellor questions (to check understanding, open-ended questions and feeling questions) and questions asked by patients; the incidence of using strategies to check patient understanding
- Use of jargon: Examples of medical jargon used and whether or not the jargon was explained
- Topic shifting: How did participants discuss 'difficult' topics such as sex, disclosure and cultural practices; Instances of topic shifting
- Mitigation
- Management of session endings: How consultations ended: Which information was included in wrapping up sessions
- Use of gesture

Rater team perceptions of whether or not patient needs were met

d. Re-examination of transcripts using the list of phenomena

The researcher then revisited each consultation, working from the list of phenomena compiled from the data analysis meeting, looking for evidence to support/ disclaim the phenomena. Examples in support of or against each item on the list, were indexed by transcript label and turn number so that these could be easily retrieved when writing up the results. Only phenomena that could be substantiated with an example and that had been agreed upon as illustrating a particular phenomena by at least two of the raters, or one rater and the researcher, were considered valid.

e. Grouping of consultations for comparison of pre vs post; and between counsellors

The researcher then grouped the consultations to allow for a comparison between pre- and post- training, and across counsellors, looking for similarities and differences across each comparison to see if any trends emerged. The results from the consultation analysis were then triangulated with the results from the interview data and the ethnographic analysis.

5.8.3 Data analysis in the design and implementation of the training programme

The video footage from the training programme implementation was not transcribed. The researcher observed the footage and made fieldnotes on the following:

- What topics were discussed, how they were discussed and what perceptions were expressed by participants on the topics
- How did the participants appear to engage with the facilitators
- How did the facilitators appear to engage with the participants
- What information covered in the training programme did participants appear to remember or not remember
- What reflections did participants make about their own communication
- How adept participants were at identifying communication facilitators or inhibitors in the video recordings of their consultations

These fieldnotes were then triangulated with the facilitator reflections and the comments from the participant evaluations. These notes comprised the formative evaluation of the training programme which was based on Buskens and Jaffe's (2008) recommendations as described in Chapter 4. The evaluation of the training programme is discussed in Chapter 8.

5.9 ETHICAL CONSIDERATIONS

5.9.1 Ethics approval

Research approval was granted by the research ethics committees at the University of the Witwatersrand (Ref: M060407) and the University of Cape Town (Ref: 166/2006) for permission to collect data at sites within their jurisdiction. A report on the progress of the research was submitted to each institution on completion of the research.

5.9.2 Informed consent and safe-guarding confidentiality

The counsellors and patients were assured of confidentiality and their informed consent was obtained both verbally and in written form by the researcher in the first language of the research participant, working with a trained research assistant where necessary (i.e. with isiXhosa-speaking participants). In order to safeguard the confidentiality of the participants, the following measures were taken:

- The names of the counsellors and the patients were not linked by name or description to any of the data or results
- Consultations and interviews were conducted in private
- All research team assistants (isiXhosa-speaking mediator, transcribers and translators) received training in confidentiality and protecting participants' rights from the researcher herself
- The name of the clinic and identifying organizations have been omitted or given pseudonyms

Special effort was made to minimize the video recording of any of the children and the caregivers. The focus of the camera was on the counsellors and not on the caregivers themselves. On no occasion were other health care team members able to view the footage of their colleagues or of the caregivers. Only the researcher, her supervisor and the research assistants who transcribed, translated and analysed the data were able to view the video data.

5.9.3 Vulnerability and Potential risks to participants

All of the participants in this research were considered vulnerable. The caregivers were vulnerable by virtue of the fact that they were poor, female and caring for a terminally ill child and in some instances ill themselves. The counsellors and health professionals were vulnerable as they were being investigated within their work environment.

The caregivers were at risk for being stigmatized and for their HIV status and that of their child being disclosed. To protect them, every effort was made to ensure patient and caregiver anonymity at all stages of this process. Participation was entirely voluntary and any of the participants were able to withdraw from the study at any time. The counsellors at the research site were able to provide continued emotional support to the caregivers for the full duration of the study and beyond.

The counsellors and the health care team were at risk as their practices within their work environment were examined. No feedback on individual employees was given to the hospital or the specific HIV unit within which they are working. Counsellors and the health care team had access to continued emotional support from the consulting psychologist who was contracted to support the counsellors on a fortnightly basis, and counsellors were offered the opportunity for external support from a trained counsellor at a local NGO should they prefer alternative support other than that already offered at the clinic, for the full duration of the study.

5.9.4 A note on the enrollment of the counsellors to participate in this research

All of the counsellors at the clinic initially expressed an interest in the communication skills training research. However, when the researcher explained how the training programme could render them vulnerable, and that they would need to be video-recorded and analysed for the purposes of the research, two of the six counsellors then expressed that there was ‘no need’ for them to have communication skills training as they had already received training whilst studying. It is undeniably the right of potential participants to decline to participate, and for this reason, in order to ensure that the participation of the other counsellors truly was voluntary, consent was obtained from the other participants at the beginning of the research, at each video-recorded counselling consultation and at the start of the group- and individual-training.

After continued negotiations with those counsellors who did not want to participate in the research study, they volunteered to participate in the ethnographic study, the interviews and the training programme. This was with the understanding that they would not be recorded or observed working with any patients. They were offered the opportunity to have video-analysis that would not be included within the research sample, however this offer was declined. One side-effect of their resistance to participating in the study, was that one other counsellor who had initially expressed an interest in participating, then expressed anxiety about being video-

recorded post-training. For this reason, the researcher made field notes which were fed back to her rather than video-recording her for her post-consultation.

The counsellors who expressed no need for further communication training, were the ones that the other health professionals at the research site felt were not doing any work, and who, in the researcher's ethnographic field notes, appeared not to be counselling patients on the researcher's visits to the clinic. As not all of the counsellors agreed to participate in the study, and as the ones who did not participate appeared not to be motivated to improve their skills or to counsel patients within the clinic, it is possible that the results from this study are skewed towards showing greater improvement than may generally be the case if all of the counsellors had participated.

Similar decreased participation in research with increased information sharing is documented in the literature. Recent research suggests that in the context of HIV vaccine trials, increasing levels of information may reduce the likelihood of trial participation (Koblin, Holte, Lenderking & Heagerty, 2000 in Swartz & Kagee, 2006). Swartz & Kagee (2006) outline the potential contradiction that community empowerment interventions may work against scientific expediency in that lower numbers of community members may volunteer to participate than would have been the case in the absence of such interventions.

5.9.5 Perceived benefit to the participants

It was anticipated that the patients receiving HIV/AIDS counselling and the counsellors providing this service would benefit from participating in this study. Counsellors would benefit from having free training in communication skills which would assist them in counselling and in other general communication. Patients would benefit from better communication leading to a more supportive interaction with their counsellor and better understanding of HIV, ARVs and the treatment process. The clinic site benefited from being provided with an on-site training service to improve the skills of employees. The health care sector and policy-makers had the potential benefit of a much-needed analysis of existing counselling practices and a potentially-useful training programme.

5.9.6 Dissemination of findings and storage of data on completion of the study

General written and verbal feedback was given to participants throughout the study and at the end of the project. Individual feedback was given to each participating counsellor on an ongoing basis for the duration of the study. The raw data in the form of the isiXhosa and the English video tapes, transcriptions and translations, were securely stored by Prof Penn at Wits University as part of a larger health communication project.

CHAPTER 5 PART 2

THE DESIGN AND IMPLEMENTATION OF THE COMMUNICATION SKILLS TRAINING PROGRAMME

5.10 INTRODUCTION

In this section, the process of designing and implementing the communication skills training programme is described. The training programme was developed based on a review of relevant literature and clinical experience in communication skills training, and then piloted at two sites. This chapter contains only a brief summary as these pilot studies have been published elsewhere (Penn & Evans 2009, 2010). The communication skills training programme was tailored to the specific context of the research clinic based on the recommendations from the pilot studies, the findings from the description of the research context and the baseline analysis (Chapter 6).

The communication skills training programme consisted of two components:

- (1) Multi-disciplinary group training
- (2) Individual video analysis and feedback for the four counsellors participating in this research.

In the process of developing the training programme, a number of different materials were developed. These included:

- A training programme manual for participants and background reading material
- A facilitators' guide and teaching materials (e.g. powerpoint presentation, didactic notes)
- Video vignettes of communication scenarios based on the pre-training consultation scripts
- Some examples for developing a 'communication toolkit'

Inclusion of these materials is beyond the scope of this dissertation. Where length allows, examples have been included as appendices.

In this chapter, the implementation of both the group and individual training is described, with attention to the level of participation of participants and their ability to apply reflection

in analysing their own videoed interactions. This chapter discusses a number of recommendations for improving the training programme in future applications.

5.11 THE METHODOLOGY FOR DESIGNING AND IMPLEMENTING THE COMMUNICATION SKILLS TRAINING PROGRAMME

Designing and implementing the training programme constitutes the third sub-study of the overall research methodology of this project as described in detail in Part 1 of this chapter.

Figure 5.8 is a summary of the process followed within this stage.

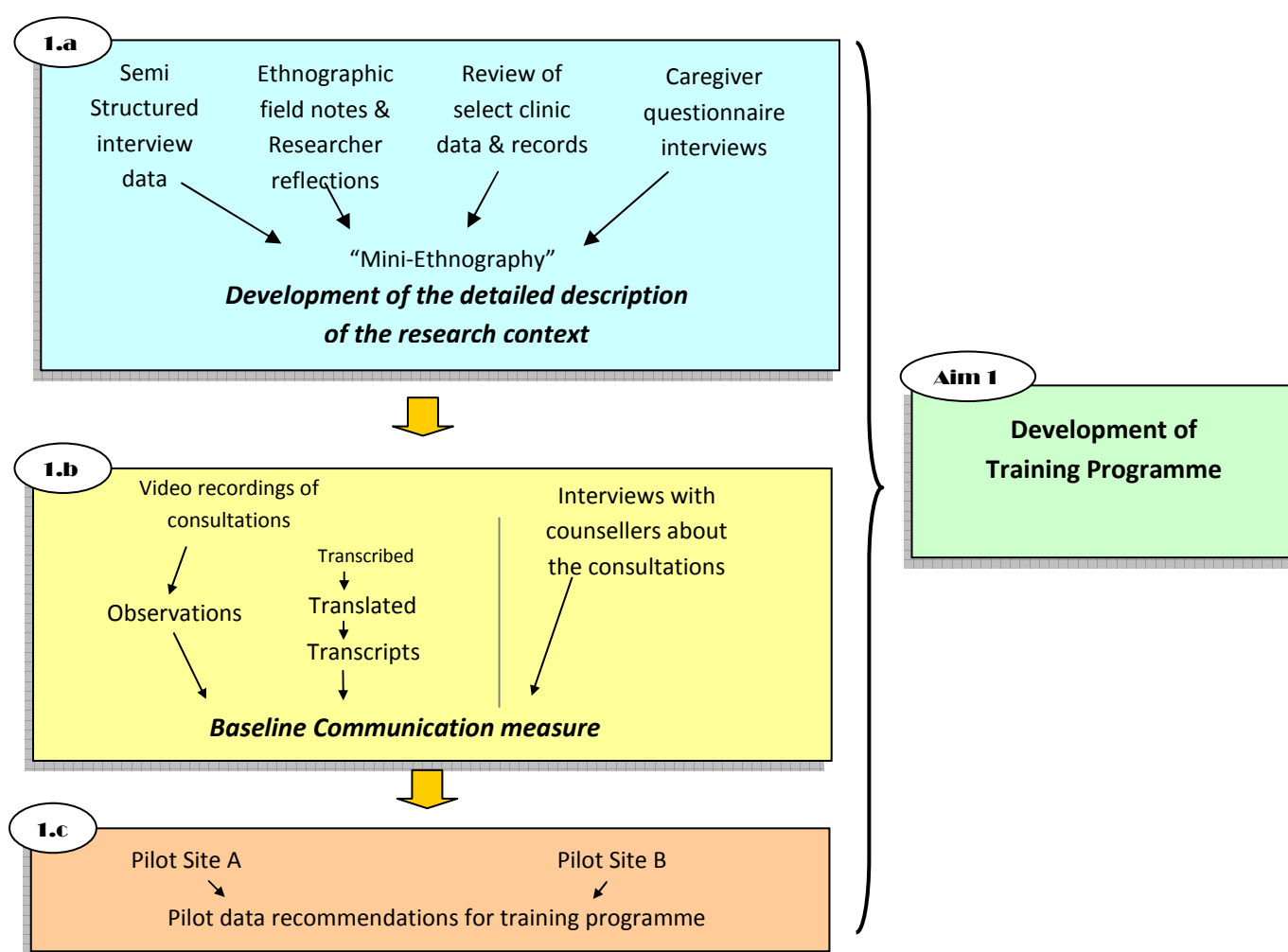


Figure 5.8 The design and implementation of the communication skills training programme

5.12 DESIGNING THE TRAINING PROGRAMME

A review of the literature on communication skills training programmes conducted in medical interactions, enabled the researcher to identify features of successful intervention programmes and to contrast these programmes. Elements of the programmes that were shown to be successful, as well as being practical in a naturalistic clinical context and which were within the resource and time constraints of this research, were incorporated into the training programme. The development of this training programme was thus based on a literature review of existing programmes, the theory of health communication, adult education and adherence counselling, a review of documents from accredited groups, professional organizations and foundations and was guided by the clinical experience and expertise of my research supervisor, Prof Penn, in this field.

Table 5.15 Principles guiding the design of the training programme drawn from Makoul et al. (2000), Maguire & Pitceathly (2002), Fallowfield et al. (2002), Byrne et al. (2006) and Kalet et al., (1994).

Adult education	Amount of information: Too much too fast won't last Teaching Methods: Experiential learning, group work, learner-centered High interest: fun, varied activities
Health communication	Teaching Methods: Interactive, hands on, actual practice and feedback Strategies : Teaching of simultaneous as opposed to sequential skills i.e. many skills taught simultaneously from one case scenario
Field of speech pathology	Methods of assessment: Verbal and non-verbal information assessment, The value of qualitative and ethnographic research methodologies, evidence-based
Relevance within the South African healthcare system	Diversity: Cultural, linguistic, racial, economic PHC Principles: Equity, affordable, available, accessible, effective, efficient, multidisciplinary
Participatory action Research	Participant-led: Relevant, clinically applicable, incorporate specific institutional needs, recognition of different areas of expertise and learning needs from different professionals, knowledge production by participants themselves, empowerment through participants constructing their own knowledge Reflection

This research differs from past research in that it involves in-service training with already-qualified health care workers who are not a homogenous group (i.e. doctors, nurses,

counsellors combined) and who are working within the diverse South African health care context. As a result, although the lessons learnt from other programmes are extremely valuable, the programme needed to be tailored to meet the needs of the specific field of paediatric HIV counselling in a clinical context.

5.12.1 Characteristics of successful communication training programmes

A review of the literature examining evaluations of successful communication training programmes identified a number of characteristics that have been adapted to meet the needs of the current study.

a. Staged study design

The training programme closely follows the format of Byrne et al. (2006) which involved three stages, namely an initial consultation, the training package itself, and a follow-up consultation. The advantage to following this format is that the researcher could meet with staff prior to the implementation of the programme to identify specific training needs, and to identify existing areas of strength that could be reinforced (Byrne et al., 2006). These focused specifically on clinical situations that staff identified as both common and challenging.

b. Time allocation

Although communication skills training programmes have been effectively implemented in a number of different fields, few of them have been implemented as in-service training. The majority documented in the literature have been implemented as part of medical curricula. One exception is the training programme by Byrne et al. (2006) that was implemented during clinic hours on a day when the clinic was routinely closed for staff meetings and six months later there was a follow-up and trouble-shooting session. A challenge in selecting an appropriate intervention time for Lady Evelina Clinic was finding a time when the majority of the multidisciplinary team could attend training. Ideally, training would encompass morning sessions when participants felt most fresh and unstressed by other clinical constraints. However, in reality the clinic is at its busiest in the morning and staff had different starting times. Consequently, afternoon training during the week on days in which the majority of the participants were available, was selected.

c. Setting

Fallowfield et al.'s (1998) successful implementation of the Lipkin model with oncologists was conducted out of the hospital setting in small hotels as the clinic setting was considered

to be too distracting. Unfortunately, given the time constraints of busy staff and in order to avoid having to factor in additional time for travel, the training was conducted in the clinic in a large room to allow for space and privacy.

d. Grouping of participants

Research suggests that same-discipline training sometimes makes participants feel safer whereas others enjoy the interaction and learning from multidisciplinary participation (Maguire & Pitceathly, 2002). In this study it was anticipated that a multidisciplinary intervention would be further complicated by the dynamics between the different disciplines, feelings of distrust, scepticism and defensiveness regarding skills possibly due to a lack of confidence in their own ability (See Chapter 6 Part 1). However in the interest of fostering good teamwork and in order to promote counsellor 'buy-in' to the training programme, multidisciplinary group training was selected.

Group size should be limited to 4 to 6 participants to create a sense of personal safety required for participants to disclose and explore relevant attitudes and feelings and more time to practise tasks and to allow for manageable facilitation (Maguire & Pitceathly, 2002; Fallowfield et al., 2002). As thirteen participants would be involved in the multidisciplinary group training, they were divided into two groups for most of the exercises and two facilitators worked together.

e. Relevance to participants

Maguire and Pitceathly (2002) state that doctors are more likely to attend training when they know that substantial time will be devoted to their own agenda. In order to ensure relevance and to promote interest, examples from Lady Evelina Clinic were used throughout the training.

A difference in effectiveness of training with participants who have had similar feedback training than those who have not, was anticipated. It was hoped that counsellors, whose voices are traditionally less-heard in medical team discussions, might feel comfortable with exercises such as role play and using simulated patients as they had experience with these methods from their pre-service training.

f. Trainers and facilitators

Fallowfield et al. (1998) used two of the authors of the training programme as facilitators in their training programme. In my research, in an attempt to prevent researcher bias, two trained facilitators were used instead.

g. Development of teaching resources

Teaching resources for the course were developed by the researcher in conjunction with her supervisor, Prof Claire Penn, and the Chief Medical Officer of the test site. In this study, video vignettes were developed from the scripts of the pre-training consultations and acted out by an actor and one of the facilitators. These formed the basis for discussion videos of communication aspects.

Selection of the tools chosen in an educational or evaluation programme is dependent on the resources available and the level of reliability and validity required (Duffy et al., 2004). It is recommended that courses should include detailed handouts and/or short lectures that provide evidence of communication deficiencies, reasons for these and the adverse consequences (Maguire & Pitceathly, 2002).

5.12.2 Teaching methods in adult education

Adult learners come from diverse backgrounds, aptitudes and learning styles (Makoul, Curry & Thompson, 2000). Adult education models embrace this breadth of varied experience and provide a framework for continuous self-directed learning that extends beyond formal curricula. Interactive, discussion-based small-group activities and peer observation and feedback are suitable formats for adult learners (Makoul et al., 2000). Appendix VIII contains a review of appropriate teaching methods in adult education that informed the training programme development.

5.13 PILOTING THE TRAINING PROGRAMME

As the process of researching a communication intervention programme had not previously been conducted within a health care context or in HIV counsellor-patient interactions, aspects of this study were piloted with counsellors and other health professionals at two HIV trial sites (one in the Western Cape Province, and one in Gauteng) prior to being conducted within the study site.

As both of the pilot sites were part of a larger multi-site trial in South Africa, the study provided the counsellors at those sites with an opportunity to practice enrolling patients onto

the trial, and to learn communication strategies to improve the enrollment process. Further details on these aims, methods and results are described in Penn and Evans (2009, 2010).

For the purpose of this research, the pilot studies allowed the researcher to establish the following:

1. Whether there is a need for counsellor communication skills training in HIV
2. What the interactional characteristics and special needs of communication in HIV interactions are
3. How communication skills training impacts on patient understanding
4. Whether the training programme model (described above) contains the necessary components and is an appropriate format for the HIV context
5. What analysis methods are appropriately sensitive for describing and measuring the impact of communication skills training

In both pilot studies, the same methodology of a pre-/ post- intervention design was used. Data comprised of:

- Observational notes on the interactions by three independent raters.
- Interviews of counsellor and patient perceptions of communication
- Questionnaires measuring patient understanding

Ethical approval for these pilot projects was obtained under the umbrella consent from a larger project being conducted by the Wits Health Communication Project. These pilot studies included the participation of nineteen students acting as ‘patients’ working with thirteen counsellors (11 female and 2 male) in the informed consent process prior to commencing a drug trial. None of the students participated in the actual larger research trial and their HIV status was unknown. At the end of the study, counsellors were debriefed regarding the non-patient status of the students.

The first languages of the students were English, Tswana, seSotho, isiXhosa , isiZulu and Portuguese; and the first languages of the counsellors were seSotho, isiXhosa, isiZulu and all were fluent in English.

The counsellors were trained in English, and training consisted of both group training and individual feedback. The counsellors’ communication strategies used before and after training

were recorded and analysed by three experienced raters (independent of the study). The enrollment interviews were observed through a one-way mirror and the observers' notes on the perceived effectiveness of verbal and nonverbal characteristics in achieving mutual understanding between participants, were compared and collated.

Using a semi-structured interview technique, both counsellor and student participants were interviewed after each consultation about their perceptions of the communication and rapport in the session, and about other factors relating to the informed consent process. In addition, each student was asked a set of yes/ no questions about the trial to gauge their understanding of the trial's protocol.

Table 5.16 summarises the outcomes learnt from the pilot studies that are relevant to this research. The outcomes of each pilot have been combined as one.

Table 5.16 Pilot study outcomes relevant to this research

Pilot aims:	Outcomes
To establish the need for communication skills intervention in HIV	Counsellors welcomed the communication intervention; Patients misunderstood key concepts which counsellors had not expected.
To describe the interactional characteristics and special communication needs of HIV interactions	The role of the counsellor is critical in ensuring effective mediation when there is a language divide between patients and service providers. Communicating complex messages in HIV is complicated by the following: • Use of jargon • Poor eye contact • Lack of attention to linguistic choice: Exclusive use of English, regardless of the first language of the patient • Excessive interaction with paperwork • No use of props • Lack of comment on the overall bigger picture • Emphasis on the negatives eg side-effects • No emphasis on the patient's adherence, commitment and responsibilities • A large portion of time spent explaining the medication • No breaks between topics: Rapid and surprising topic shifting • Generally nervous behavior and evidence of the counsellor's self-doubt in own abilities • When going through written information with patients, there was an excessive interaction with paperwork and a tendency to only read information and to emphasise small details, rather than explaining information • A lack of strategies to make information accessible to patients. Such as the use of props or other modalities in explanations
To describe the impact of communication skills training in the HIV context	Patient understanding of key concepts improved post-intervention Counsellors expressed that they had learnt new skills from the intervention Training effected the following changes in communication: • More attention to room layout and seating • A confident approach to the task • Warm introductions with appropriate discussions about the process and language variables • Regular checking of the patient's understanding through questioning strategies • Good eye contact and a friendlier, more smiling manner • Repetition of key facts • Full coverage of procedural aspects • Offering practical examples from everyday life • Using multiple modalities (props, drawings) in explanations • Drawing attention to key information through highlight/ underlining • Verbal indication of transition between topics • Stressing patient commitment as a key factor to success • Use of gestures to enhance the interaction
To identify the necessary components and appropriate format of a communication training package for the HIV context	Verbal and non-verbal aspects of the training programme are described later in Appendix VII and various aspects are published as Penn & Evans (2009, 2010)
To identify appropriate analysis methods for describing and measuring the impact of communication skills training	Audio recording was insufficient for analysing non-verbal communication. Observational fieldnotes provided detailed descriptions of interactional behaviours, however transcription of dialogue was preferable for allowing more detailed analysis and would enable revisiting of data after the time of data collection for multiple raters. By describing 'what worked'/ 'what didn't work' the analysis was able to yield rich descriptions of verbal/ non-verbal facilitators and inhibitors. Asking the health professionals for a list of key information to be communicated and 'testing' patients on these aspects, yielded unexpected results and was very useful.

The pilot studies established a need for communication skills training. Observational notes on the interactions highlighted difficulties with terminology, communication about disclosure and poor patient understanding. Participants commented positively about the training programme and made use of the strategies they were taught in training. Patient understanding was shown to improve post-training. The pilot studies were useful in providing focus to the overall research study in terms of population group, selection of ARV site and the methodology. The results suggested that more focus was needed for the overall study in terms of population as populations from different areas, genders and ages have different management and counselling needs. Type of site i.e. drug trial site, community level clinic or ARV rollout site, needed to be carefully selected in order to prevent this variable from impacting on the study findings.

5.14 REFINING THE TRAINING PROGRAMME

The training programme was modified based on lessons learnt from the two pilot studies, the results from the detailed description of the research context, and the preliminary baseline analysis (both described in Chapter 6).

The pilot studies demonstrated the value of combining a group and an individual training approach. Individual training appeared to be particularly beneficial for effecting individual skills change; group training appeared to be a ‘bonding’ experience through the sharing of experiences within the counselling group.

Analysing one pre- and one post- training encounter for each counsellor did not allow for measuring the effectiveness of the intervention over time, or account for ‘difficult’ patient variables. In order to account for a potential ‘wear-off’ effect, post-training consultations would need to be recorded up to six months post-training. Multiple analyses for each counsellor should be recorded to account for patient variables.

One of the aims of improving health professional communication skills in adherence counselling, is to improve patient understanding. Patient understanding can be viewed as being an outcome measure that links potential impact of training to actual clinical practice. In the pilot studies, increases in simulated patient understanding were found. One disadvantage to judging the success of training by measuring patient understanding, was that counsellors tended to focus specifically on the information asked within the patient understanding questionnaires (i.e. ‘prepping’ them for the post-training questionnaires). This had not been a problem in the pilot studies as the counsellors were unaware of which questions were asked. However, in the actual study, as multiple recordings would be made, and as the findings from

the baseline measures would be communicated to counsellors in the group training, the counsellors would be aware of the patient questionnaires. For this reason, the patient questionnaires were developed into a checklist format to encourage counsellors to check patient understanding themselves, and were not used as a measure of patient understanding post-training. It was also felt that if counsellors felt that patient understanding was the main measure of the study, that this would be emphasised to the detriment of interactional characteristics and might adversely impact on the communication in the interactions.

The institutional dynamics presented a challenge and it was unknown to what extent training could be effective given the breakdown in trust between the health professionals in the clinic and the counsellors as discussed in detail in Chapter 6.

The complex lines of reporting meant that 'buy-in' from the counselling NGO authorities and not just the hospital authorities was necessary. When approached, the counselling NGO authorities consented to the counsellors participating in the study and indicated their support for the in-service training for counsellors who wished to participate. The counselling NGO also consented to being interviewed by the researcher and encouraged the counsellors to participate in the study.

Low levels of counsellor motivation to participate in the study further supported the involvement of the whole multidisciplinary team in the training so that no perceived difference between professions was created. As some of the counsellors had expressed wariness of the research process, informed consent would need to be re-taken at intervals throughout the study to ensure that participation truly was voluntary and that counsellors understood that they could withdraw at any point. As the pilot study had demonstrated that fieldnotes of observations of interactions provided sufficient detail for analysing the impact of communication training, this could be used as a back-up option for counsellors who did not wish to be video-taped.

Only a small group of all of the counsellors volunteered to participate in the study, therefore protecting the confidentiality of these counsellors became even more critical. Feedback to counsellors was provided individually rather than in a group. As language and descriptions of counsellors might render them recognisable to the other clinic staff, more creative feedback methods were devised rather than a presentation and written report. For this reason, the consultations were developed into case scenarios for use within a facilitated discussion within the clinic meetings, rather than presented as findings from within the clinic.

Based on the interviews with the health professionals and an analysis of the baseline communication, it was decided that training needed to incorporate the whole multi-disciplinary team as many of the issues impacting on the communication were related to relations between the team as a whole or were linked to how the clinic operates.

5.15 A BRIEF DESCRIPTION OF THE TRAINING PROGRAMME MODEL

The training programme was built around the analogy of a communication bus (Penn, 2006) in which the body of the bus represents the interaction itself, and the wheels of the bus are the elements that move the interaction forward. As there are two sets of wheels at the front and back, one set of wheels represents the interaction between the doctor and counsellor that occurs prior to the interaction, and one is the interaction between the doctor and counsellor after the interaction to emphasise that communication is not limited to the interaction itself.

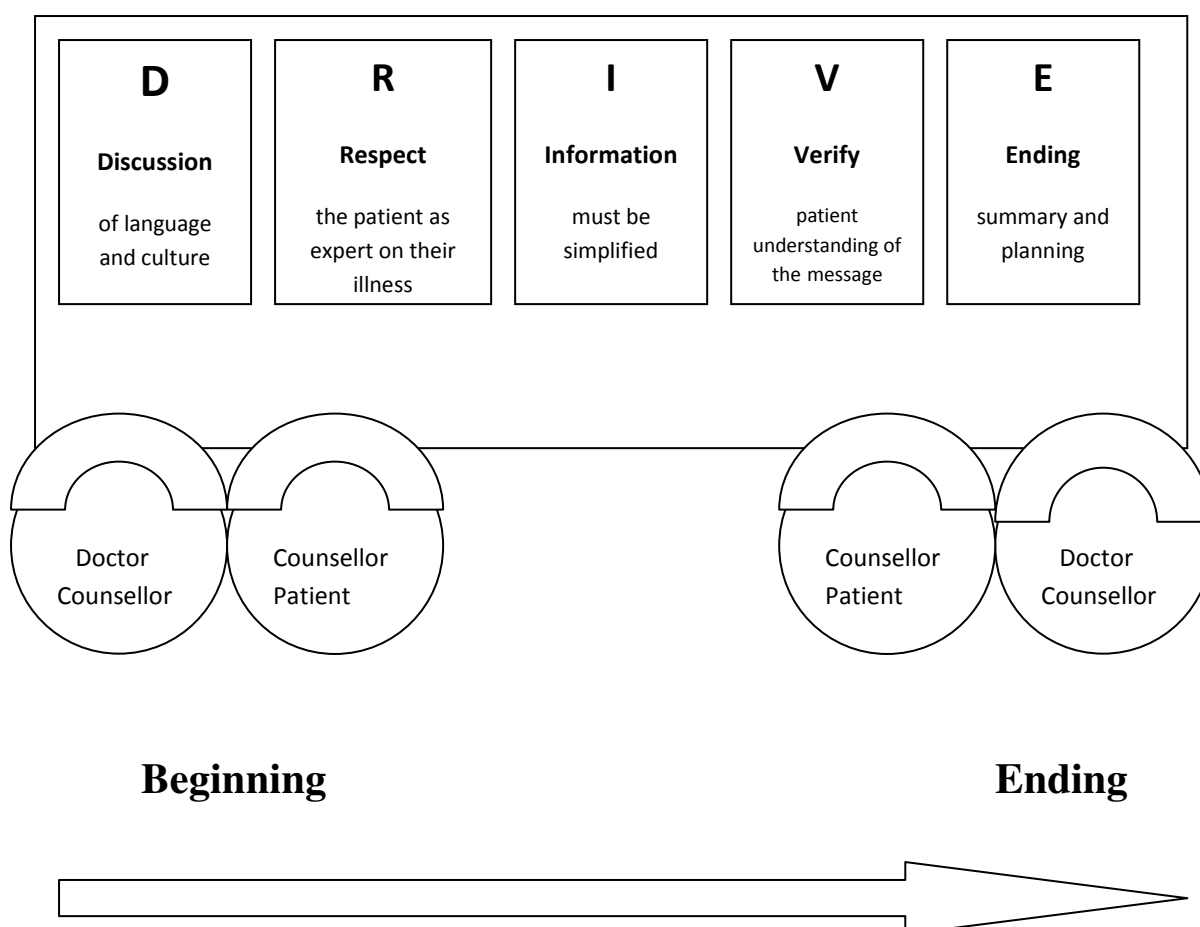
The acronym DRIVE was developed for the purpose of this study to help participants to remember the following elements that are significant within the interaction:

- Discussion of language:
- Respect the patient as the expert
- Information must be simplified
- Verify patient understanding of the message
- Ending:



Figure 5.9 illustrates the communication bus model with the DRIVE acronym. Appendix VIII illustrates recommended verbal and non-verbal strategies that were presented to participants.

The Communication Bus



Discussion	Respect	Information	Verify	Ending
of language and culture	the patient as expert on their illness through non-judgmental questioning	must be simplified	patient understanding of the message	Summary and planning
1. Introductions 2. Names 3. Language history – record in folder 4. Aim of the session 5. Roles 6. Assess level of understanding 7. Patient choice of language and counsellor 8. Structure of consultation/ time	1. Open-ended questions for exploration – narratives are lovely to use 2. Closed-ended for specifics 3. Forced-choice for difficult ‘taboo’ topics 4. Avoid scolding 5. Take notes throughout the consultation 6. Non-verbals: Seating, gesture, eye contact & tone	1. No medical jargon (CD4 count) 2. Short sentences 3. Topic shifting – structured 4. Non-mitigation 5. Examples 6. Analogies 7. Humour	1. A different modality 2. Examples 3. Repetition 4. Ask patients for their own explanation 5. Use of props – freedom to write on them/ make them your own	1. Summarise key points 2. Structured plan of action 3. Write down key points 4. Materials to take home 5. Folder records 6. Communication with the rest of the treatment team

Figure 5.9 The Communication Bus Model with the DRIVE acronym

Within the group training, communication games, brainstorming, paired role plays and video vignettes were used to illustrate aspects of the DRIVE model.

5.16 IMPLEMENTATION OF THE GROUP TRAINING

The group training was implemented on two consecutive afternoons at a large meeting room within the clinic. Twelve multidisciplinary health care team members and two facilitators participated. Video recording of the training and the completion of anonymous written questionnaires of the training enabled the researcher to evaluate the process of implementing the training. The researcher did not sit in on the training but made observational notes on the implementation process from the video footage.

5.17 IMPLEMENTATION OF THE INDIVIDUAL TRAINING

All four counsellors participated in the individual training which involved both recapping the DRIVE model proposed in the group training, and video analysis of their own counselling sessions. On average, each training session lasted 90 minutes, with the facilitator spending approximately four hours with three of the counsellors and five hours with one counsellor who requested a third training session.

On completion of each training session, the counsellors and the facilitator completed a written evaluation form. The results from these evaluation forms are summarized below.

5.17.1 Activities that went well

All of the counsellors provided very positive feedback about the training session in their written evaluations and were extremely enthusiastic about the training in discussion with the researcher afterwards. Requests were made for additional training periodically as well as further opportunities to review their video tapes at will.

The session was enjoyable because I learnt what my mistakes are and I was able to practice to do the best now. How to sit with the client. I did know about that but I was unaware of my sitting. (Counsellor)

All four of the counsellors recommended the training as being helpful to other counsellors and an exercise that should be repeated. Both the facilitator and the counsellors commented that the counsellors benefited from the opportunity to watch themselves on video. The facilitator commented that all of the counsellors were able to note down good communication strategies that they observed and were able to highlight at least one problematic behaviour in the excerpts that the facilitator had strategically chosen to review.

When you watch your mistakes, it makes it easier to rectify them. (Counsellor)

The facilitator felt that all of the counsellors seemed to benefit from the roleplay activities and from watching the facilitator roleplay. Despite counsellor self-reports that they were familiar with role plays and had done a great deal of this in prior training, roleplay was at first awkward for three of the four participants. This is not unusual, however to overcome this in future training sessions, scripted role plays could be considered as an alternative as they may save time and prevent this awkwardness.

The video footage of the training sessions as well as the facilitator feedback revealed that the counsellors needed extensive reviewing of the DRIVE model, despite it having been covered in two half day sessions in the larger group. This reinforced the importance and value of the individual training sessions. Only one of the counsellors could recall in detail the contents of the group training session at which the DRIVE model was introduced. The other three remembered aspects of the model only. This does suggest that the value of the group training lies in the multi-disciplinary interaction and discussions, rather than in improving communication knowledge.

The counsellors and the facilitator felt that good rapport was established in the session. The facilitator was pleased with the interpersonal relationships that she felt she built with each counsellor, and was confident that the counsellors were supported and listened to in their sessions. This was confirmed in the counsellor feedback and in ongoing queries from the counsellors on how the facilitator is and what she is doing at the moment.

5.17.2 Activities that were a challenge

The facilitator commented that it was difficult to discuss and practice note-taking.

All counsellors described different demands and clinic procedures that they were required to follow and I felt it was hard to provide any guidance here without knowing the context of the clinic. Our discussions therefore remained general and included how to write in the folders without blocking the client, what information needs to be included and what opportunities are there for client discussion in the clinic and with the team. (Facilitator)

The facilitator felt that note-taking within the actual training session was problematic for two reasons, firstly because of practical reasons (in terms of the limited space on the desk and seating and in terms of time constraints) and secondly because of language reasons. The counsellors could not easily jot down in words their observations on the video or complete the tables.

On more than one occasion, counsellors were more than 20 minutes late for their session for various reasons (including, in some cases but not all, clinic duties). There were disruptions to most sessions by other members of the team or by clinic patients.

The facilitator reported that all of the counsellors were cooperative throughout the sessions and tried their best at the training tasks. There was some difficulty in keeping one of the counsellors focused on the topic at hand, however the facilitator felt that although she was quite tangential and digressed frequently, her conversations always centred around communication strategies and certain clients that highlighted for her the necessity of certain aspects of the DRIVE model so in fact this enriched their sessions.

The facilitator expressed concern about one counsellor in particular for the following reason:

She seemed not to take in what we were discussing and from week to week she was unable to provide me with any specific feedback. Although she was not overtly uncooperative, I was concerned about her attentiveness. (Facilitator)

The facilitator reported that it was tricky to manage being recorded and showing the recordings. An extra pair of hands to assist with technical aspects was recommended to replace tapes etc. Despite this, both the videoing and showing the tapes worked well. Space within the feedback room was fairly confined and was not ideal for note taking for the counsellors. However, it was small enough to feel intimate and personalized, and as a participant commented, it felt “*more like a counselling session, and less like training*”.

Although all of the counsellors were positive in their feedback about the content of the training session, the facilitator highlighted particular challenges. She felt that the logical progression of the training and the specific foci of each session worked well and that following the structured DRIVE model within each session worked particularly effectively.

I feel honoured to have spent time with this insightful and genuinely interested-to-learn counsellor. I love the DRIVE model and feel it captures a very effective approach to communication that works well in this context. (Facilitator, reflective journal notes)

In addition, the opportunity for review and roleplay was beneficial and the video was a powerful educational tool. However the following were problematic:

- Too much content to cover in too short a time, considering the language and educational level of the counsellors. This reduced the amount of time available to spend on analysis of the videos or on practice.
- The jargon and communication-specific constructs in the DRIVE model made it difficult to apply directly and were necessarily modified by the facilitator: In particular, the following concepts were not understood by some of the counsellors and additional time was needed to explain it to them: ‘non-medical’, ‘jargon’, ‘plan of action’, ‘goal setting’, ‘key points’, ‘narrative’, ‘non-mitigation’, ‘topic shifting’ and ‘structured’, ‘plan of action’, ‘summary’, ‘open vs. closed ended questions’, ‘taboo’, ‘forced choice’, ‘non-verbal’, ‘modes’, ‘scolding’, ‘examples’ and ‘analogies’.
- The notes were difficult for the counsellors to use, specifically those which included tables.

The facilitator acknowledged the difficulty in following a standard program for individualized training and felt that both were partly compromised in the process, but that a balance between the two was achieved. The facilitator would have liked more time for counsellors to watch their tapes and make notes on them, allowing for the time that it takes them to write notes.

It is such a great educational tool that shouldn't be lost in the amount of information that was included in training. The video I felt formed a learning tool that didn't require the knowledge of communication jargon and the learnings could be more personal and more easily applied. Perhaps this can still be offered to counsellors. It is always great for them to see where they are doing well. (Facilitator)

The facilitator recognized the varying needs and competence of each counsellor. Some of them struggled considerably with communicating in English. This is of importance for beyond the context of this training programme as their lack of ability to understand and communicate effectively in English will compromise them in other opportunities within the clinic or in their own counselling mentoring sessions with the psychologist at the clinic (if conducted in English). The facilitator felt that at times she gave too much input despite attempting to balance her input with eliciting counsellor thoughts and feelings.

The reasons for this I feel are multiple – the level of understanding of the counsellors made it necessary to be more directive when introducing aspects of the DRIVE model, the need to clarify and explain concepts of health communication without the time to do it experientially also contributed to this and lastly it is something that I myself as a

trainer tend to do. I am also aware that I myself use a lot of jargon and highly technical terms and find it difficult to make myself understood, I tried hard to follow the DRIVE model myself and keep information simple, and I hope I was successful in this regard. (Facilitator)

One complication is that not all counsellors were familiar with goal-setting so facilitator input was needed to encourage them to identify goals for improvement. Generally, the individualised attention and structured but interactive teaching approach appeared to be unfamiliar to counsellors. This is an area for development within the clinic generally as counsellors might benefit from practicing this through case studies or closer mentoring.

5.18 GENERAL RECOMMENDATIONS TO IMPROVE THE TRAINING PROGRAMME

The training programme facilitator manual will need to be modified to take into account the feedback of the facilitator, in particular with regards to jargon and amount of content. The counsellor and facilitator recommendations regarding how to assist them in improving the communication within their clinic will be reported back to the clinic team. Something as simple as just showing support for counsellors by providing individualized attention from within the clinic, might show benefits within the clinic context.

The counsellors requested the following as potentially helpful to improve the communication in counselling:

- Having a separate page for notes on counselling in each patient's folder would be helpful to them.
- Copies of the counsellor DVDs of their own sessions available to them so that the counsellors can review them at will
- The counsellors would like to learn more about how to communicate with other staff members

The facilitator recommended making a box of scrap paper and black markers available as a useful resource to the counsellors. All of the counsellors supported this idea. Table 5.17 summarises what worked well and what challenges were reported in the evaluations of the individual training.

Table 5.17 A summary of what worked well and the challenges in the individual training

What worked well:	Challenges:
Video analysis	Note-taking
Role play	Punctuality and attendance
Review of the DRIVE Model	Receptiveness of some counsellors
Rapport between the counsellors and the facilitator	Technical and procedural issues
Content and structure:	Content and structure:
• Logical progression of each session • Foci for each session • Structure of the session	• Time : too little time to cover all the content • Language : communication jargon
	Trade-off between following a standardized programme and offering individualized training

5.19 SIMILARITY BETWEEN THIS STUDY AND OTHER COUNSELLING STUDIES

A number of similarities in design were noted between this study and other recent counselling intervention studies:

- The action research group in Baldassini's study provided counsellors with a safe space to tackle problems. In a number of studies, the presence of a mentor or research assistant boosted counsellor confidence and helped to energize counsellors (Baldassini, 2006; Nulty & Edwards, 2005).
- The studies showed that consideration of site selection is an important variable, as sites that were more successful received more support from management (Mash et al., 2008). Furthermore, successful sites had spent more time reviewing and reflecting on recordings (Mash et al., 2008). Such findings support the consideration of site-specific variables on the impact of interventions.
- Counsellors did not make much use of journaling and reflections, with some researchers concluding that video and audio tapes were better formats for interventions of this nature (Baldassini, 2006).
- An initial reluctance to be on a study, possibly due to wariness about research and a pre-existing sense of being overwhelmed, was commented on in a number of studies (e.g. Baldassini, 2006). In these studies, as the research progressed and counsellors realised that it was a safe and supportive environment, they engaged more and offered to participate. This is an important consideration for study enrollment.

- Motivation to attend training is a significant consideration. When mandated to attend training, less improvement has been noted (Miller and Mount, 2001 in Evangeli et al., 2009).

5.20 SUMMARY

The first part of this chapter described the methods used to examine the three main aims of the study, namely to design, to implement and to evaluate a communication skills training programme. This research followed a qualitative research design in the five sub-studies described to achieve these overall aims. A number of measures were adopted to ensure that the data collection and analysis methods were linguistically and culturally sensitive to the South African context. Triangulation across types of data and methods of analysis is described in order to strengthen the reliability and validity of findings. Ethical considerations are discussed and stringent measures were adopted to ensure informed consent and the safeguarding of confidentiality, particularly given the vulnerability of the research participants.

The second part of this chapter described the process of designing and implementing the communication skills training programme which was tailored to the specific research context. The training programme consisted of both a group and an individual component and was piloted at two sites, the results of which are described in Penn and Evans (2009, 2010). The training programme used in this research was modified based on the results from the description of the research context, the pilot studies and the baseline data collected.

In implementing the training programme, it would appear that some of the difficulties apparent in the training session mirror those difficulties reported by the counsellors themselves and the healthcare team, within actual counselling sessions at the clinic. These include limited space, time constraints, disruptions by patients and other team members, language issues (cross-lingual as well as competence), punctuality and attendance.

So, inadvertently, an evaluation of the facilitator's feedback suggests that the individual feedback sessions became a microcosm of actual counselling sessions in an ironic role reversal. The programme is to some degree, problematic in that it overestimated the abilities of trained counsellors and fell into its own trap of providing too much information in too short a time, as well as using communication-specific jargon. However, it was successful in showing how a trained facilitator with communication-specific expertise, could tailor-make the training programme to fit the needs and level of the participants. Furthermore, the value of using a combination of video analysis, role play and theoretical input appeared successful.

5.21 PRESENTATION OF RESULTS IN THIS THESIS

The challenge with qualitative intervention research lies in the management of a large body of data and how to present it. To avoid repetition, I have chosen to present findings that were common across the group of counsellors, and then illustrated with select examples. In order to avoid generalizing the findings thereby reducing the richness and depth of the data, where individual counsellors differed from the group, these were also illustrated for each counsellor. Wherever possible, actual quotes from video data are used to illustrate points.

Results are subsequently presented in the following order:

Baseline Measures (Presented in Chapter 6)

- Description of the research context
- A description of the general consultation characteristics
- General Communication facilitators for all the counsellors
- General communication inhibitors for all the counsellors
- Specific facilitators and inhibitors for each of the 4 counsellors

Comparative measure (Presented in Chapter 7)

- A description of the general consultation characteristics
- Changes in the general communication for all the counsellors (pre- vs post)
- Specific changes for each of the 4 counsellors
- Common themes across the pre- and post- consultations

A note on confidentiality:

It is a challenge to protect the confidentiality of the clinic and participants whilst providing rich and detailed information on the research context. In order to maintain this tension between full disclosure and ethical integrity, all identifying features have been omitted, pseudonyms have been given to the participants, institutions and organizations involved, and the publication details of research from which the site could be identified have been withheld.

Wherever possible where meaning will not be lost, reference will not be made to individual counsellors. This is a protective measure for the counsellors as it would be easy to identify counsellors based on age, language they speak and length of time for which they have been working in the clinic. It is felt that many of the issues raised in discussions with the

counsellors are applicable to the counsellors as a group and communication in counselling generally, so wherever applicable they are referred to as a group rather than individually.

A note on the selection of results from the consultation analyses for presentation in this thesis:

A substantial amount of data was collected for this thesis. In order to select which data from the consultation analyses would be presented, data was required to meet the criteria of: (1) *Consensus*, (2) *Substantiation* with a concrete example from the transcript or video, and (3) *Cross-consultation occurrence*.

A note on the presentation of the rater team comments:

The descriptions of the phenomena in this section are written as close as possible to the words used by the rater team to describe the phenomena observed. Italics have not been used as it was felt that this would disrupt the flow of the discussion and to avoid confusion between rater comments and the quotes from actual consultation transcripts, the inclusion of which is critical to substantiating the comments made by the raters. If the words of a specific rater are quoted, they are referenced to that rater.

A note on the referencing of examples from the transcripts:

Where the analysts' comments can be illustrated by a specific turn, these are referenced in square brackets e.g. [B15] with the letter indicating the consultation number, and the number indicating the numbered turn within the transcript for that consultation. Where analyst comments refer to consultations generally rather than to a specific turn, then just the consultation letter is indicated [B]. A sample of extracts for each counsellor can be found at the end of each sub-section.

CHAPTER 6

PRE-TRAINING (BASELINE) RESULTS

6.1 CHAPTER ORIENTATION

Chapter 6 describes the baseline results compiled from data collected prior to the implementation of the training programme. This chapter is divided into two parts:

Chapter 6 Part 1 presents the results from the mini-ethnography of the research site which was conducted prior to the implementation of the communication skills training programme in the clinic. These results sit on the cusp of the methodology and the results sections of this thesis, and set the research context within which subsequent results are interpreted.

Chapter 6 Part 2 of the baseline results describes the analysis of twelve video-recorded counsellor-caregiver interactions that were recorded prior to the implementation of the training programme. These interactions are analysed according to the phenomena described in Chapter 5 and listed in Table 5.14.

CHAPTER 6 PART 1: A DESCRIPTION OF THE RESEARCH CONTEXT

6.2 METHODS USED TO COMPILE THE DESCRIPTION OF THE RESEARCH CONTEXT

The results presented in this section constitute the first step in the research process. The aim of this stage was to develop a detailed description of the communication context of the research site that could influence the design of the training programme so that it could be tailored to the particular clinic context. In order to do so, the following data have been compiled:

- Ethnographic field notes to determine the common routines of the clinic, how the clinic participants work together and the general layout of the clinic
- A review of relevant clinic day sheets and patient folders to determine how often patients are documented as attending counselling and to determine the nature of the counselling consultation notes

- Focus groups and individual interviews with the medical officers, counsellors, nurses and patients to determine their perceptions of the communication and counselling within the clinic
- Questionnaires with patients aimed at determining their recall and understanding of information that the clinic staff had deemed essential components of treatment literacy for adherence.

The results from these different data methods are presented as an integrated whole and are linked to the relevant literature within this chapter. A map of the clinic (Figure 6.1) and an extract from the researcher's fieldnotes are presented below to provide a sense of the clinic atmosphere. Counselling was conducted in two 20m² counselling rooms, each equipped with plastic chairs and a writing surface. One room held a bookshelf and a cot used for deceased children. The other room, which is shared with the physiotherapist on some clinic days, held cupboards which tended to be used as a storage area by other staff members and researchers. Counsellors were able to rearrange the plastic chairs for counselling as they wished.

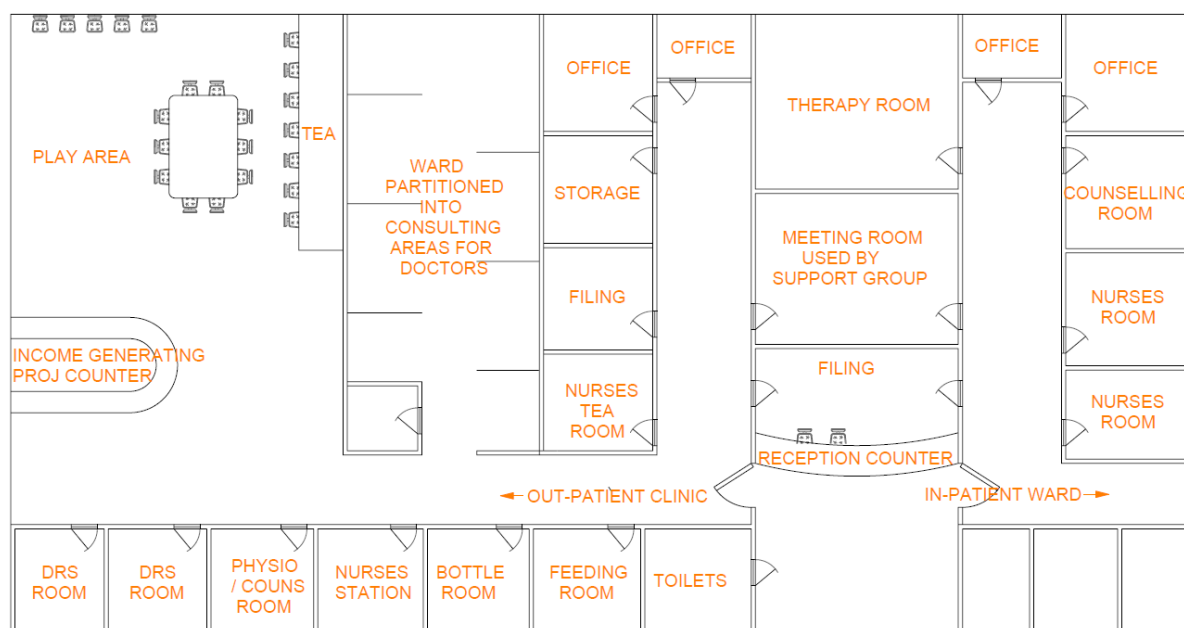


Figure 6.1 Map of the clinic

Researcher fieldnotes: Thursday, outpatient clinic

7:55am: *It is too early for anyone to be sitting at the front reception – a typical windowed counter littered with phones, files and appointment books. Painted murals brighten the atmosphere, unsuccessfully disguising that I am in a hospital. To the left, through a small gate (whose function I soon learn is to keep the children in) I pass the open door to the nurse's station. Immaculately dressed, the sister greets me warmly and comments that it will be a quiet day due to the incessant rain. I take a plastic chair across to the corner by the window, on the far side away from a high circular counter that stands empty. A coffee station is being set up in the corner by a counsellor. Children's toys have been laid out to one side, and a large table on the other is already occupied by three very wet caregivers, waiting. An assortment of plastic bags and raincoats lies at their feet. Pre-school aged children romp on the floor, oblivious to the waiting. A much younger child, very well-wrapped up, lies in her mother's lap. I recognize two counsellors who amble in. They see me and nod in recognition. Another counsellor arrives and the three of them enter the room opposite and close the door.*

10am: *Doctors walk past looking harassed. Patient names are called out, surname first. When the mother is slow to respond the doctor tries again, struggling to pronounce the isiXhosa name, inevitably scanning the file and calling out the child's name. Mothers help each other, prodding those being called, into action. It takes time to gather together bags, plastic packets, wet raincoats and a pre-school child who does not want to leave the toys now strewn across the floor. Behind the counter, caregivers and volunteers are sorting items for the income generating project. On the long table adjacent to where I am sitting, two mothers are busy working, and four others chat to them loudly. A counsellor is sitting on a bench in the passageway, chatting softly to a young caregiver with a baby on her back. Opposite to where she's sitting, a female doctor comes out of the empty ward partitioned into consultation booths. 'Have you seen X [a counsellor]?' she asks. When there is no response, she looks around the waiting room and then approaches the counsellor chatting to the young mother. She asks the counsellor to interpret for her as she can't find another counsellor. The counsellor excuses herself from the caregiver and follows the doctor. The other three counsellors remain in the room with the closed door.*

12pm: *The waiting area has almost emptied. Income generation materials are still being sorted behind the counter by the volunteers. Most of the caregivers have moved on to the large meeting room where the support group is being held. Others are down at the pharmacy on another floor, waiting for their prescriptions. Doctors are still consulting, but the nurse's station, a hive of activity an hour earlier, has emptied. The harmony of sung prayers filters out from the support group. Despite the nurse's prediction that the weather would impact on attendance, more than 20 voices sing in unison.*

6.3 A DESCRIPTION OF THE CLINIC WITHIN THE HOSPITAL AND THE HEALTH CARE SYSTEM

The data for this study was collected between January 2005 and December 2007 in the Western Cape, South Africa. The study clinic is a government funded entity situated within a secondary/tertiary level¹⁷ public service hospital referred to as the Lady Evelina Clinic for the purpose of this study. Although physically situated within a secondary/tertiary level facility, the clinic has been providing care from a primary level upwards. This arose out of its establishment in 2001 by an NGO to raise support for families affected by HIV/AIDS, and ARVs were provided to patients prior to the government's ARV rollout programme which was only announced in November 2003. The study clinic, as well as those from the pilot studies, serves predominantly black urban and peri-urban working class communities and are broadly representative of the types of services available for HIV positive caregivers and their children within the Western Cape. Based on data reported in other HIV studies conducted around the time of this one, we can assume that about a quarter of residents of the communities served by the clinic have no high school education, 40% of households earn less than US\$2000 per annum and that antenatal prevalence is estimated to be between 25 – 30% (Cooper et al., 2007).

The clinic has a number of funding sources resulting in complex staffing arrangements and lines of reporting for personnel. Table 6.1 presents personnel positions in relation to lines of reporting and funding sources drawn from the document *Lady Evelina Clinic Partnerships* (unpublished, 2006).

Table 6.1 Personnel at Lady Evelina Clinic described by number, employer, funding source, line of reporting and language

Position	Number	Employer	Funding source	Line of reporting	Language
Head of clinic	1	Joint staff, University/ PGWC	Hospital	HOD of paediatrics and outpatients	English, Afrikaans
Medical officers	Varies 4 – 6	Hospital	HIV/AIDS Directorate of WC	Head of clinic	English (5), French (1), IsiXhosa (1)
Nurses	3	Hospital nursing	HIV/AIDS Directorate of WC	Hospital nursing	IsiXhosa, Afrikaans

¹⁷ A facility providing secondary/tertiary level care can be described as a large facility that involves university teaching facilities and patients at this level of care will be involved with subspecialists (Kibel & Wagstaff, 1995).

Table 6.1 continued

Counsellors	4	NGO 'Buyiswa' subcontracted to the HIV/AIDS Directorate	NGO 'Buyiswa'	NGO 'Buyiswa'	IsiXhosa (4), English (4), Afrikaans (1)
Counsellor, leader of children's support group	1	NGO 'Khuthala'	NGO 'Khuthala'	Head of clinic	IsiXhosa, English
Volunteer counsellor, children's support group assistant	1	Volunteer	Volunteer	Head of clinic	IsiXhosa, English
Physiotherapist	1	NGO 'Khuthala'	NGO 'Khuthala'	Head of clinic	English
Social Worker	1	Hospital	Hospital	Head of social work	English
Interns, registrars & students	Varies	Hospital	Hospital	Head of clinic	Varies
Administrative assistant	1	NGO 'Khuthala'	NGO 'Khuthala'	Head of clinic	IsiXhosa, English
Data capturer	1	NGO 'Khuthala'	NGO 'Khuthala'	Head of clinic	IsiXhosa, English

The clinic emphasizes accessibility of care through its 'no wrong days' policy; a caregiver can bring her child to the clinic, 24 hours a day, on any day. Care is integrated and the clinic operates a one-stop policy of treating caregivers and children. Comprehensive care is provided along the full continuum of primary health care.

Inter-sectoral collaboration through work with the NGO *Khuthala* (meaning 'hard work') is evident through an income-generating project for caregivers which is an integral part of the clinic and is accessed by the most needy caregivers. The clinic also has strong links with other similar facilities both nationally and internationally. Apart from the income and the increased sense of self-worth that comes with being employed, the mothers have the benefit of support from other caregivers in a similar position to themselves¹⁸.

There is a research culture within the clinic with a number of ongoing research projects at the time of data collection (an adherence pill cap study by a visiting student, monitoring of audiological results by university students and researching growth factors in children by one of the medical officers). The clinic forms part of the Paediatric Aids Treatment for Africa¹⁹ (PATA) network that is centered on developing models of excellence in service delivery of ARVs.

¹⁸ Referencing sources withheld to protect the confidentiality of the NGOs and the clinic

¹⁹ PATA was developed with the aim of bringing together teams of front-line health care workers to exchange experience, to examine current practice and to explore ways of developing an improved clinical model for the delivery of health care and ARV therapy to children in sub-Saharan Africa (www.teamkata.org).

Only the medical officers, data capturer and students are involved in research directly. Within the counselling group, only two of the four counsellors employed by the counselling NGO *Buyiswa* (meaning ‘Come’), consented to participate in this research. The counsellors expressed wariness about research generally and a perception that they were being assessed. Job security is a concern within this group and this study could make the counsellors vulnerable within their workplace, and so strict measures of confidentiality were adopted to prevent this. The counsellors who did consent to participating in the study (two adherence counsellors from *Buyiswa* and the two from the children’s support group employed by *Khuthala*) viewed participating in research as a way of developing personally, and all four of them commented on the benefit of research to the clinic functioning and the welfare of the patients. All of these participants were highly motivated about their job and interested in self-improvement. As such, the results reflected in this study might be skewed positively as these four counsellors appeared more motivated, expressed great job satisfaction and felt most confident about their skills. This is also the case in other published counselling studies (e.g. Baldassini, 2006; Mash et al., 2008).

6.4 ADHERENCE MONITORING WITHIN THE CLINIC

Adherence monitoring is central to the ongoing management of ART in the clinic. Pill counts are routinely conducted with patients at consultations and adherence is emphasized within the support group. Subsequent to the completion of this research, the clinic had been exploring SMS options for reminding patients about clinic appointments and collection of medicines.

At the time of this study, an electronic pill cap measurement with children under ten years on liquid formulations was conducted over a two to three month period and has subsequently been published²⁰. Electronic measurements were shown to correlate with levels of HIV suppression. However, electronic measurements were significantly lower than caregiver self-reports of adherence using a visual analogue scale. In the study, 36% of patients using the electronic pill cap measure had adherence of greater than 9%, in contrast to 91% of patients that had reported having adherence of greater than 95%. These rates are comparable with adherence rates in developed countries. These results provide evidence that caregiver reports of adherence are not reliable measures of ART adherence in children.

²⁰ Referencing source withheld to protect the confidentiality of the clinic

6.5 PATIENTS

In 2006, 489 paediatric patients were recorded as being managed by the clinic²¹. No statistics were available for the adult patients. 6 children died in that year, and 14 were lost to follow up. The clinic was in a state of transition at the time, with a large number of clinic patients being transferred to outlying clinics in accordance with the primary health care system strategy. It was due to the historic lack of provision of ARVs at these sites, that these patients were being managed by the study clinic. Close to 100 patients were recorded as having transferred mostly to clinics in townships within the Cape Metropole (predominantly to Crossroads, Mitchell's Plain, Gugulethu and Nulungile Clinics) and a smaller number out of the province (mostly to the Eastern Cape). Clinic day sheets show that in the region of 20 patients were seen per day on the two outpatient days per week. The clinic had been set the target of transferring out fifteen patients per month. This was a matter of considerable anxiety to patients, many of whom were happy with the care they had received in the clinic. This decentralization to outlying clinics is in line with the *Guidelines for the management of HIV-infected Children: Caring together for life* (DOH, 2005) described in Chapter 2.

The majority of the patients in the clinic were isiXhosa-speaking with English as their second language. Of the 45 isiXhosa-speaking patients interviewed, 18% reported needing a counsellor present in interactions with doctors and other English-speaking staff members. A very small proportion of patients spoke Afrikaans or English as their first language. The need for interpretation for many patients in South African clinics is well-established as described in Chapter 3.

Annually, over the December/ January school holiday period, and to a lesser extent over the shorter July school holidays, many of the patients travelled to the Eastern Cape to visit family as is customary with South African circular migratory patterns (SADHS, 2008). This created logistical problems for all: doctors and the hospital pharmacy needed to provide sufficient medication for the extended period; counsellors needed to prepare patients for what to do in the case of unexpected 'disasters' such as running out of medication or losing the medication in transit; and caregivers were faced with the issue of whether or not to disclose to their extended family with whom they live over this period as well as managing the change in routine.

²¹ Personal correspondence with a medical officer and the data capturer at the clinic, March 2009

6.6 COUNSELLING WITHIN THE CULTURE OF THE CLINIC

The counselling service was added on to the original doctor-centered model of service delivery in 2005. From discussions with a caregiver who had attended the clinic since its inception, counselling was initiated to bridge language divides between patients and service providers and to provide psychosocial support for caregivers. Counselling services existed on the periphery. In general, the counsellors appeared to keep themselves apart from other staff members. They sat and ate separately, and did not interact socially with other staff members.

In the clinic, counselling was provided by two main sources:

- A group of adherence counsellors subcontracted through a nationwide counselling NGO, Buyiswa, to provide adherence counselling
- Independent counsellors who are employed by another NGO, Khuthala. One of these counsellors (leader of the children's support group) was employed on a full-time basis to run support groups, provide play therapy for the children and for general counselling. She was assisted by a volunteer counsellor.

The distinction between the two groups of counsellors is made because different dynamics exist between the two groups, and they differ in terms of lines of reporting, training and roles within the clinic. All of the counsellors in the clinic are female. They are all able to speak English and isiXhosa fluently. One of the counsellors is also able to speak Afrikaans.

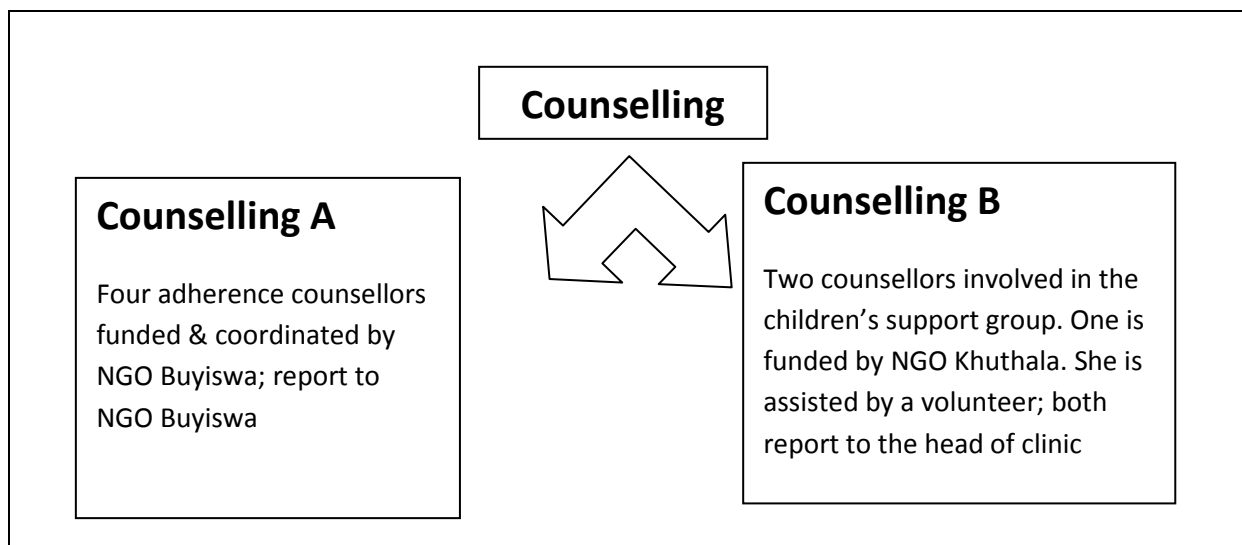


Figure 6.2 The two types of counselling within Lady Evelina Clinic

The adherence counselling service in the clinic is provided by NGO Buyiswa that had been subcontracted to the hospital to provide HIV/AIDs adherence counselling. This NGO supplies counsellors to many other facilities that fall under the management of the Provincial Government of the Western Cape (PGWC). Four adherence counsellors (Agnes, Beatrice, Elsie and Lindiwe) work in the clinic on the two outpatient days, and on the other days, these four counsellors work as HIV counsellors in other areas in the hospital. There is no 'head' counsellor.

Semi-structured interviews with the adherence counsellors revealed that they liaise with the NGO Buyiswa themselves or through the head nurse of some of the clinics within which they work. Counsellor support is provided by the NGO that employs them in the form of weekly meetings with a member from the NGO and a monthly debriefing and case study meeting with a psychologist, both outside the context of the clinic. Weekly staff meetings are also held within the clinic. Counsellors reported infrequent attendance at staff meetings often due to miscommunications about the time of the meetings. Counsellors sometimes wore navy and white uniforms and name badges. As space was at a premium in the clinic, counsellors shared rooms with each other and with other staff. The problem of a lack of space within clinics generally is well-documented in the literature.

A strong independence from the clinic and the counsellors' lack of accountability to the head of the clinic or any of the clinic staff was always asserted by the adherence counsellors from NGO Buyiswa in the interviews. The importance of good team work and good communication within the clinic, was also emphasized. This lack of CHW integration is one of many recognized barriers to care described in Chapter 2. Individual counsellor levels of experience and motivation varied greatly. The experience of the counsellors that participated in this study is summarized in Table 6.2.

Table 6.2 Participating counsellor training and experience

Nokuzola became involved in the clinic as a patient and the mother of an HIV positive child who is also treated at the clinic. Her enthusiasm in the clinic was noticed by the staff, and she was employed by the NGO Khuthala to run a mother's support group. As the children managed by the clinic grew older, a children's support group was also started which she also manages. Her involvement in the mother's support group meant that she became involved informally in counselling many of the mothers who turned to her for assistance. Nokuzola then attended the ATICC adherence course and has been involved in counselling in the clinic for a few years.
Elsie was an experienced counsellor who has completed the ATICC basic counselling, adherence counselling and VCT training courses. She had been counselling mothers in the clinic since the start of the partnership between the NGO and the DOH.
Babalwa became involved in the clinic 2 years prior to this study, as the mother of one of the children being treated in the clinic. She had no formal counselling training, and her experience was limited to volunteering in the clinic as a counsellor, and helping with the children's support group. Babalwa was informally mentored in this role by Nokuzola. During the course of the data collection period, Babalwa's role became more formalized within the clinic as she received a stipend from another NGO for employment as an 'expert patient'.
Lindiwe is an experienced counsellor who has completed numerous short courses (ATICC, Lifeline, Denta and Caring network among others) and the Delta phase 1 training (1 year). She had been involved in training and assessing counsellors on the Lifeline course. She was a mother and the eldest of the counsellors participating in the study. Lindiwe became a counsellor because she had a positive counselling experience in her own life.

6.7 ROLE OF THE COUNSELLOR: PARTICIPANT SELF-REPORTS

The counsellors described themselves as adherence counsellors whose duty was twofold, namely to educate patients (about anti-retrovirals, the course of HIV and the functioning of the clinic), and to provide support for the patients. New patients to the clinic should be counselled three times by counsellors prior to commencing treatment on ARVs. They were encouraged to attend the mothers' support group which meets on a weekly basis for ongoing education and support, and to make use of the counselling facilities. The counsellors also identified interpreting for the health professionals as being part of their role. They stated that this interpreting role was described within their DOH job description (Appendix III) and that interpreting was '*just another part of the job*'. They stated that they had been trained in

communication skills but not in interpreting. Some of the counsellors felt that communication skills training would be necessary to help them fill their role better. However others felt that there was nothing that they needed to learn. Overall, counsellor perceptions of their job description were narrower than that described in the DOH literature as outlined in Chapter 2.

An important counselling role identified by the doctors in the clinic, was that of informing the health professionals which patients were or were not ready to commence treatment. The doctors felt that this role was not necessarily fulfilled by counsellors as the counsellors never told them if the patients were not ready to begin treatment. The counsellors acknowledged that advising the doctors which patients were or were not ready for treatment was part of their role. However, in practice, this created difficulties, as they would be seen as a barrier to care if they recommended withholding treatment from a patient due to lack of preparedness. Given the limited training of counsellors and their lowly position in the hospital hierarchy, it appeared to be unrealistic of the medical officers to expect the counsellors to take on the responsibility of a gate-keeping role. Furthermore, this role contradicts the assumed one of adherence counsellors *increasing* access to treatment.

6.8 CAREGIVER UPTAKE OF COUNSELLING

Caregiver reports on the number of counselling sessions they had attended, ranged from 1 to 10, with the average number of counselling visits being 3.8. Of the 45 caregivers interviewed, 60% said that they would ask their doctor and not a counsellor if they had a query about their medication and 27% said that they would approach a counsellor if they needed to discuss psychosocial concerns; the remaining 73% said that they would rather discuss these concerns with a family member or a friend. Of those caregivers interviewed, 42% stated that they would only go to counselling if they were sent by their doctor. Some of the reasons cited by caregivers for not wishing to attend counselling were that [P21] “*Counsellors don’t keep the secret*” and [P25] “*No, I don’t like it. It doesn’t help me*”. Patients that had attended counselling sessions reported that they had discussed disclosure, their child’s health, medication, problems at home and how the virus works. Figure 6.3 illustrates the number of counselling sessions reported by caregivers. Many caregivers reported attending less than the stipulated three counselling sessions prior to initiation of ART.

Number of counselling sessions attended	0	1	2	3	4	5	6	7	8	9	10
Caregiver reported incidence for attending counselling sessions	0	2	9	10	11	5	4	2	1	0	1

Figure 6.3 Number of counselling sessions reported by caregivers

Clinic records were examined to determine the number of patients recorded as being seen at the clinic on outpatient days, the number of patients recorded as being scheduled (through bookings) for counselling on these days, and the number of patients recorded in patient folders as having attended counselling. 50 files of patients currently being seen at the clinic were randomly drawn from the adult's and from the children's sections; and all of the folders on 3 separate clinic visit days were examined.

Doctors had expressed that they felt that insufficient counselling activity was happening and that the lines of reporting of the counsellors reporting directly to their NGO, made it impossible to determine whether or not this was the case. When folders were examined for evidence of counselling, of the 100 (50 children and 50 adult) folders randomly drawn, less than 3 of the folders contained records of counselling. Very few of the patients attending the clinic on any given day were attending counselling. Individual counsellor day sheets could not be examined because not all of the counsellors wished to participate in this study. Monthly records including number of patients seen (but not patient names) were submitted to the counselling NGO. These could not be accessed. From observational notes whilst stationed at the clinic, it was evident that counselling was happening. However counselling only occurred when it was initiated by doctors, patients themselves, or two of the counsellors. Nonetheless, very little counselling was observed. Ethnographic fieldnotes and discussions with patients suggested that more counselling appeared to be happening than was recorded in the patient folders. Furthermore, counsellors appeared to be particularly wary about reporting statistics. This may have been due in part to the incompatibility of counsellors following a client-centered approach within an outcomes-based health care system as identified by Rohelder and Swartz (2005) and described in Chapter 2. Another explanation offered by counsellors was the perception that as caregiver confidentiality was paramount, this justified non-documentation of counselling sessions in folders. A lack of counsellor motivation as documented in the CHW literature and described in Chapter 2 appeared to be the underlying reason for low levels of counsellor productivity. Certainly, the DOH (2005) recommendation

that accurate counselling of caregivers should occur at every visit to the primary health centre, was not met by counsellors.

Long-term psychosocial and treatment literacy support is provided to the caregivers in the clinic by the counselling staff, in addition to the support provided by the medical officers and nursing staff. Within this context, counselling is undoubtedly a process in which caregivers receive input from the whole multidisciplinary team. As the overall responsibility for appropriate counselling lies ‘with the health care provider and not lay counsellors’ (NDOH, 2005) this need may have been met by other members of the health care team. However, in reality, as it is the counsellors who speak the same language as the patients, they tend to shoulder the overall burden for treatment literacy. As treatment literacy is a combination of input from many people within and outside of the clinic (including the media, community organizations, education programmes etc), and cannot be viewed as a once-off event, levels of patient understanding need to be interpreted with this in mind. Patient understanding is, however, interesting in terms of determining which aspects of treatment literacy are difficult for patients to understand.

6.9 CAREGIVER UNDERSTANDING

45 caregivers were interviewed in isiXhosa over a four week period in October 2006 to determine their understanding of certain aspects of ART. The questions they were asked were developed from discussions with the multidisciplinary team as to the minimum knowledge they wanted all patients on ARV treatment to understand. A response schedule was drawn up in consultation with the medical officers at the clinic. Patients were interviewed in their own language.

Results showed that by far the majority of patients had a good understanding of the name of their medication, the dosing, what to do in case of side-effects or planning for visits to the Eastern Cape, why they needed to use condoms and what to do if they fell pregnant. Table 6.3 presents the questions and percentage of correct answers obtained by the caregivers who were interviewed.

Table 6.3 Percentage of questions correctly answered in establishing patient understanding of items identified by the multidisciplinary team as constituting the minimum knowledge patients on ARVs should understand

Question	Number correct	% correct explanations
1. What is the name of your child's medication?	43/ 45	96%
2. How much medicine must your child take and when must they take it?	45/ 45	100%
3. Why is it important to stick to taking the medicine at the right time?	35/45	78%
4. What must you do if you forget to give your child their treatment?	17/45	16%
5. What must you do if your child experiences side effects such as diarrhoea and vomiting?	44/45	98%
6. If you are going to the Eastern Cape for a holiday, what must you do about your medication?	44/45	98%
7. What is a CD4 count?	12/45	27%
8. What is viral load?	14/45	31%
9. How do ARVs work in the blood?	31/45	69%
10. Why do you need to practice safe sex?	41/45	91%
11. What must you do if you fall pregnant / if you want to fall pregnant?	40/45	89%

e.g. Q3 Patient explanation: *“ARVs are not the same as other medicines. You must take them at exact times. The virus gets more if you don't take your medicines at the exact times.”*

The results showed that many of the patients did not understand what to do if they had forgotten to take their medication or the meaning of often-used medical terminology (CD4 count & Viral load). Of those patients who understood one of these terms correctly, approximately 50% did not understand the other term. When discussing how ARVs work, many patients seemed focused on *cure*. In interpreting this data, it is important to remember that as the interviews were semi-structured and patients were asked to recall and explain information, failure to explain a term does not equate with failure to understand the term. The results are useful in highlighting what patients were able to explain well, and factors that they are unable to explain, which may suggest a lack of understanding. These findings support the health communication literature that jargon can contribute to communication breakdowns as explored in Chapter 3. Table 6.4 includes some examples of patient answers to questions.

Table 6.4 Patient explanations of particular adherence-related topics

Topic	Examples from Patients:
On forgetting to give the medication:	“If I forget in the morning, then I just don’t give in the evening too. Instead, I write it on the diary card.” “If I forget, then I won’t take it in the evening too”. “I don’t know, but they tell me not to change the times.”
On CD4 counts :	“I don’t know”. “It’s your kidneys”.
On Viral Load :	“It is a body part”

Although the majority of the patients had a good understanding of essential ART information, a minority of patients expressed their lack of understanding of key concepts such as transmission and how ARVs work. Evidence of this can be found in the quote from one of the patients which is presented below:

P: “I just give my child all these tablets without knowing the reason. I will probably end up giving him all the tablets we come across, because even the ones that I have I don’t know what they are for. I just want my child to get better. I don’t want this HIV and TB because I don’t know how he got it.”

6.10 COUNSELLOR PERCEPTIONS OF COUNSELLING IN THE CLINIC

The counsellors identified space and a lack of resources for patient education (condoms, dildos, videos) as the primary problems with the counselling service. Some of the counsellors felt that there were very poor relations within the counselling team and between them and the rest of the staff. A lack of motivation also appeared to be a problem. All of these reports were substantiated by the researcher’s observations.

6.11 HEALTH PROFESSIONAL PERCEPTIONS OF COUNSELLING IN THE CLINIC

Quotes to support health professional perceptions are referenced to Table 6.5 at the end of this section.

The doctors and nursing sister did not feel that the existing counselling service was meeting the clinic demands. Difficulties were identified as arising out of a lack of space for counselling [1], the lack of leadership within the counselling team and issues surrounding accountability as the counsellors are employed by an independent institution and not the clinic itself [2]. Some support in the form of information on adherence had been provided, but this was not used by the counsellors [3].

The medical officers perceived the counsellors as lacking initiative and not actively engaging in their activities [4]. At times, their apparent lack of activity, structure and secretive activities (when sitting behind closed doors) was a source of frustration to the medical officers [5]. It was felt that the counsellors needed to be empowered to be more proactive and caring towards patients as there appeared to be little rapport between counsellors and patients [6].

Despite these challenges, the medical officers acknowledged the importance of the counselling role in bridging the language, cultural and traditional doctor/patient divide [7]. It was mentioned that some counsellors did show initiative such as in the pill counting and following up on caregivers in the adult wards [8]. They also acknowledged the complexities of adherence counselling [9] which needs to be tailored to the individual patient and explored as a process rather than a once-off event [10]. The following information was mentioned as being important content information to be mentioned within adherence counselling sessions:

- The life-long commitment to taking ARVs
- Planning for taking ARVs including trouble-shooting events such as going on holiday and running out of pills
- Contingency measures for if tablets were forgotten
- Disclosure
- Exploration of biopsychosocial factors
- Emotional support

Institutional and systemic changes were suggested to deal with the issues of implementing greater structure and accountability. It was felt that counsellors needed to broaden their topics of discussion with patients [11] and that greater continuity was needed between patients and counsellors and doctors [12]. The doctors and nurses felt that the training the counsellors had did not appear to have prepared them for the job at hand and that additional training was needed [13].

Table 6.5 References for the extracts from the semi-structured interviews with doctors and the nursing sister at Lady Evelina clinic

Quotes from semi-structured interview data with the doctors and the nursing sister	
1	<i>“And no space. If they had two rooms that were designated to them then they could sit there with their appointment book they could have space to do their job and that I think would make such big difference”</i>
2	<i>“... their supervisor is outside of this clinic. So we don’t really have any authority here... And a leader. You see [Nokuzola] is not employed by the same people as them. That changed [another hospital’s] counselling. I think that is something that would really make a difference. Somebody that will be not accountable but responsible for organizing things for the four of them to make sure that things are working for the four of them”</i>
3	<i>“I put together a folder for the counsellors with information on HIV and adherence that I have never seen since... I gave each one of them a folder and I have never seen it used or even available here since then.”</i>
4	<i>“I would like the counsellors to book appointments for their patients. To go one more step and to say we have covered this much; These are the issues we have discussed, there is more to discuss so when are you next coming? Oh! You’re coming again in 4 weeks so let’s make an appointment then...ya and so I want them to identify patients and to actually say Oh! This actually needs to be followed up. And I am going to see when you come back next time so next time you come in I am personally going to go and count your tablets or whatever and I’m going to follow up. So for the counsellor to take ownership of the patient and that patient’s problems.”</i> <i>“And also about being empowered to make to say to the doctor but I don’t think this patient is ready to start treatment and I’ve never had anyone who has come to me yet and yet they are supposed to be assessing whether or not the patient is ready for treatment. And nobody has ever come to me...”</i> <i>And definitely, patients are not always ready.</i> <i>This is an important decision and it’s a decision about whether patients are ready to change, whether this patient has changed, whether or not we should start in the first place and whether or not ya sorry that’s another content thing that’s really important and that is that we have got two regimens and there ain’t nothing else and that’s it. And that must be expressed.”</i>
5	<i>“And something that really annoys me is that I’ll have to go and open the door. Because they’re sitting behind a closed door. What really gets to me is that they’ll all be sitting there with the door closed and then I’ll go in and open the door and they’ll be sitting between themselves and it’s supposed to be that they’re the ever accessible counsellor.”</i>

Table 6.5 continued

6	<i>“Or whether she just didn’t care or and obviously this was not important to her. It’s procedural but it’s also showing initiative and maybe showing insight into the counselling process because this is not just a once off. It’s something that we want to support this woman get medication or help this woman get medication herself. To me it’s about really caring.”</i> <i>“There seems to be no rapport between the counsellors and the mums.”</i>
7	<i>“To be able to share intimate things with them [counsellors] because as doctors it is very difficult for us to break that barrier we have the chance to... We can help but I think they probably have a better chance to because of the isiXhosa and their culture.”</i> <i>“And so I think it might also take away that feeling that they have to please the doctor so as a doctor when you ask them so are you taking your medicines twice a day because you are a doctor they say of course I am when as a doctor we can see that they haven’t been doing that so for the counsellors to have the bond to be able to actually allow someone to say.”</i>
8	<i>“You get to work, and before they do anything they have their breakfast which seems to go on for a long time. And then they sit and wait to be called to do something. Well that’s a generalization because one or two if they’re seeing patients and one of them has been fantastic and on her own initiative has started doing pill counts which I’m really excited about because now we can latch on to this because now she can be leader of the pill counts. But it’s the waiting to be called and asked to do something and there is a lot of sitting around.”</i> <i>“But it’s like they do nothing. They sit and wait and maybe when you want to find them you can’t and maybe it’s about space.”</i> <i>“But they do also do work for us in the adult clinic and there they do have space they’ve got some rooms and they are involved in the support group here. They do sometimes go and see adult patients in the ward and they are quite good about following up there...Ya Ya they go on their own steam. They are they’ll often be asked to go and then I’ll go a week or so later and find that they have followed up sometimes as much as 3 times.”</i>
9	<i>“I think we need an adherence counsellor... one who goes a step further than just the pills and also (wiggles hands indicating around and forwards) towards ya towards it in the direction of social support... it would be handy if they could have actual developed counselling skills but I know that’s not necessarily possible... if they were better because a lot of our patients have more complex problems than just I’m not willing to take pills. So counsellors who play more of a role in the team approach.”</i>
10	<i>“There are multiple steps that it [adherence counselling] can be broken down into and so the difference is that we need people that can identify really identify what is important at each stage...</i> <i>“ You know working out whether someone is exposed to ARVs, the discussion of ARVs versus someone who’s been on it for 6 months vs someone who’s been on them for longer then also that she can discuss things like alcohol issues uhhh to go in depth into and I think they do to some degree to be able to identify that they are ready for adherence and then to establish some sort of rapport or some sort of a bond to be able to confide in them.”</i>

Table 6.5 continued

11	<i>“Obviously why the pills are important and what often or what seems often not to get across is that actually you can’t run out of medicine you can’t go away and not plan it and that idea that I have to plan my life around these medicines and that I have to always think about having enough medicine every time I go away that before I go away I think about my medicine that this is a long-term need for treatment that doesn’t go away.</i> <i>Just to emphasis that ya not that you must just take them everyday but also just that you mustn’t run out because I just think that that is something that often the patients go away they often run out and they are not really too phased and I think that that could just possibly be something that could be prevented if you went through those things before they started treatment...</i> <i>but then that is another aspect but then then that thing about getting consistency... this but then you have to take this at the same time everyday and that this is a lifetime commitment ya and that if you are an hour late do not skip the dose but rather just take it then... Sometimes I almost have the impression that I want to ask them about this and I want them to talk with patients and to discuss this but that they just discuss CD4s CD4s CD4s and that they do not tell me if the patient is ready or not.</i> <i>Ya this should be something individual. It should be something individual for each patient.”</i>
12	<i>“And having a structure with one counsellor seeing one specific patient and that counsellor working with a specific doctor with that patient. There is no matching between counsellors and doctors. You get who you find.”</i>
13	<i>“I mean all this is supposedly with people who have been trained who have been trained through NGO I they’ve been trained yet but what we are seeing doesn’t suggest that they are not prepared to go the long haul to give effective service.”</i> <i>“They need to have structure and to have training because sometimes the counsellors they run out of argument / what to teach the patient. They always come in with viral load and CD4 count. It should be something individual.”</i>

6.12 DISCUSSION OF THE PARTICIPANT PERCEPTIONS ABOUT COUNSELLING AND COMMUNICATION IN THE CLINIC

From interviews with the health professionals at the clinic, the following common challenges emerged:

- Patient complexity and diversity
- Content ‘message’ factors
- Centrality of counselling
- Continuity of care
- Partnership building

There was general recognition by all team members that patients are diverse and have complex problems and constantly evolving needs. Counsellors in particular were aware of the language diversity of patients and the problems that this presents for treatment literacy. Counsellors expressed pride in increasing patient understanding with poorly educated and naïve patients with whom they needed to spend more time. In contrast with the nurses and doctors, the counsellors believed that not all patients required counselling for treatment literacy.

Doctors, nurses and counsellors all used the words '*bridge*' to describe how counsellors assist patients in crossing the doctor-patient divide. Doctors acknowledged the communication barriers they faced in communicating with isiXhosa-speaking patients in particular and felt that patients lied to please them at times, and they were unsure of whether or not patients understood what they told them. All of the doctors expressed that counsellors are ideally placed to bridge the doctor/ patient divide. This was reiterated by the nursing sister who felt that counsellors have more time than doctors do to speak to patients and to develop a relationship with them. The nursing sister did caution that there was some mistrust of the counsellors from a small but '*influential*' group of patients who had attended the clinic before the addition of the counselling service. Counsellors felt that since the support groups had started, patient understanding had improved dramatically. They all acknowledged that interpreting for doctors fell within their job description, and they expressed that this was a task that they were happy to do and in which they felt competent despite the fact that it was difficult.

The doctors acknowledged the complexity of the counselling task, the multiple roles that counsellors need to play and the stresses of their job. They felt that there was a need for counsellors to develop better counselling and communication skills that were individualized to each patients' needs. They felt that counsellors tended to just discuss CD4 counts all of the time and didn't address patient psychosocial issues. In the counselling focus group on the other hand, the counsellors expressed the feeling that their training was sufficient for them to meet patients' needs. Most of the counsellors felt that they had already been taught communication skills and that no further training in that area was needed. The value of conducting both individual and focus group interviews was apparent, as a minority of the counsellors, in individual interview sessions, expressed the value of lifelong learning and felt that communication training would be beneficial.

Doctors stated that patients need to know the dosage, times, planning for disruptions to schedules and the importance of medicines. They felt that counsellors needed assistance in discussing psychosocial factors. In contrast, counsellors had mixed feelings about what constitutes adherence counselling and which factors they needed to discuss with patients. A few of the counsellors felt that adherence counselling was purely about patient understanding of ARVs and the consequences of not taking ARVs, and that their job did not extend beyond discussing adherence and treatment. Although counsellors all stated that they had a copy of the DOH adherence counselling job description, this description differs markedly from the narrow role described by some of them. In order to assist them in explaining information to patients, counsellors expressed that they needed resources such as videos, dildos, condoms and female condoms, and that they needed space to keep these resources safe and a person in charge of maintaining and re-ordering stock of these resources.

Doctors felt that one change that could improve the communication in counselling sessions, would be for caregivers to have their tablets with them prior to the counselling session so that the counsellors could go through the medication using the actual pills and formulas. However, due to delays at the pharmacy and with patients wishing to leave straight after obtaining their pills, this did not always happen. The nurse also linked the pharmacy at the clinic to creating difficulties with counselling. She felt that at Lady Evelina clinic there was more margin for error than at other clinics as patients did not return to the clinic after being dispensed tablets, and that these were invariably the patients that needed the most counselling.

“So what we have here is actually a doctor-oriented programme; So what we need in their mind is to actually make them understand that the counsellors are key to the programme”. (Doctor)

The doctors expressed that it has been challenging to make the counselling viewed as an integral part of the clinic as they are employed by an NGO that falls outside of their jurisdiction. They felt that guidelines were needed on how the NGO and the clinic could work together and function so that lines of reporting were better structured. The nursing sister and the counsellors all echoed this sentiment that counselling needs to be the ‘backbone’ of the clinic, but that Lady Evelina clinic remained doctor-centered. The nurse and counsellors recognized that the external loci of the clinic *outside* of the community of patients by virtue of its secondary/ tertiary level, contributed to the doctor-centeredness.

Within this environment, the counsellors expressed initial shock at having to operate from this doctor-centered framework which was very different from the model from within which they had been trained. They unanimously expressed difficulties initially in the expectation that they would have to modify what they had been taught to fit in with the way the clinic runs. One example of having to compromise their training ideals, was in having to reduce the number of patient sessions (from the ideal of three) prior to starting treatment as there was perceived pressure from doctors for them to start patients on treatment earlier. The doctors attributed counsellor ‘*inflexibility*’ and difficulty in ‘*thinking out of the box*’ to their limited experience and training. Doctors expressed a desire for counsellors who showed greater initiative in booking their own patients or standing up to the doctors when they felt that patients weren’t ready to start on treatment. They wanted counsellors to assess patient literacy readiness prior to starting treatment. None of the counsellors had recommended that a patient not be allowed to start treatment.

All of the participants were unanimous in their belief that space was a key factor preventing counselling from becoming central to the way the clinic was run. A lack of space was not limited just to the counsellors, and was acknowledged by the nursing sister: ‘*Everyone is suffering due to space*’.

The doctors felt that there was no continuity of care between counsellors and doctors. They expressed a need for clarity on who was responsible for which communication tasks and that there was no pairing up between doctors, counsellors and patients and that this could be resulting in ‘*information falling between the cracks*’. There appeared to be some contradictions regarding the number of counselling sessions patients should have. The doctors all agreed that patients needed counselling on an ongoing basis as their needs change. They felt that there was no limit to the number of counselling sessions needed and that three sessions was the absolute minimum that any patient should have had in the clinic. The counsellors expressed that patients did not all need three sessions, and ironically they attributed patients having less than three sessions to the doctors not giving them enough time to have three sessions with patients prior to them being discharged or to patients being discharged without them being notified. Both the nurse and the doctors felt that patients were receiving less than the required three counselling sessions due to counsellor lethargy and inactivity. The doctors expressed that counsellors spent too long over tea time and that a staggered lunch break was needed to ensure continuous availability of counselling.

In order to improve the continuity of care, the doctors and nurse felt that the counsellors had to pay better attention to record keeping. Irregularities in the folders had been observed by some doctors and the nurse felt that day sheets and appointment logs were not checked up on as these were submitted to the managing NGO. There was a perception that some of these records did not accurately reflect the amount of counselling in the clinic. The counsellors all acknowledged that writing in the folders was helpful to ensure continuity of care, but felt that they were ethically bound not to include confidential information in the folders. The counsellors all reported that they wrote counselling notes in the patient folders and in their own diaries after each appointment. Attending the doctors' meetings was also regarded by the counsellors as being helpful in ensuring continuity of care.

A need for partnership building between the counsellors and the other clinic staff was expressed by all of the participants, as well as between members of the counselling group. The nurse interpreted counsellor lethargy and the lack of counselling happening to counsellor stress, burnout and relationship difficulties within the team, rather than to procedural difficulties. She felt that counselling non-invitation to some clinic meetings reflected the lack of centrality of counselling and the lack of value that the doctors placed in the counselling service. The counsellors reported that they felt unsure about which meetings they should attend. When they did attend, the lack of attention and opportunities to contribute meant that they felt excluded even further.

The doctors also expressed that relationship-building was needed between the counsellors and the patients, as they did not feel that there was any rapport between counsellors and the caregivers. However, the nursing sister felt that this lack of rapport was a result of the mistrust caused by counselling being a recent addition to the clinic services, rather than to the quality of the counselling or the skills of the counsellors.

All of the participants acknowledged that partnership building with the employing NGOs needed to be strengthened, and the nurse felt that she was ideally placed to act as a liaison between the NGO and the clinic. This was supported by the counsellors who had heard from counsellors at other clinics that the nurses who worked with them assisted in helping counsellors locate counselling resources and in re-ordering equipment such as posters and information brochures as needed.

6.13 SECTION SUMMARY

These findings support the CHW and counselling literature described in *Chapter 2* that points to a myriad of institutional factors contributing to poor counsellor motivation and sub-optimal participation within the multidisciplinary team. At the centre of this appeared to be the fragmentation caused by the involvement of external NGOs which complicated lines of reporting and obscured accountability, not to mention causing a rift between the counsellors themselves. There was some evidence to suggest that within this particular clinic, less than the prescribed ideal amount of counselling was happening, and that the counselling burden was shouldered by a few of the counsellors whilst others did little work. Motivation levels varied considerably between counsellors. Many of the clinic patients chose to seek psychosocial support elsewhere. However for some patients, counselling was valued and considered helpful.

As the accounts above are purely based on observations outside of the counselling room and on participant anecdotes, recordings of actual consultations were analysed and are described in the next part of this chapter to provide a direct measure of the quality of the communication within actual consultations.

CHAPTER 6 PART 2

PRE-TRAINING COUNSELLOR COMMUNICATION

In this section, the general characteristics of the pre-training counselling consultations are described to provide the communication context in which the interactions were analysed. Thereafter, the results from the analysis of the communication skills (first generally and then for each counsellor specifically) are described in terms of facilitators (communication judged to lead to better patient understanding and rapport) and inhibitors (communication judged to be a barrier to patient understanding and leading to poor rapport). The characteristics that are described in this section and in Chapter 7, address the list of phenomena raised within the rater discussion group (See Chapter 5).

6.14 CHARACTERISTICS OF THE PRE-TRAINING COUNSELLING CONSULTATIONS

As a baseline measure, twelve consultations were video-recorded from the four counsellors working with different patients at the clinic over a period of three months as illustrated in Table 6.6.

On average, the consultations were 23 minutes long, ranging from 5 min to 85 min. The consultations were all conducted in the privacy of a room in the clinic with the door closed. At times, as is commonplace in a busy clinic, there were interruptions from colleagues/ other patients walking in. The transcripts had an average of 151 turns (ranging from 40 to 617) and an average of 1835 words (ranging from 478 to 5422). There was no general trend in the ratio of words spoken by the counsellors relative to that of the patient. This was the same across all four counsellors. Conversational length appeared to be determined by the topics of discussion and the time available to the participants.

As demonstrated in Table 6.6, all of the counsellors had some consultations in which they spoke more than the patients (Transcripts A,B,D,E,F,M,P) and vice versa (C,K,L,Q,R). Of these, consultations C, K, Q and R were self-referrals, and L was a standard follow up consultation after starting on ARVs. This suggests that patients that self-refer are likely to speak for a greater proportion of the consultation than those who are referred by their doctor or counsellor. Exceptions to this, were case A (self-referral but patient only spoke 45%) and

case K (doctor referral – patient has difficulties with substance misuse and this impacted on the conversational pattern).

Generally, there was an equal balance between the amount spoken by the counsellors relative to the patient. The exceptions to this were cases D and P, in which the two counsellors spoke for 80% of each consultation. In both of these cases, the caregivers appeared shy and withdrawn and the counsellors attempted to draw them into the discussion with lengthier small talk and a discussion of their clan origins.

Table 6.6 Pre-training transcript dimensions described by case, participants, referral and key issues, title, time, turns, word count and ratio of Counsellor: Patient words

Case no, language	Participants	Referral & key issues	Title/ Quote from transcript	Time	Turns	Word count	Counsellor	Patient	Other
Case A IsiXhosa	Counsellor (NOKUZOLA) & mother	Self-referral: Caregiver wants to view the folder and is confused about TB/HIV diagnosis	P: "I don't want this HIV and TB because I don't know how she [child] got it" C: "The child doesn't have TB, <i>the folder</i> is saying that"	0:18:16	75	1361	753 (55%)	608 (45%)	0
Case B isi Xhosa	Counsellor (NOKUZOLA) & mother	Doctor-referred: Non-adherence due to timing practicalities	C: "These are our children and we infected them unpurposefully"	0:20:00	48	1447	925 (64%)	522 (36%)	0
Case C isi Xhosa	Counsellor (NOKUZOLA) & mother	Self-referred: Wants access to HC system (folder); assistance with disclosing and financial reasons	P: "He [boyfriend] says it's a myth, there is no HIV" P: "He [traditional healer] saw that the child was on ARVs but gave him the other medicine anyway"	0:09:00	138	1946	822 (42%)	1124 (58%)	0
Case D IsiXhosa	Counsellor (NOKUZOLA) & mother	Doctor-referred for TB meningitis and hospitalization explanation	C: "To kill the child of the [clan name]'s and say he died of HIV while he did not die of it but he got killed by your carelessness"	0:10:00	102	1408	1248 (86%)	92 (7%)	66 (5%)
Case E IsiXhosa	Counsellor (NOKUZOLA) & mother	Counsellor referred for mediation between doctor & patient	[4] P: "I think she [doctor] should have called me aside and called someone to interpret for me because I do not understand English" [7] C: "I do understand what you are saying doctor, but I mean she [patient] was just telling you her feelings"	0:08:30	91	1794	1004 (56%)	126 (7%)	664 (37%)
Case F IsiXhosa	Counsellor (NOKUZOLA) & mother	Doctor-referred for grant application.	C: "These are things we have to ask."	0:08:50	51	478	260 (54%)	218 (45%)	0
			Average for Nokuzola's consultations	12 min	84	1406	60%	33%	NA
Case K Afrikaans & English	Counsellor (ELSIE) & Mother & Granny	Doctor referred; substance abuse & poor adherence	C: "She [mother] got a chance to open up today. She will sleep relieved"	0:54:00	675	5961	455 (8%)	5094 (85%)	413 (7%)
			Average for Elsie's consultations	54 min	675	5961	8%	(85%)	NA
Case L IsiXhosa	Counsellor (BABALWA) & mother	Routine follow up after starting ARVs	P: "I never told the father about the virus, and he didn't die from it. He died from a	1:25:00	617	5422	2298 (42%)	3124 (58%)	0

			horrible headache.”						
Case M IsiXhosa	Counsellor (BABALWA) & mother	Counsellor-referred for disclosure discussion.	P: “I am scared because they [family] think HIV kills.”	0:05:30	62	713	382 (54%)	318 (45%)	R: 13
			Average for Babalwa’s consultations	45 min	340	628	48%	52%	NA
Case P IsiXhosa	Counsellor (LINDIWE) & Mother	Doctor-referred : Child starting ARVs.	C: “Do you have any stories that you heard maybe, that you heard when you were sitting with the mothers?”	0:10:00	42	738	594 (80%)	144 (20%)	0
Case Q IsiXhosa	Counsellor (LINDIWE) & Mother	Self-referred : wants to be transferred out	P: “I don’t think that she [child] got it [HIV] from me”	0:09:00	40	590	234 (40%)	356 (60%)	0
Case R IsiXhosa	Counsellor (LINDIWE) & Father & girlfriend	Self-referred : Relationship difficulties	C: “As a parent...”	0:55:00	396	4286	1186 (28%)	(Dad) 2700 (63%)+	(girl- friend) 400 (9%)
			Average for Lindiwe’s consultations	25 min	159	1871	49%	51%	NA

6.14.1 Consultation topics

Adherence counsellors have a varied caseload that is unpredictable with the majority of cases being referred to counsellors on the day, leaving minimal, if any, preparation time. An additional challenge is that a variety of topics are discussed within each counselling consultation. Table 6.8 summarises the storyline of each consultation as a background to each case and illustrates the variety of topics discussed.

Table 6.7 Storyline summary of the pre-training consultations

Case A : Nokuzola counsels the mother about TB/HIV

The caregiver appears anxious and emotional (high-pitched, breaking voice). She has had a previously bad experience of accessing care at another clinic. Reference is made to ‘the folder’ as holding importance for the caregiver. An association between asthma, TB and living in a damp house is made by the counsellor. There is confusion regarding whether or not the child is on medication because she is HIV positive or has TB. The counsellor offers to look at the pills the child uses to help to establish this. The caregiver wants to know what causes HIV and why her child has it. She says she does not know her own diagnosis and the counsellor says that ‘the folder’ does not say. The counsellor refers her to the support group and for HIV testing afterwards.

Case B: Nokuzola counsels the mother about adherence

The counsellor introduces herself and asks about the caregiver’s case history. She checks the caregiver’s understanding of the child’s medication by asking her to name the tablets. The counsellor uses the analogy of losing your ID book to demonstrate that one must always carry ARVs on you. They discuss how important the timing of dosing is in relation to how HIV spreads, and the caregiver expresses how difficult this is for her as she does shift work. In problem solving this together, the counsellor expresses shared empathy for the difficult role of being a parent and briefly urges the patient to adhere to the dosing to avoid going on to the second line of treatment.

Case C: Nokuzola counsels the mother about disclosure

The caregiver states that she has a bladder problem and that she was unable to access services as she didn’t have a clinic card. The counsellor finds out where she was staying and the patient expresses that there are only poor services in that area and she would prefer to go to another hospital. The patient reiterates the bladder problem and the counsellor encourages her to see a doctor. They discuss the difficulty of there being only one doctor at the community clinic and the patient expresses a lack of knowledge about the services there and that she will try to open a folder. The patient then states that the reason for her visit to the counsellor is because she wants advice on how to tell her boyfriend that she is HIV positive. The boyfriend has told the patient he doesn’t believe that HIV exists, but he

had been for VCT. The counsellor probes why he did this and asks about condom use. The patient raises the issue of a grant and they discuss the Eastern Cape and a traditional healer that the grandmother took the child to in the Eastern Cape. They discuss the possibility of the patient joining the income generating project, the support group and the importance of community.

Case D: Nokuzola counsels the mother about TB Meningitis

The child is going to be hospitalized for 9 months because she has TB Meningitis (TBM). The doctor has told the mother this in the ward, and the counsellor is going over the implications. The mother disclosed to the child's father the day before. The counsellor explains the benefits of TB and ARV medication and urges the mother to be strong. There is reference to her clan and that of her in-laws to give her strength. She urges the mother to follow the doctor's recommendations and they discuss a grant application. While the mother takes the child to the toilet, a colleague informs the counsellor that the doctor diagnosed the child as having TBM in the ward and that the mother is upset that this did not happen in private. On her return, the counsellor raises this with the mother and asks if she would like her to take this up with the doctor.

Case E: Nokuzola interprets for the doctor who outlines the management of TB Meningitis

The counsellor mediates between the doctor and the patient as the patient is upset that the doctor violated her right to privacy by diagnosing the child as having TBM by the bedside in the ward where other parents heard the discussion. The doctor believes that all of the caregivers in the ward have HIV positive children and that it was unnecessary to find a more private area. The caregiver stated that she speaks poor English and needed an interpreter as she is confused by what the doctor said and does not understand the diagnosis or where/ when the child is going. The doctor explains to the patient and makes a time to meet with her and the child's father to discuss further with the counsellor as interpreter.

Case F: Nokuzola counsels the mother about a social grant application

The counsellor and patient discuss socio-economic status and living conditions for the application of a grant.

Case K: Elsie counsels the mother and grandmother about substance abuse linked to adherence

The caregiver is reluctantly consulting the counsellor on the doctor's recommendation. She has a history of substance misuse and is accompanied by the child's grandmother, who participates in some of the counselling consultation. The caregiver describes the impact of her relationship with her boyfriend on her life.

Table 6.7 continued

Case L: Babalwa counsels the mother about adherence The child is going to start treatment and the counsellor discusses numerous issues with the mother including the case history, child's CD4 count and ARVs. The mother has not disclosed to the father or to other family members. Grant applications and the burden of being a parent are discussed as well as the importance of religion and having hope for the future.
Case M: Babalwa counsels the mother about disclosure The caregiver would like advice on how to disclose to her sister. She is concerned about telling her family because of their perception that HIV kills you. The caregiver plans to disclose to her sister that afternoon.
Case P: Lindiwe counsels the mother about adherence The counsellor asks about the caregiver's understanding of ARVs and how she remembers to take them. Disclosure is discussed and the counsellor explains ARVs and the two regimens. She outlines parental responsibility. The mother is concerned about how the baby will feel on ARVs. The counsellor explains the side-effects and asks if she has heard anything from the mothers at the support group.
Case Q: Lindiwe counsels the mother about transferring to another clinic The patient would like to be transferred to another clinic. They discuss management of her 16 year old daughter who is HIV positive. According to the mother, this is not from vertical transmission.
Case R: Lindiwe counsels the father and his girlfriend about relationship difficulties The patient and his girlfriend are having relationship difficulties. There appears to be a substance abuse problem which has impacted on his adherence and a breakdown of trust with his girlfriend. The consultation starts with only the patient and the counsellor, and the girlfriend arrives half way through. The counsellor was not aware that she was at the clinic or she would have included her from the start. The patient and his girlfriend have been transferred to another clinic. A follow up appointment is discussed.

Three of the consultations (A, D, E) focused mainly on TB/HIV, three on treatment literacy and adherence (B, L, P), two on disclosure (C, M) and one each on relationship difficulties (R), grant applications (F) and transferring out of the clinic (Q). However, within each of these consultations, numerous topics were covered. Some of these topics are introduced by counsellors (Counsellor-Initiated indicated by CI in Table 6.8), and some by the patients/caregivers themselves (Patient-Initiated indicated by PI in Table 6.8). The participant who introduced the topic in the consultations is referred to as the topic initiator. Initiation of a

topic does not mean that a topic was explored in any great length and gives no indication of how long it was discussed.

Conversational topics from the consultation data as summarized in Table 6.8 below, broadly encompassed medical, clinic procedural and psychosocial aspects of care. The majority of topics were introduced by the counsellor, regardless of topic type. There was a general tendency for patients who initiated topics, to initiate more than one topic (e.g. Patients A, K, M, R); so patient factors (i.e. talkative or confident rather than shy) were probably a contributing factor. The greatest predictor of patient-topic-initiation, was being asked an open-ended question by the counsellor, and not referral (doctor-, counsellor-, self-), type of topic (medical, procedural, psychosocial) or counsellor.

An example of patient topic-initiation can be illustrated in Case M; after a discussion of the patient's background and living circumstances, the counsellor asks the patient an open question and the patient introduces the topic of disclosure.

[M14] C: *So how can I help you my sister?*

[M15] P: *Yes you can help, I am living with my sister and I have not told her that I am living with HIV because I'm scared but I have decided to tell her.*

Table 6.8 Medical, procedural and psychosocial topic initiation in the baseline counselling according to counsellor and consultation

Counsellor:	Nokuzola						Elsie	Babalwa		Lindiwe		
MEDICAL TOPICS	A	B	C	D	E	F	K	L	M	P	Q	R
1st 2nd line treatment		CI								CI		PI
Case History		CI		CI				CI				
Cause of HIV	PI										CI	
Child's health			CI					CI		CI	PI	
Virus progression: CD4, viral load		CI						CI		CI		
Infections & side-effects			PI	CI								
Medical procedures eg intubation	CI			CI								
Medication: Tablets & starting ARVs	PI	CI	CI	CI		CI	PI	CI		CI		
Nutrition						CI						
Prognosis	PI			CI								
TB/ HIV	CI				CI	CI						
Timing of medication		PI								CI		
Traditional medicine and practices eg circumcision			CI									CI
PROCEDURAL TOPICS	A	B	C	D	E	F	K	L	M	P	Q	R
Follow up, transfer & referral				CI	CI			CI		CI	PI	PI

Table 6.8 continued

PSYCHOSOCIAL TOPICS	A	B	C	D	E	F	K	L	M	P	Q	R
Grants			CI	CI	CI			CI				
Role of the counsellor								CI	CI			CI
Role of the doctor				CI	CI							
Role of the parent & patient responsibilities		CI		CI				CI		CI		
Care for the carer	CI											
Child's feelings										PI		
Clan names/ cultural				CI								CI
Death		CI		CI				CI	PI			CI
Disclosure & stigma	CI		CI	CI	CI	CI		CI	PI	CI	CI	
Lifeworld: Family, work & living circumstances	CI	CI		CI		CI		CI	CI			
Patient advocacy, rights, confidentiality			CI	CI	CI			CI				
Preparing for the future				CI	CI			CI				
Relationship difficulties							PI					PI
Religion & Faith				CI				PI				
Sexual activity		CI									CI	
Socio-economic status & finances						CI	PI					
Stress				CI			PI	CI				CI
Substance use/ abuse							PI					PI
Support from family, friends & support group			CI		CI	CI		CI	PI	CI	CI	PI

Although the conversation topics summarized in the table above are ascribed to the broad categories of medical, procedural and psychosocial topics, it is acknowledged that this distinction is fairly arbitrary as many of the topics overlap spheres. The purpose of dividing them into these three categories is to portray the types of discussion taking place within counselling sessions.

In some consultations, as many as 9 different topics were raised. The topics which were most commonly raised were: Disclosure and related stigma (9), Medication (8), Support from family, friends and support groups (8), Lifeworld issues (6) and Death (5).

6.14.2 Code-switching to English in the isiXhosa consultations

Patient and counsellor code-switching of single words and short phrases from isiXhosa to English occurred commonly. The frequency of code-switching was dependent on who the counsellor was (Nokuzola code-switched more than the other counsellors; and Babalwa code-switched the least) as well as who the patient was. In consultations in which the patient

frequently code-switched, so did the counsellor e.g. [A]. Code-switching tended to be used for the following categories of words:

- Conjunctions and other connecting words such as relative pronouns (*'that', 'because', 'sometimes', 'so'* etc)
- For medical jargon: (*'viral load', names of medicines* etc)
- For clinic jargon i.e. jargon which is not necessarily medical or complex but is often used in the clinic context (*'maintain', 'dosages', '1st/ 2nd line', 'weight', 'folder', 'treatment'*)
- Community / commonly used words: (*'ID book', 'transport'*)
- Counting, numbers, dates and the time
- For emphasis of particularly salient points or to appeal to the caregiver (*'It's very important', 'Exactly', 'Please', 'You are the parent', 'You are playing a big role'*)

An example of this is found in Nokuzola's code-switching from isiXhosa to English [in B32]. The original isiXhosa transcript is written in italics, with the code-switched words highlighted in bold.

*C: Okay mamela ke, ndicinga mna uyijike kula **ten o'clock** umtyise ngo **ten o'clock**. because ngo **ten o'clock** ebusuku uzobe usendlini andithi, Mtyise ngo **ten o'clock** kusasa, untyise ngo **ten o'clock** ebusuku. **At least** ukhe ujonge*

P: ubalance(sise)

*C: ubalance(sise) elaxesha then ucheck(ish) xa ephind etsalwa **iCD4 count the viral load** yakhe ukuba izabanjani uyaqonda.*

P: uyaqond

*C: Khamtshintshe sisi umtyise ngo **ten o'clock in the morning** uphinde umtyise ngo **ten o'clock** ebusuku uzojonga kengoku ubone into yokuba imphethe njani uzakumva nogqirha ukuba uzakuthini na. kubalulekile, ixesha libalulekile as ba bendikuxelele libalulekile sisi nyhani ixesha. And ke ubomi bakhe buxhomekele kuwe **and you are the only parent** athembele ngayo. **She is so beautiful** uba ngu she, uba ngu **she, she is so beautiful** akaku-deserve ukufa. **Please** ngiyakuceke ke sisi ucelwa ndimi.*

P: ewe.

C: Oku-worse akayazi ukuba kuqhubaka ntoni elife(ini) nguwe umntu oyaziyo, nguwe wena umntu o-aware ngayo yonke into yena akazi nicks akazi nicks.

Reciprocal code-switching in the isiXhosa consultations by both counsellors and patients matched expectations from the literature (see Chapter 3). Code-switching occurred most

frequently in counsellor utterances. Consultation K was conducted in Afrikaans and English with both participants frequently alternating between these languages.

6.14.3 Cultural language and terms of address

The counsellors and the caregivers matched each other in terms of language, race and cultural group and this was evident in the use of informal ‘slang’ (e.g. ‘*Homies*’ meaning people who come from the same area in the Eastern Cape, and ‘*Joe*’ meaning girlfriend/ boyfriend) and in references to culture and heritage (e.g. discussion of emaXhoseni and clan names). The caregivers referred to Nokuzola, Elsie and Babalwa as ‘Sisi’ reciprocally; Lindiwe was referred to as ‘Mama’ by most of the caregivers because of her relative age.

In two of the consultations (involving counsellors Nokuzola and Lindiwe), the counsellors asked the caregivers to which clan they belonged [D, R]. On one occasion, the caregiver appeared very shy and reticent, and the counsellor’s question appeared to be an attempt to find common ground with her and to draw her into the discussion. On the other occasion, Lindiwe used the question to divert a tense situation by joking with the patient about his clan [R271]. In this same interaction, the caregiver used a number of slang terms, ‘Joe’, ‘Maan’ and ‘Tjommies’ and the counsellor refers to the traditional practice of circumcision. The practice of calling friends from ‘emaXhoseni’ (‘Xhosaland/ Eastern Cape’) ‘Homies’ was evident in a number of transcripts suggesting counsellor attempts to establish a bond with caregivers from the same area [D, L, M].

6.14.4 Summary of the characteristics of the baseline consultations

The baseline consultations varied in length and in number of turns. A large variety of different topics were discussed, which is unsurprising given the many issues specified in the counselling guidelines, training protocols and job description outlined in Chapter 2. This suggests that there is merit in portraying the counselling role as ‘complex’. Generally, counsellors spoke more than patients and initiated more conversation topics. This fits with health communication models such as Mishler’s ‘unremarkable interview’ which follows a pattern of health professional issuing questions and patients responding as described in Chapter 3. Consultations varied in terms of reason for referral and topics discussed. Counsellors and patients frequently code-switched between isiXhosa and English (and between English and Afrikaans in one consultation). Code-switching was used by counsellors

to develop rapport and was partially dependent on the interactional dynamics, but was more common in counsellors than patients. Terms of address appeared to be age-determined.

In general, the characteristics described demonstrated the value of the cultural mediating role of the counsellor in establishing rapport and joking with patients in their language. Establishing common terms of reference would not have been achievable in a mediated context to the same extent. The consultations also demonstrated the diversity of topic and complexity, as well as the counsellor depth of knowledge required.

This description of general consultation characteristics provides the backdrop against which the counsellor communication skills were analysed, described and interpreted in section 6.15 that follows.

6.15 ANALYSIS OF THE COMMUNICATION SKILLS BY THE RATING TEAM

Counsellor communication skills are described first generally, and then specifically for each of the four counsellors. This analysis was compiled from the qualitative descriptive notes made by the team of communication raters as described in the methodology.

6.15.1 Communication Facilitators (What worked well)

Counsellor communication was analysed to determine what worked well (as described in Chapter 5). In other words what factors in *how* the message was conveyed made it easiest for patients to understand. In conveying the message, communication that was accessible (simple in terms of language choice, level of difficulty and practical application), clear (unambiguous and non-mitigating) and structured (logically presented) was considered to be a facilitator to patient understanding. Evidence of the communication being more understandable could be found in patient demonstrations of understanding (verbally and non-verbally), a lack of confusion in their responses, a lack of breakdown in communication, and in the analysts being able to trace the thread of meaning and themselves understanding what the counsellors were trying to convey. In addition to making the message easier to understand, communication that facilitated the expression of empathy and added to an atmosphere of collaboration, was considered to be a facilitator. Table 6.9 summarises the communication facilitators identified by rater consensus in the baseline consultations.

Table 6.9 Communication facilitators identified by rater consensus in the baseline consultations

Communication that facilitated better patient understanding	Communication that facilitated empathy and collaboration
Practical examples	Shared moments including humour
Analogies	Non-judgmentalism
Non-mitigation of the issue of ‘cure’	Non-verbal gestures
Open questions	Patient advocacy: Bridging traditional divides

a. Practical examples

Regardless of whether or not the counsellors were HIV positive themselves, they adjusted the typically medical information about ARV treatment so that it had greater application in the caregivers’ worlds. They did this by making practical suggestions on how to make adherence easier. In addition, those counsellors who were openly HIV positive caregivers themselves (and were mothers attending the clinic themselves), expressed empathy with the caregivers in their shared experience.

Sharing similar cultural and socioeconomic backgrounds with the patients, the counsellors could empathise with the patients’ lifeworld and knew which questions to ask about their lives. In consultation P for example, Lindiwe advised the patient on which tablets to give the child first, as some taste better than others. In this same case, the counsellor and the mother also discussed setting an alarm on the patient’s cellphone and getting a friend to SMS reminders, to help the mother remember to take her ARVs [P17]. In case M, Babalwa recommended using the common experience of watching a popular TV programme as a starting point for the caregiver to imagine how her family might respond to her disclosure.

As openly HIV positive mothers themselves with children being managed by the clinic, Nokuzola and Babalwa shared their own experiences of motherhood with caregivers to give them a sense of hope and psychosocial support. Traditionally, counsellors are required to remain objective and not to share their own experiences although the value of prudent self-disclosure in the field of HIV/AIDS has been acknowledged (Van Dyk, 2004). With the advent of HIV counselling by people who are themselves HIV positive, there has been a shift away from complete objectivity. In many of the consultations, the two counsellors who were openly HIV positive, shared their own experiences of motherhood and living positively to motivate the caregivers.

Babalwa implored caregiver L not to think about being HIV positive all of the time, as *‘there is life beyond HIV’* [L417]. She also encouraged the caregiver to join the support group as this was a way that she had personally gained strength from the solidarity of the other mothers [L406]. Babalwa tried to motivate caregiver L to have hope, by referring to the miracle of the TB drugs and ARVS.

Nokuzola used highly emotive language to appeal to the caregiver to step up and take responsibility for her child’s adherence to the regimen. She mentioned that as the sole parent, it was critical to take appropriate measures to prevent the death of her child, who *‘is too young to know what is happening to her’*. A few lines later she stated that *“we have infected them unintentionally and we are hurting about that [B32-36]”*. The use of ‘We’ created the sense of working together and mutual support. Nokuzola emphasised that the mother was not to blame but that she is responsible for her child’s health. The counsellors had a difficult task balancing encouragement for caregivers to be responsible for the child’s adherence without apportioning blame [D].

The counsellors that shared their HIV status with the caregivers discussed the patient’s lifeworld in more detail than the other counsellors did. In case C, the caregiver and counsellor discussed how real-world circumstances make it challenging to be adherent when it is a struggle just to provide for ones family. Caregiver C explained how losing a job as a result of pregnancy and the perception that she is too unskilled to participate in the income-generating project have resulted in financial stress [C]. In case B, the counsellor’s questioning about shift work and potential transport difficulties, demonstrated to the caregiver that she understood the caregiver’s lifeworld and that she knew how these circumstances could impact on her adherence [B].

b. Analogies

Nokuzola highlighted the importance of always carrying some medication on you at all times, as well as in knowing the names of the tablets, through an analogy of an Identity Document (ID) [B]. This was particularly powerful given South Africa’s historic association with carrying identification, but very realistic as the need to produce an ID book is essential for many tasks, such as opening a bank account, applying for a grant/ loan and admission to a hospital etc.

c. Non-mitigation of the issue of cure

Caregivers showed different levels of sophistication in their understanding of HIV and ARVS. Many of the caregivers have a very thorough understanding of the medical management of HIV. However, despite all of the information available in the media on HIV and ARVs, for some patients, there was still an association between tablets and cure. Nokuzola was asked by Caregiver A whether or not HIV can be cured, and when she explained that HIV cannot be cured, the caregiver persisted in asking whether the doctors can't perhaps cure HIV. Nokuzola answered very simply and straightforwardly that there is no cure yet for HIV [A 37 – 43].

d. Open-questions

In instances in which the counsellor asked an open question for an explanation of treatment failure, the caregivers responded clearly showing their understanding of the link between viral load increase, adherence and the importance of timing in dosing [B14-15].

e. Shared moments including humour

Greater collaboration between counsellor and patient was evident in 'shared moments'. *Shared moments* were 'ah!' instances identified by the analysis team and included shared smiles/ laughter/ emotion. In consultation R for example, Lindiwe used humour effectively to ease a tense situation involving the patient and his girlfriend.

f. Non-judgmentalism

All of the counsellors were felt to be non-judgmental in most of their responses to patients, despite many contentious issues being raised. Non-judgmental responses were considered to be counsellor responses to an emotive or potentially controversial topic on the part of the patient which were deemed by the raters to be particularly neutral or non-evaluative. Evidence to support this can be found in counsellor neutral responses to emotive topics, and in patients freely expressing their opinions. Caregivers raised issues such as using traditional medicine [C] and substance abuse [R], which they probably would not have done had they felt judged by the counsellor. In consultation B, Nokuzola appeared sympathetic and non-judgmental, even when she brought up the reason for the referral – which was the fact that the child's viral load has increased due to non-adherence.

g. Non-verbal skills

In the majority of the consultations, the counsellors had good eye contact and posture, and used an appropriate tone. The counsellors spoke at an even and appropriately slow pace to enable caregivers to understand them. Non-verbal skills appeared to be largely individual-personality-dependent rather than related to prior training. In particular, Babalwa (who had no prior training) and Lindiwe (who had prior training), displayed excellent non-verbal skills in all of their consultations.

h. Patient advocacy: Bridging traditional divides

The counsellors provided caregivers with a point of access into the health care ‘system’. This was evident in consultation Q when the caregiver approached a counsellor to help her to organize to be transferred out to another clinic. The caregiver did not take this up with the doctor herself, but asked the counsellor to do so instead. In consultation D, the counsellor emphasised the importance of the hospital and its benefits to the patient, and in doing so, brokered the medical/ non-medical divide.

It was evident in a number of interactions that the counsellors bridged the gap between:

- **The doctor/ health care institution and patient** [A, D, E]: Counsellors acted as patient advocates, upholding their rights to confidentiality and privacy. In consultation E, the patient was upset that the doctor had stated the child’s diagnosis in front of others. The doctor expressed that within an HIV ward, all of the other mothers and children are also HIV positive. It may be that from working in an environment surrounded by patients who have TB and HIV, the doctor had become less concerned with the privacy of individual patients or had become more blasé about HIV. Regardless of the diagnosis of HIV or MDR TB (as in this case), the patient did have a right to privacy and to having an interpreter present.
- **Western medicine vs traditional medicine** [C]: As discussed in Chapter 2, it is common for patients to consult traditional healers. Caregivers appeared to feel comfortable discussing alternative medical practices with counsellors. In case C, the caregiver raised an incident in which her mother-in-law insisted that the child be seen by a ‘specialist’ (explained later by the counsellor as a traditional healer) in the Eastern Cape who gave the child some medicine which was mixed for the child at the house. The counsellor tried to draw out more details from the patient by discussing whether or not the specialist worked at a hospital and if he did house visits. At the end

of the discussion, the counsellor reminded the mother that ARVs shouldn't be mixed with other medications.

- **English and isiXhosa cultures [D, R]:** Counsellors acted as language brokers, mediating between English and isiXhosa cultures through interpretation, and in displaying their knowledge of isiXhosa practices and the Eastern Cape in particular. In consultations D and R, the counsellors asked if the patient was from a rural area and made reference to isiXhosa clans.

6.15.2 Communication Inhibitors (What did not work well)

A number of barriers to effective communication were identified in the baseline consultations. These factors contributed to misunderstandings and to patient needs not being met. These communication inhibitors are summarized in Table 6.10 and described thereafter.

Table 6.10 Barriers to effective communication

Lack of introductions
Questioning and verification
Presence of jargon
Poor topic Shifting
Failure to check patient understanding
Mitigation of 'taboo' topics
Poor management of session ending
Non-verbal skills

a. Introductions

With the exception of Babalwa, none of the counsellors introduced themselves, their role or the reason for the session to the patients at the start of the session. The start of each consultation was usually marked by a brief greeting followed by case history taking. The lack of introduction led to unstructured and unfocused consultations. The counsellor's role within the multidisciplinary team was not explained in any of the introductions and the caregivers were not given an opportunity to choose the language of the interaction. Some of the

consultations were self-referrals and follow-up consultations, so name introductions and explaining the counsellor's role may have been unnecessary. However establishing the purpose of the session, outlining the structure of the consultation and language choice would still have been helpful. Table 6.11 illustrates which elements of introductions were included by counsellors in each consultation.

Table 6.11 Elements of introductions included by counsellors in the baseline consultation introductions

		Elements included by counsellors in their introductions						
Counsellor	Consultation	Name	Position	Role	Aim of the session	Small talk	Language choice	Open question
Nokuzola	A	-	-	-	-	-	-	-
Nokuzola	B	Yes	Yes	-	-	-	-	-
Nokuzola	C	-	-	-	-	-	-	-
Nokuzola	D	-	-	-	-	-	-	-
Nokuzola	E	-	-	-	-	-	-	-
Nokuzola	F	-	-	-	-	-	-	-
Elsie	K	-	-	-	-	-	-	-
Babalwa	L	Yes	Yes	-	-	Yes	-	Yes
Babalwa	M	Yes	Yes	Yes	-	-	-	Yes
Lindiwe	P	Yes	-	-	-	Yes	-	Yes
Lindiwe	Q	-	-	-	-	-	-	-
Lindiwe	R	-	-	-	-	-	-	-

b. Questioning & verification

In all of the consultations, the counsellors consistently asked 90% or more of the total number of questions per session. Of these questions, only 12% related to asking about patient understanding (a range of 0 to 9 instances per session) and there was a total of 3 instances (these all occurred within one consultation) in which the patient was asked to name her medication or to explain the dosing/ timing thereof. In total, 7 questions enquired about patient feelings [D43] '*How do you feel now?*', and two of the counsellors asked for the patients' interpretation of circumstances.

Table 6.12 Pre-training questioning categorized by the number of counsellor questions (to check understanding, open-ended questions and feeling questions) and questions asked by patients

		Questions	Counsellor	Counsellor	Counsellor	Counsellor	Patient
Counsellor	Consultation	Total	Total	To check understanding	Understanding checked with an open-ended question	Asking about feelings	Total
Nokuzola	A	29	24	4	0	2	5
Nokuzola	B	20	20	5	3	0	0
Nokuzola	C	38	32	2	0	1	6
Nokuzola	D	49	48	4	0	1	1
Nokuzola	E	24	23	9	0	0	1
Nokuzola	F	20	17	2	0	0	3
Nokuzola	Average	30	27 (91%)	4 (15%)		1	3 (9%)
Elsie	K	44	19(43%)	0	0	5	29(57%)
Elsie	Average	44	19(43%)	0	0	5	29(57%)
Babalwa	L	56	52 (93%)	6	0	0	4 (7%)
Babalwa	M	22	22 (100%)	0	0	2	0
Babalwa	Average	39	37 (96.5%)	3 (8%)		1	2 (4%)
Lindiwe	P	16	13 (81%)	6	3 [8]	1	3 (19%)
Lindiwe	Q	13	13 (100%)	1	0	0	0
Lindiwe	R	53	47 (89%)	4	0	5	6 (11%)
Lindiwe	Average	27	24 (90%)	3 (13%)	1	2	3 (10%)

As illustrated in Table 6.12, counsellors very seldom asked about or tried to interpret patient feelings. However, when they did, they successfully elicited more information out of patients than they did with the information-gathering questions which were asked most of the time e.g. [C21] *'So you are uncomfortable talking to doctor?'*

Caregiver understanding of HIV and ARVs was seldom discussed. In consultation A for example, the counsellor asked twenty-four questions in total, only four of which related to patient understanding. In all of these, counsellors asked patients *if* they understood, rather than asking patients *what* they understood or for them to demonstrate their understanding. Typical questions were:

[A25] *'Do you understand?'* [A61] *'You understand?'* And [A73] *'So now you are OK about the information I gave you?'*

Sexual activity was mentioned in two of the twelve interactions. In case C, the counsellor asked the caregiver if she used condoms. Her question is phrased in such a way that it is unlikely that the caregiver would answer that she does not use condoms [C]. The counsellor's

advice seemed particularly misplaced as it does not match the caregiver's concerns (disclosing to the boyfriend).

Particularly when discussing 'difficult to discuss' or traditionally taboo topics, counsellors asked leading questions. This appeared to restrict patient responses to that which is socially acceptable, as if a path of least discomfort is followed. For example, asking a patient '*So, you do condomise?*' [C] when everyone knows that you *should* use condoms makes it very difficult for the patient to respond in any way other than '*Yes, we condomise*' [C]. Similarly, disclosing one's status is likely (in theory) to make it easier to stick to the ARV regime and should provide more psychosocial support, and is subsequently something that is emphasized and encouraged within clinics. Inadvertently, however, this appeared to lead to caregivers not being truthful to their counsellors about whether or not they had disclosed. In one of the consultations, the caregiver stated that she has disclosed to her partner when questioned by the counsellor. Yet later on in the same interaction, it became apparent that she has in fact not disclosed to her partner. Conversations about disclosure were thus developed within a framework of what is socially acceptable behavior rather than reality e.g. [L123].

c. Asking about Patient Understanding

As most of the consultations included some discussion of ARVs and medication (see Table 6.8 listing topics discussed), there was an opportunity in each consultation (except R) for the counsellors to check patient understanding. However, counsellors did not take advantage of these opportunities. Strategies such as asking patients to name their medication or demonstrate the dosing, were not used as illustrated in Table 6.13.

Table 6.13 The use of different strategies to check patient understanding in baseline communication

Counsellor		Nokuzola						Elsie	Babalwa		Lindiwe		
Method of checking understanding / Consultation		A	B	C	D	E	F	K	L	M	P	Q	R
1	(do) you understand?	4	2	2	4	7	2	0	4	0	2		4
2	Forced choice alternative or leading questions	0	0	0	1	2	0	0	0	0	0		0
3	Closed set questions: What is the name of / what time do you take it	0	2	0	0	0	0	0	1	0	0		0
4	Open-ended, asking for an explanation e.g. How do you.../ what are you going to do...	0	0	0	0	1	0	0	1	1	1		0
5	Open –ended interpretive: (Inviting patient's own interpretation e.g. What do you think could have caused such an unexpected increase in viral load?)	0	1	2	2	0	0	0	0	4	2		94
6	Show me ...(inviting demonstration)	0	0	0	0	0	0	0		0	0		0
7	Write down the names of...	0	0	0	0	0	0	0		0	0		0

d. Jargon

Medical jargon, or terminology that is related specifically to the medical or clinical context, is useful when used between health professionals to communicate quickly and precisely with each other. However, when used with patients who have limited understanding of what the jargon means, it acts as a barrier to understanding. Jargon was routinely used by all of the counsellors. More often than not, this jargon was not explained to the patient. In isiXhosa and Afrikaans consultations, the jargon was further complicated by code-switching into English jargon.

Table 6.14 provides examples of terminology that was considered to be medical jargon. In other words, when used out of context between members out of the health profession and the clinic, would probably not be accurately understood by the general public. Deciding on whether a word is or is not jargon, is a subjective judgment and some of the jargon included in the table could be disputed. However, it is the opinion of the researcher, that with the added complexity of these words being code-switched into English despite the patients being isiXhosa or Afrikaans-speaking, it is probable that their true meaning may be misunderstood. Conversely, for patients who have been attending the clinics for a while and who have

become part of the clinic community through attendance at the support group and ongoing counselling sessions, some of the jargon used might be familiar to them and so might not have warranted explanation by the counsellor.

Table 6.14 Examples of medical jargon used and whether or not the jargon was explained²²

Counsellor	Nokuzola						Elsie	Babalwa		Lindiwe		
Medical terminology/	A	B	C	D	E	F	K	L	M	P	Q	R
Antibiotics	No	-	-	-	-	-	-	-	-	-	-	-
ARVs	No	No	No	No	No	No	No	No	No	No	No	No
Asthma	No	-	-	-	-	-	-	-	-	-	-	-
Bactrim	No	-	-	-	-	-	-	No	-	-	-	-
Biological changes	-	-	-	-	-	-	-	-	-	No	-	-
Brooklyn for BCH	-	-	-	No	No	-	-	-	-	-	-	-
CD4 count	-	-	-	-	No	-	-	No	-	-	-	-
D4T, 3TC, Kaletra	-	No	-	-	-	-	-	-	-	No	-	-
Dosages	-	No	-	-	-	-	-	-	-	-	-	-
First line, second line	-	No	-	-	-	-	-	-	-	No	-	-
HIV	No	-	-	No	No	-	-	-	No	-	-	No
HIV positive / Negative	-	-	-	No	No	-	-	-	-	-	No	-
Immune system ('booster')	No	-	-	-	-	-	-	-	-	-	-	-
Iron age	-	-	-	-	-	-	-	No	-	-	-	-
MSF	-	-	No	-	-	-	-	-	-	-	-	-
Nausea	-	-	-	-	-	-	-	-	-	No	-	-
Pap smear	-	-	No	-	-	-	-	-	-	-	-	-
Pneumonia	No	-	-	-	-	-	-	-	-	-	-	-
Primary Health Care	-	-	-	-	-	-	-	-	-	-	No	-
Sexually active	-	-	-	-	-	-	-	-	-	-	No	-
TB	No	-	-	-	No	No	-	-	-	-	-	-
TBM/ TB Meningitis	-	-	-	No	No	-	-	-	-	-	No	-
Viral load	-	No	-	-	-	-	-	No	-	No	-	-

Table 6.14 illustrates that counsellors did not explain the medical jargon they were using. A number of medical concepts appeared problematic for counsellors to explain. For example, in case L, the counsellor unsuccessfully tried to link the calculation of a child's CD4 count to

²² Key to Table 6.14: 'Yes' indicates that the terminology was used and explained; 'No' indicates that the terminology was used but was not explained. Where abbreviations are given in the table, this was the form of the word used. [-] indicates that that specific term was not used in that consultation. When the same word was used by both patient and counsellor, the word has not been included in this list.

percentages. At this point there is an adjacent pair mismatch with overlapping of counsellor and caregiver turns. In case A, the counsellor struggled to explain the difference between HIV and TB treatment. It becomes apparent within the interaction that neither the counsellor nor the caregiver knew whether the child had TB, HIV or TB and HIV. Although it is likely that both the patient and the counsellor have an understanding of what HIV and TB are, the explanation given by the counsellor in consultation A suggests a blurring of the two. Given the high co-occurrence of HIV and TB in the Western Cape, this is not surprising. However, an explanation that provides a clear distinction between the two would have eliminated the mother's confusion as to whether her child had TB, HIV or both.

The difficulty of diagnosing the child as having TB or HIV in consultation A, also highlights the issue of the boundaries of counsellor responsibility. In a number of cases counsellors told caregivers their diagnosis as the caregivers had not understood the doctors' explanation. In consultation D, the counsellor needed to explain to the caregiver what TB Meningitis was. She does not do so, resulting in the caregiver not only not understanding what is wrong with her child, but also not grasping the motivation for hospitalizing the child for 9 months. A follow up appointment is made for a week later, meaning that the caregiver will not know what the diagnosis is until then. When faced with the prospect of trying to communicate what she does not understand (because she has not been told) to her husband, she asks the doctor to do so for her at the follow up appointment. In this case, the lack of a clear message from both the doctor and the counsellor to the caregiver, resulted in the caregiver herself not being able to communicate the message to her husband.

e. Topic-shifting

Consultations were poorly structured. This was evident in the rapid topic shifting and many loose ends. Patients were not given a conversational framework within which to work. In consultation C [55], Nokuzola asked a patient for her explanation of why her boyfriend had bothered to have an HIV test if he didn't believe that HIV existed. In response, the caregiver changed the topic to grant applications. The counsellor did not revert back to the original question but allowed the caregiver to change topic and in doing so shifted away from the issue of disclosure. In consultation D, the counsellor's very rapid topic shifting meant that the counsellor's explanations were not full or clear, and were interspersed with other discussions (e.g. patient's clan name). The transcript raters commented that in analyzing the transcripts, they were left with a sense of incompleteness as many topics were discussed but discussions lacked depth.

f. Mitigation

On a number of occasions, caregivers stated information that the counsellors would have realized was inaccurate or was an attempt at hiding the truth. Counsellors tended not to follow up on this mitigation. In most cases, this occurred when discussing sensitive topics, such as the caregiver acceptance of her child's ill-health and her husband's cause of death. When patients did not name HIV, the counsellor followed suit e.g. Caregiver P avoided naming HIV [380] and refers to it as '*this*' e.g. '*I will not die from **this***'. In consultation L, the caregiver ardently repeats that '*the baby is fine*' throughout the consultation. The counsellor does not pursue this. In consultation Q, the counsellor shied away from exploring how the caregiver's sixteen year old daughter became HIV positive. There is no discussion of where she is being managed and if she has attended a support group or counselling. The transcript analysts commented that they felt that there were many missed opportunities in case Q in particular that needed to be followed up on.

One particularly difficult issue for counsellors to discuss, appeared to be the inadvertent diagnosis of the mother by virtue of her child's status. When the caregivers stated that they had tested negatively or that they have heard that a child can be born HIV negative even though the parents are HIV positive [D], the counsellors did not correct this. Perhaps because doing so would necessarily mean telling the mother that she must also be HIV positive.

g. Management of session endings

None of the counsellors included a summary or 'ending' to their consultation. In only one consultation [A] the caregiver was asked if she had any questions. In a few of the consultations, the counsellors outlined the follow up procedures [B, E, F, P, R]. However this was not the case in the other seven consultations. The lack of an ending, meant that follow up procedures and caregiver and counsellor responsibilities in light of the discussions in the consultation, were not clearly laid out. Table 6.15 summarises which aspects of session endings were included by each counsellor.

Table 6.15 Pre-training consultation endings

Counsellor	Case	Comment	Inclusion of a summary	Patients given the opportunity to ask questions	Procedures outlined
Nokuzola	A	Asks if the patient is satisfied with the information she has received, and the counsellor thanks her and wishes her well.	No	Yes	No
Nokuzola	B	Counsellor asks if they have reached some agreement (this is quite sudden and unexpected) and says she will see them at their next appointment.	No	No	Yes
Nokuzola	C	Patient brings the session to an end saying “Yes, that’s true. I will see you then” And the counsellor says “OK my sister”.	No	No	No
Nokuzola	D	Not on tape	No	No	No
Nokuzola	E	Session brought to a close by the doctor	No	No	Yes
Nokuzola	F	Counsellor tells her that they are finished and outlines the procedures she needs to follow. The patient reminds her to give her the date for the next appointment and the patient initiates her own questions. Both thank each other at the end.	No	No	Yes
Elsie	K	The counsellor starts writing in the folder and the patient hints that maybe the counsellor is in a hurry. The counsellor reassures her that there is still time for her to talk if she needs to. Other staff drift in and out of the room. The counsellor encourages the patient to adhere to her regimen and wishes her a good day.	No	No	No
Babalwa	L	Patient draws the session to a close by suggesting that they are finished and she must go. The counsellor encourages her to return should she have any further questions and they both thank each other.	No	No	No
Babalwa	M	Counsellor reiterates the importance of disclosure. The caregiver thanks her and says that the session has been of value to her.	No	No	No
Lindiwe	P	No warning of ending. Discussing procedures and the counsellor asks if they understand, and then the caregiver thanks her and the counsellor thanks her back.	No	No	Yes
Lindiwe	Q	No ‘ending’. Just ‘OK sisi’	No	No	No
Lindiwe	R	Lengthy discussion of follow up arrangements.	No	No	Yes

h. Non-verbal skills

Two of the counsellors (Nokuzola and Elsie) were rated as having particularly poor non-verbal skills in a number of consultations. Nokuzola appeared fatigued and unwell in many of

her consultations. She often closed her eyes whilst listening, and rubbed her nose and eyes. In consultation K, Elsie lay backwards in her chair with her legs open and out in front of her, and her eyes closed for long periods of her consultation. With her arms folded across her chest and her eyes closed, she appeared to be asleep.

6.15.3 Rater perceptions of whether caregiver needs were met?

The raters were required to answer whether or not they felt that the patients needs had been met in the consultation and to substantiate this from the transcript and video data. In many of the consultations, one was left wondering, *what did the caregivers get out of this consultation?* The analyst team had commented that it felt as though some of the caregivers had gained “*Not much more than if she spoke to her neighbor*” (Rater 2).

In examining why the caregivers went for counselling and what questions they had, and then at the counsellor’s responses, we can analyse whether or not the caregivers’ needs appeared to be met. These are summarized in Table 6.16.

Table 6.16 Pre-training consultations: Rater perceptions of whether patient needs were met

Counsellor	Case	Reason patient attended the counselling / needs the patient expresses	Analyst team perception of whether or not the patient's needs were met
Nokuzola	A	The reason the patient attended the clinic was unclear. The patient stated that she wants to discuss her folder.	To some extent, the patient's need was met as she did get some information from the folder. However, the caregiver remained confused and vague about what she was doing there, who is treating her child and why. It was not clear when she left what her course of action would be as this was not explained to her. The counselling session appeared not to have a specific goal.
Nokuzola	B	There is increased resistance due to the child not taking medication at 12 hourly intervals.	There is no negotiation of solutions to problems e.g. unrealistic timing set for taking ARVs. We are left unsure of how the mother feels about the suggested times? Will the mother be able to stick to the suggested times? The lack of clear explanations means that she is unsure about what the first and second line treatment is.
Nokuzola	C	Patient C wants assistance with where she should go to have the problem of burning urine sorted out, how to disclose to her boyfriend, how to start a grant application progress and with questions about consulting other professionals/ healers for advice.	At the end of the consultation, we are left with many unanswered questions: Will the patient see the doctor about the burning urine? How can the patient open a folder to access the clinic? How can the patient tackle the issue of disclosure to her boyfriend? What can the patient do to find out about her grant? Is the patient going to continue to consult with the 'specialist' / 'traditional healer' that she has mentioned?
Nokuzola	D	Patient D is struggling to deal with diagnosis and coping – containment is needed.	In the consultation, the counsellor's response to the caregiver's emotions is to state 'relax, everything will be fine'. Procedural aspects are not clearly explained and there is a lack of understanding of what will happen next. Initially, the counselling was about the child's diagnosis and the caregiver's need for an explanation about TBM and the child's impending hospitalization. This need was not met as no information on why hospitalization is necessary for TBM was given, nor for why the child needed to be hospitalized for 9 months. No explanation of TBM was given either.
Nokuzola	E	The patient needs the counsellor to act as mediator between Dr and patient – very much patient advocate rather than just an interpreter.	Procedural aspects are unclear. The patient is going to have to wait from Thursday until Tuesday afternoon before she can speak to the doctor again. She is left without knowing what TBM is? What is 'Brooklyn' [Chest Hospital]? Where is it? How long will the child stay there? However, the counsellor does fill the patient's need for an interpreter between her and the doctor.
Nokuzola	F	Not clear what the patient's needs were – either an initial consultation or about a grant application.	Unsure whether or not the patient got what they needed from the consultation but it looks pretty straight forward and that she has.
Elsie	K	Patient needs unclear – but she appears to need to talk and off-load her problems.	Yes, the counsellor lets her talk. There is no indication of other treatment needs not being met as the counsellor says very little throughout.
Babalwa	L	The caregiver needs to learn about ARVs to start treatment.	The lack of clarity in Babalwa's explanation means that this need is not met
Babalwa	M	The caregiver would like the counsellor to advise her on practical steps for disclosure to her sister.	No practical steps are discussed so the raters presumed that this need was not met; however, there is discussion about disclosure so the opportunity to voice her concerns may have helped the patient.
Lindiwe	P	Patient P wanted to know how the baby would feel on medication.	Yes, the counsellor explains this to her.
Lindiwe	Q	Patient Q wanted the counsellor to negotiate a transfer to another hospital on her behalf.	Yes, the counsellor organized this.
Lindiwe	R	Patient R had relationship difficulties.	Yes, the counsellor listened to his problems and arranged a follow up appointment for couple counselling.

In consultation [A] for example, the patient initially stated that she had attended the session because she wanted to see the patient's folder. As the consultation unfolded, it became evident that she was not aware of her HIV status or that of her child, and she had questions as to what her child's tablets were for, how the child contracted TB and/ or HIV, and whether or

not ARVs can cure HIV. At the end of the consultation, a number of these issues were still unresolved as a result of the sometimes unclear information from the counsellor. This meant that more questions were raised than had been answered. What does the patient actually understand about HIV? Does the child have TB? What tablets must the child take, when and why? What does the patient understand the cause of TB to be? Is the caregiver or the child to be tested for HIV? What happens next? When will the patient be seen again?

Counsellor experience and prior training appeared to impact on whether or not patient needs are met. Nokuzola and Babalwa, both untrained, were not able to meet these patient needs; in contrast, Lindiwe, the most experienced counsellor with the most training, met the needs of the caregivers (as identified by the analyst team from the transcripts) in all three of her pre-consultations, as did Elsie.

6.16 RATER TEAM'S ANALYSIS OF INDIVIDUAL COMMUNICATION SKILLS

The previous sub-section described the general characteristics of the counsellor communication. This next section summarises the specific communication characteristics for each counsellor. After the description of the characteristics of each counsellor's communication, the relevant transcript references are tabulated.

6.16.1 Nokuzola

Reviewing the transcripts and the communication analyst team's comments, Nokuzola's pre-training consultations appear to be characterized by lost opportunities; lost opportunities for checking understanding, for explaining the requirements of adherence and the commitment required from the patient and the procedures that need to be followed. When viewing the video footage, the shifts in energy levels with the fluctuating health of the counsellor are very apparent. Equally apparent, is the bravery and feistiness of the counsellor's efforts as a patient advocate, in encouraging them to demand their rights to quality and confidential care. Extracts from Nokuzola's transcripts are presented in Table 6.17.

Nokuzola's interactions had a definite beginning marked by social greetings. She allowed the caregivers to talk without interruption [A], using back channel responses and repetition of the caregiver's words to show that she was listening. In addition, the counsellor clarified the patient's questions [A] before answering them to ensure that she understood what the

caregiver meant. The analyst team felt that the counsellor's straight-forward answers to questions such as whether HIV is curable, were helpful [A37].

To emphasise key information, Nokuzola used emotive and personalized language when discussing the importance of sticking to the treatment regimen '*please, I'm begging you*'. In case B, both counsellor and caregiver had a similar pattern of code-switching [B14]. In [B33], when trying to console and motivate the mother, Nokuzola's voice softened and she looked straight at the mother, code-switching frequently to English to encourage the mother. Nokuzola explained time concepts and how the virus multiplies in a straight forward way that appeared easy to understand [B]. Nokuzola followed the patient's lead and did not dictate the content of the sessions [C]. Through her involvement in the support group at the clinic, Nokuzola knew many of the mothers, so a formal 'name' introduction at the beginning of each session was unnecessary. Nokuzola built rapport with the caregivers, as demonstrated in her use of a shortened form of the caregiver's name 'Thuli' in case B. She also showed empathy [C10] and the patients showed they were comfortable talking to her [C16]. In consultation E, the counsellor was able to control the mediated consultation and successfully shifted from her role of being a counsellor to an interpreter.

Nokuzola acted as a patient advocate and mediator. She did not change her opinion in the doctor's presence and defended the patient to the doctor e.g. [E7] '*She was just telling you her feelings*'. In consultation F, she provided a good explanation for the reason for some of the questions about the patient's home and living circumstances. This made the questions less intrusive and allowed the patient to feel that her well-being was of concern.

At times, Nokuzola had good eye contact, and leant forward to show that she was listening and shared personal moments such as laughing with the caregiver [C]. However, there were marked changes in her posture and eye contact depending on her energy levels. In most of the consultations, the counsellor appeared unwell and was very lethargic. In the consultation involving the doctor [E], the counsellor appeared most attentive and her body language was extremely supportive of the mother (leaning towards her, excellent eye contact with both the mother and the doctor, and softens her tone when speaking to the mother).

In many of her sessions, Nokuzola's interactions were chaotic and poorly structured. There was a lack of preparedness, with the counsellor often reviewing the folder in the middle of the session in front of the patient [A]. Sessions did not include introductions or conclusions, with

the result that the sessions lacked focus and there were many loose ends. Towards the end of case A for example, the caregiver acknowledged that *'there is a lot for me to think about'*, an ideal opportunity for the counsellor to summarise the many issues discussed within the consultation, but this did not happen.

In cases in which the caregiver was confused about hospital protocol, there was a need for instructions to be reiterated at the end of the sessions, but this was not done. Within the body of the sessions, the lack of a framework being set by the counsellor, resulted in rapid topic shifting and a failure to address issues in any depth. This manifested itself in incoherent interactions at times. In case A for example, the patient was provided with confusing and contradictory information about TB and HIV. In consultation F, Nokuzola made an off-hand comment about going to the pharmacy and the support group *'perhaps the information there will help you'* when more precise information was needed, especially as this was a new patient. Concepts that she did not explain clearly included TB and first and second line regimens [B]. The transcript analysis team felt that there was ambiguity around the use of *'high and low'* and *'positive and negative'* in a number of consultations [D].

There was a tendency for Nokuzola to assign medical diagnoses to patient complaints (e.g. In response to a patient discussing her child's cough she asked, [A] *'Do you know why he is asthmatic? Is he a child that likes playing with water or what?'*) and she imposed her own, not always accurate, causal beliefs on to the patient (e.g. cause of TB). Nokuzola used many English phrases in her code-switching e.g. *'to minimize the danger'* and *'you should be tested as soon as possible to avoid any damage'*. Other code-switching of borrowed medical terms, included *'pap smear'*, *'private doctor'* and *'specialist'* [C].

In checking whether or not patients were adhering, Nokuzola did on one occasion request that the patient show her the medication so that she could explain it to her. However, this was not followed through and no demonstration was given [A 44].

Many opportunities to clear up some of the caregiver's confusion regarding HIV, were lost. For example, when the patient stated that she was unsure of how her child became HIV positive [A54] P: *'I don't want this HIV and TB because I don't know how he got it.'*, the counsellor did not follow up on this issue. In this same consultation, there was an assumption from the counsellor that the patient knew her own status, when in fact it emerged that the mother did not know and had never been tested for HIV. The opportunity to introduce the

idea of having an HIV test was lost. When the patient replied [A68] that she has never been tested, Nokuzola reverted to discussing procedural aspects rather than addressing why the patient had never been tested or encouraging her to go for a test. Topic shifting occurred repeatedly, for example, when the patient asked her what the tablets were for [A56]. Nokuzola appeared unable to deal with difficult to discuss topics such as disclosure, traditional healers, sex and condoms [D]. In consultation D, Nokuzola's topic shifting was rapid with pairs being non-sequential. Counsellor turns were longer than patient turns. However the counsellor did not expand on any of the emerging issues.

At times, the counsellor interrupted the caregiver [A: 20]. The caregiver stated '*it's not that I'm being difficult*' as if the counsellor was making her feel as if she is being difficult. In the interactions, there was often no solidarity expressed between the counsellor and the patient – in giving suggestions on what the patient could do, the counsellor tended to use '*you*' rather than '*we*' e.g. [C12] '*You can follow up...*'.

In many of Nokuzola's consultations, she yawned, rubbed her eyes, engaged in self-grooming and appeared very subdued [F]. In some consultations she closed her eyes and moved her lips in and out, appearing bored. She seldom smiled. No gesture was used for emphasis. When holding the patient's folder, the counsellor looked at the folder rather than at the patient. In consultation F for example, the counsellor was very busy with the hospital folder, writing and collecting information with very little focus on the patient. She seemed tired and disinterested and eager to bring the session to a close.

Table 6.17 Transcript references from Nokuzola's pre-training consultations

Straight talking [A37-43]

- P: Hhayi i-HIV, iyanyangeka mosi masinyane emntaneni? *No, for HIV, can it be cured quickly on the baby?*
- C: I-HIV ayinyangeki kaloku Nosipho akwangoku. Alikabikho iyeza le-HIV. Iyeza elikhona lelokuba liyithomalalise ibesenzantsi ibekwizinga elisezantsi ingabi nabungozi emtaneni ingamgulisi, uyaqonda. Ngoku anayo intsholongwane ibe kwizinga elisezantsi kakhulu, uyaqonda. Otherwise ayiyinyangi iphele tu alikakabi bikho iyeza lokunyanga i-HIV.
No we can't heal or cure HIV. We don't have that kind of treatment yet. The only treatment that we have and are giving for HIV is tablets that minimise the danger and progression of the virus of HIV. Even though she has the virus the medication minimise the danger. Otherwise there is no cure for HIV yet.
- P: okay,alikhho *Okay there is no cure?*
- C: mhm mhm alikhho. *Yes there is no cure.*
- P: Nalapha koggirha? *Even the doctors?*
- C: Nalapha koggirha alikabikho alikafumaneki iyeza lokuba kuthiwe iyanyangwa iphele tu into ekhoyo zezizithomalalisi. *No even with the doctors there is no cure for HIV, the medication that they have minimises the virus in the body.*
- P: okay iyathonyalalisw. *Okay, it minimises*
- C: ewe iyathonyalaliswa. *yes it does*

Table 6.17 continued**Patient advocacy [E7]**

P: Hayi andibizele ecaleni andibizele umntu endizothetha naye ngoba andikwazi ukhumsha. *I think she [the doctor] should have called me aside and called someone to interpret for me because I do not understand English.*

C (to the Dr): Okay, you should have called her aside in private.

Dr: We don't usually call mothers aside to talk to them about TBM. We only call the child to discuss TBM. I don't understand why I should call her and discuss the child's TBM and that's how we deal with this with the entire mums. Most of the times we discuss issues about children in the ward next to the bedside. If it's something highly confidential then it's treated differently. Most of the mums in the ward of the child who are HIV positive and the whole idea is to point to them where it's like TB and how comfortable to deal with it. That is why it was inappropriate to call them aside.

C (to the Dr): I do understand what you are saying doctor but I mean she was just telling her feelings.

Patient topic shifting when difficult to discuss topics are raised [C32]

C: Ebesiyo-testela ntoni kanti yinto engekho? So why was he testing if he knows that HIV/AIDS does not exist?

P: Andimazi (laughing). Sisi Thembakazi la-form ye-grant iphelelwa emva kwexesha elingakanani? oh hayi inoba seyiphelelwe le ndandiyinikwe apha.
I don't know (laughing). Sister Nokuzola, when is the expiry date for the grant form? I think the one I got from here expired long ago.

Abrupt counsellor topic shifting [D23]

C: Into enayo into ebalulekileyo iyi-one kukuba ugcine ixesha njengokuba ndandisithso mos ne. ugcine ixesha omtyisa ngalo uKuhle. Wazi ukuba ngexesha elithile nakanjani makatye itreatment yakhe. Mandimtyise imilinganiselo le ugqirha andixelele yona ndingaphosi ne-appointment eklinik ndizise umntwana eklinik, ukwenzela ntoni, ubomi bomntwanakho buzobaright. Subanayo neworry sisi, yonke into izakudlula. Kaloku kubakhona istage apho uva into yokuba hey ndixinene ngoku intloko igcwele zininzi ezizinto. Kodwa liyadlula elo xesha uyaqaphela ukuba noba kumnandi ubumnandi buyaphela. Noba sekukubi kuyedlula, ubuhlungu buyedlula akhonto ingedluliyo. Uvile ke unguMabani?

*The most important thing is to keep time as I've said before. You must keep the time that you give Kuhle her treatment. You must give her the measurements as directed by the doctor; you must not miss her appointments at the clinic. Don't worry sisi everything will pass. There is a stage where you get confused because there are too many things happening but that stage passes. As you have noticed, the time for happiness passes and so is the time of pain. Do you understand? **What is your clan name?***
[Bold emphasis my own]

Table 6.17 continued**Counsellor mitigation ‘everything will be fine’ [D39]**

C: Hayi mkhaya wam relaxer sisi akho niksi. Yonke into izadlula futhi kubemnandi and akhonto ezakutshintsha ngenxa yokuthi umtwana u-HIV positive. Khawume, khawundixelele, wawu-testile ngexesha ukhulelwe ne?

No my homy relax sisi there is nothing. Everything will pass and it's going to be nice. Just know that the child's HIV status is not going to change anything.

Forced-choice questioning [D41]

C: Wait, tell me; did you get tested when you were pregnant?

P: Ewe. Yes.

C: **zaphuuma zi-negative ii-results? Your results were negative?**

P: Ewe. Yes.

Missed opportunity to discuss transmission [A54]; Counsellor reinforces the patient's right to know her treatment

P: ndiyabuzwa kwathiwa awuzuyazi noba utya itreatment yantoni uyatyiswa nje iTreatment. Phofu akuchazwa ndiyamseza itreatment ixesha elingakanani. Phofu zange kuxelwe ukuba yi treatment yantoni. Yitreatment athile le uyityisa umntana. Mna ndizosuka ndimtyise zonke. Kufuneka aphile umntanam. Ndifuna aphile. Ndiyalifuna eleHIV but andilazi iyeza lalo ndicinga sele ekhona. Ndilifune eleTB kaloku bekuthiwa utya itreatment. Kuba xa ukwitreatment kufuneka wohlule ngoba sowuqala itreatment ungayazi noba yeyantoni.

I just give my child all these tablets without knowing the reason. I will probably end up giving him all tablets that are come across, because even the ones that I have I don't know what are there for. I just want my child to get better. I want the HIV cure, but I don't know I thought there was one. I also want one for TB because they said there is treatment. Because when you are on treatment you need to have them separately, its difficult when you don't know which one is which.

((C Smiling; Speech overlapped between P and C))

C: kubalulekile kakhulu kakhulu sisi lento uyithethayo akubalulekanga uba utye itreatment ungayazi noba yeyantoni. Because lento ikwenza wonqena ukutya iTreatment ungakhuthali. Kanti xa uzazi ukuba nditya le treatment ndiyintyela ntoni iyakukhuthaza lento. Uyazazi ukuba ulungiselela ukuba makuthini nje ngokuba usitya letreatment. Uyayiqonda, ibalulekile lento uyithethileyo kakhulu.

It is important, What you are saying is very important. It is not wise to have treatment that you know nothing about. Just taking treatment without proper understanding demotivates you from taking treatment. But if you know the reason for taking treatment you just become motivated. You know the end goal and understand that it is important.

6.16.2 Elsie

Elsie's pre-training consultation illustrates the impact of the patient as the conversational partner on an interaction. It differs markedly from all of the other interactions because the patient dominates the discussion speaking far more than the counsellor, and the consultation is conducted in English and Afrikaans involving a coloured caregiver from the Cape Flats²³. The caregiver had been referred by the doctor. The case details that three of the counsellors discussed prior to the consultation made it clear that this consultation was considered a last resort and that the counsellors felt it was futile counselling this particular patient as they perceived that none of the rest of the multi-disciplinary team appeared to know how to manage the patient. The consultation is a lengthy one; characterized by a patient monologue of HIV and her life, with very little input from the counsellor. Despite Afrikaans being the first language of the caregiver and the counsellor, the consultation is conducted in English and the caregiver is not given the opportunity to choose the language of her consultation. Once the consultation concludes, the caregiver immediately switches back into Afrikaans in discussion with her own mother. A series of extracts illustrating consultation K are presented in Table 6.18, 6.19 and 6.20.

Table 6.18 Extract 1 from Elsie's consultation K

[K190-212]
P: He gave everyone money, but it's not for sex,
C: Hmm. (Nods her head)
P: Or stuff like that. He just said no, "here's just some money for you". And, uhm, I started to tell the one friend, "why does this man give us money?"
C: Give us money, yes. (Sits back in her chair)
P: And my friend said no, it's fine and I, I was speaking to her, see. And every time we drink, he was looking at me. And I'm starting to get scared, I don't wanna come in mos.
C: Hmm.
P: I said no man. If he wanted to take one of us, he would have, because it's, it's before times we met him already there. And it's like, it's fun. We come, uhm, like every Saturday we got our taxi money we go to the Waterfront, and he comes.
C: (Nods her head)
P: And he did work there by Lifeguard, in Seapoint.
C: (Nods her head) Hmm.
P: And the people that walks, that saves the people in the water

²³ The Cape Flats is a geographical area in Cape Town in which gangsterism, substance abuse and crime is rampant. This caregiver differs from the isiXhosa caregivers in terms of culture, race and language.

Table 6.18 continued

C: Yes, yes, that saves them. (Nods her head)

P: At companies, yes. And so he brought, uhm, this Saturday for brought two of his friends. And we were like partying in the Waterfront, but me and my other friend got a little drunk,

C: Hmm. (Pulls at her hair)

P: And so, uhm, the other girl said OK, we must go to the flat.

C: (Pulls at her hair and nods her head)

P: So he said to me: “you must come to my flat, you and your one friend”. We went. Because we drunk, we don't, we didn't even know what we doing at the time.

C: Hmm.

P: And he said to us we must sleep on the one bed. And so we did sleep,

C: (Nods her head)

P: And the next morning I just saw like, hey, where are we now?

[K236 - 250]

P: It wasn't like a date rape or something like that. It was just plain, and see that girl, she's married now to the other guy.

C: (Nods her head)

P: But I mean, me and him also started a relationship.

C: (Nods her head)

P: But he did sleep with me without a condom.

C: Hmm.

P: The first time.

C: (Nods her head)

P: Just maybe to show me he's not... I did ask him “before we sleep together, are you sick? You must tell me now.”

C: Hmm. (Nods her head)

P: He said “no, I'm not sick. Why?” So I told him, “you know what, people that's got HIV”, so already learn about this.

C: (Nods her head)

P: “People who's got HIV, it don't show. You can look as healthy as me”. And I'm very scared.

C: Hmm.

P: So he was like, in my mind, he took my mind in another position so we'd sleep together.

Elsie gives the caregiver the space to speak, and this appears to be what she needs. She has a desire to tell her story, “*OK, I'm talk the whole story now*” [K176]. Her story follows a narrative format starting with, “*In the beginning, I met this boyfriend*” [K178]. What unfolds is a story of poverty, transactional sex and substance misuse. The story is probably typical of many women in South Africa living in abject poverty. It is nonetheless disturbing to hear, and the observer is consumed by the futility of the counselling consultation and the hardships faced by women. However, the poignancy of the caregiver's realization that she is now one of

many people who have contracted HIV, reminds the observer that each patient is an individual.

Table 6.19 Extract 2 from Elsie's consultation K

[K138-145]
P: And I mean, I'm a person in hundreds and hundreds of people. I see here...
C: (Nods her head) OK.
P: I never knew,
C: Hmm.
P: They got the same virus I have.
C: (Nods her head)
P: And I talk, sometimes when I feel so angry and I sit alone. I thought, why must I be sick?
C: Hmm.
[K162-172]
P: I said to her I was on drugs because,
C: (Nods her head)
P: Of this virus.
C: (Nods her head)
P: Because I couldn't take that, why me?
C: Hmm. (Nods her head)
P: I did nothing wrong! I never ask for this,
C: (Nods her head)
P: That was in the beginning,
C: Yeah.
P: And I was pregnant.
C: Hmm.

It was neither the absence of treatment literacy nor the lack of structure to the consultation which the rater group felt to be most problematic, but rather the inappropriacy of Elsie's non-verbals relative to the caregiver's story. The story is very long and involved, and it must have been difficult for Elsie to concentrate. The counsellor leant back in the chair with her eyes closed, opening her legs, engaging in facial grooming, including nose picking, and appeared to sleep. The rater team felt that this was particularly remarkable considering that the counsellor knew that she was being video recorded.

Ironically, the counsellor's disinterested body language and lack of verbal interaction, succeeded in giving the caregiver the space to speak.

Table 6.20 Extract 3 from Elsie's consultation K

[K547-566]
C: (Scratches her nose)
P: I did bring everything out now.
C: OK.
P: Now I feel nice.
C: Hmm
P: (Coughs) Now I feel nice. Because if I talk to my mother, only a little, and my brother and my other sister. She's like "No, but the thing is not like this, the doctor don't do, the doctor, she must go, uhm, learn again. It can't be like this!"
C: (Nods her head and smiles)
P: And you know, it's stressing me out. So how can the doctor that's helping me be telling me bull? And then I got so angry, and I take my hand, and I said to my mom "Listen, it is so, you were there! We were, you were sitting there next to me!"
C: (Nods her head)
P: "Tell them!" Then they like, " Nee , this kid is mad, Mammie you must put her there in Lentegeur."
C: (Rubs her cheek)
P: And they take, they put the light out, and they bang the door closed you know,
C: (Nods her head)
P: And then I feel so... I'm a, I'm a dog. I'm a dog, you're dirty. Your, your boss don't want you. You must go lay in the and it's like, on a time, and they,
C: (Rubs her eye)
P: OK, I was on the drugs. Maybe they, they, they did help me to do that. Like uhm, they don't wanna give me sugar. I'm sick, I mean, I did smoke. OK, I did stuff with this but I'm sick. They don't give me sugar, they don't give me bread. My mammie must go to the next-door neighbour to ask for the three spoons of sugar just for me to drink. And, uhm, you see like uh, bread to eat.
C: (Nods her head)
P: Then they also have an argument with my mom. "This girl smokes", and stuff like that. But I had to talk one night. I said to my mother, "You, you, you keep your mouth. Stop telling me, keep your mouth. Because today I'm telling you what's on my mind."
[K600-616]
C: If person wants to talk, must talk. (Drops a page, bends to pick it up)
P: It felt that it's good to talk, to get it out.
C: Out, hmm.
Grandmother (G): I told her she mustn't talk to anyone.
C: Yes. (Puts file on table)
P: Now you see.
G: I tell her. You talk, then other persons, people is listening to everything. They don't want to listen to..
C: Uh.
G: And you know what?

Table 6.20 continued

C: I know,
P: I feel now...
C: If she talk, then she go to be relieved.
G: Yes.
C: Because she talking out.
G: Yes
P: You see, I don't even care what the people think about me. I was first like, private, private, private. But I'm, I uh, I must talk to uh, my sisters and my, and my brother to tell them they must be alert for something, tomorrow they gonna skel me.
C: What is the for date today? (Writes in file)

The end result is a relieved caregiver who feels that she has been able to unburden herself. Of most concern was why this case had been referred to the counsellor in the first place; the patient speaks English so could have been referred to a psychologist with more advanced counselling skills. Or possibly not; Possibly the health care system has given up on this patient as a hopeless case for whom nothing can be done. If this is the case, the end result of a caregiver feeling unburdened by sharing her story is a good one.

6.16.3 Babalwa

Babalwa started off all of her consultations with a full introduction including her name, her role and the purpose of the consultation as well as asking for the patient's particulars. After the greeting, she commenced the counselling session with an open question to find out why the caregiver wanted counselling. This was effective in providing a platform for the caregiver to talk freely. Both her opening and ending were heartfelt and welcoming. Despite not having any training, Babalwa was the only counsellor who started off her sessions with a full introduction and an open question. She allowed patients to introduce and explore many topics. Her communication tended to be unhurried and very natural, and she interacted with the child in the session too. She fostered trust with the patients by being encouraging, asking about their feelings, including lifeworld moments in the discussion and allowing the patient to talk for long turns.

Babalwa had good eye contact, body posture, tone and pace. She appeared attentive and demonstrated active listening through discourse markers and by repeating what the patient

said ‘*So you are saying...*’. Her tone was empathic and she used a ‘*confidential tone*’ (Rater 1) when discussing some topics.

Babalwa’s explanations of medical concepts (e.g. CD4 counts) were vague and not structured [L377]. The open-ended question she asked elicited emotional responses from the caregivers, but she avoided following up on their comments by topic shifting [L374]. Her sessions reflected her lack of formal training in that they were unstructured, with no sense of the counsellor facilitating the session; her consultations were ‘*conversations*’ (Rater 3) rather than having a focus or a purpose. When practical advice was requested, the counsellor was vague in her responses and replied generally rather than case-specifically. For example, when asked for advice on how to go about disclosing, no role plays or ‘what if’ scenarios were played out.

Babalwa’s consultations appeared on the surface to be collaborative, but in reality weren’t. There were many overlapping turns, and the counsellor included a lot of medical jargon (‘CD4 count’, ‘antibodies’, ‘appetite’). At times, she did not listen to the patient, and questions were repeated e.g. ‘*don’t you have any family members...*’ when they had already talked about her sister. As one of the analysis team commented ‘*one was left feeling that the patients did not get much out of the session as no guidelines were given, and the counsellor did not follow a line of questioning which might enable the patient to help herself*’ (Rater 2). At times, leading questions were asked preventing the patient from raising difficult issues (e.g. disclosure). In extract L [121] the counsellor prevented a discussion of disclosure by saying, “*They all know at home, right?*”

In Babalwa’s pre- sessions, a number of difficult topics were raised, among them disclosure, death and stigma. She appeared to be ill-equipped to discuss these effectively. When Patient L informed her of her husband’s unexpected death, she replied ‘*mmm*’ and ‘*OK*’ [L128]. Despite the patient’s displayed emotion, there was no attempt at containment by the counsellor. Her sessions tended to fall flat towards the end, with no preparation of the patient for the ending, no summary and no invitation for additional questions. After a lengthy session [L] the counsellor appeared unsure of how to end the session, so the patient drew it to a close.

No gesture was used, and there was minimal head nodding. At times, her affect and prosody were flat. No role play or props were used. Extracts from Babalwa’s transcripts are presented in Table 6.21.

Table 6.21 Extracts from transcripts of Babalwa's pre-training consultations**Vague and unstructured explanation about CD4 count [L377-370]**

- C: You need to know your CD4 count it is important because it is your antibody
- P: Mmm
- C: It's your antibody
- P: Yes
- C: So when it is low you have to start taking ARVs the doctor will tell you
- P: Mmm
- C: Then when it is above 200 you won't have to start taking them because you still have the energy to survive on your own

Topic shifting when difficult topics are raised [L374-375]

- P: ... and I tell myself that I will die if I have to but not because of this disease
- C: How old is your sister? (topic change from death to family)

6.16.4 Lindiwe

Lindiwe spoke in a confident but soft, and '*motherly*' tone (Rater 2) in all of the interactions. Her age meant that she was referred to as '*Mama*' rather than '*Sisi*'. She came across as being dignified and confident with a '*facilitatory manner*' (Rater 3). In two of the interactions, Lindiwe appeared to have a pre-existing relationship with the caregivers and they approached her for assistance because they trusted her. She checked adherence strategies, and explained concepts very clearly using practical examples (e.g. Case P when she urged the caregiver to think of a way of reminding herself about the timing of her medication, she used a combination of open and closed questions). Lindiwe's counselling experience was demonstrated in her strategy of asking patients what they heard from other mothers as an effective way to draw-out patient misconceptions from shyer caregivers. The caregiver in this instance, took up this opportunity by saying [P] '*Some people have said ...*' Lindiwe displayed good knowledge of hospital procedures and was a point of access into the hospital system for caregivers who approached her with concerns [Q, R]. Although she was not a patient being treated within the clinic, her experience of many counselling sessions showed in her practical tip to caregiver P on which order to give the tablets to the child, as some are more bitter than others. In [R], the counsellor broke some of the tension in the session through humour, when she makes a joke about the clan to which the patient says that they belong [R269].

Lindiwe had a quiet, attentive and engaged manner. She appeared to be a very calming presence and established good rapport with the patients. Some gesture was used for emphasis. She used head nodding to show that she was listening and had appropriate eye contact. She had a non-threatening tone when asking about forgetting to take medication for example, and effectively used pausing to encourage the patient to speak. In contrast to some of the other counsellors, she was always attentive.

In some of her consultations, medical concepts were not clearly explained (e.g. first and second line regimens) and there was a large proportion of code-switching to English, particularly for medical concepts. In all of her interactions, a number of issues that were raised (nutrition, routine, family structure) were not followed up on. In case Q, Lindiwe asked an important question about how the daughter was coping with being infected with HIV, but did not follow this through when the mother said the daughter was *'fine'*.

The interactional dynamics in consultation [R] appeared more complex as it was a couple counselling session. The analyst team commented that Lindiwe appeared overwhelmed, being judgmental at times, and taking sides in the interaction. Within this context, they felt that the female patient was not well heard. For example, in R[188] she said that without her boyfriend she was *'happy and stress free'*. Lindiwe responded to this by stating, *'this means that you would be happy if he changes'*. At times in this session, the counsellor's advice sounded somewhat artificial *'Do not fight again, né'*, and she mentioned the importance of communication, but did not provide a practical example of how they can improve their communication.

In case P, the caregiver seemed anxious (posture and hand movements) and repeatedly folded and unfolded her hands. In this interaction, the counsellor was seated higher than the patient which the raters felt contributed to the submissiveness of the patient. Extracts from Lindiwe's consultations are presented in Table 6.22.

Table 6.22 Extracts from transcripts of Lindiwe's pre-training consultations**Humour [R269-274]**

C Ungumni? *What is your clan name?*

P Ndingum [Clan X] *I am [Clan X]*

C Ndizakubetha *I will beat you*

P (laughs)

C Ndizakubetha *I will beat you*

P (laughs)

Poor explanation of 1st and 2nd line treatment [P22-24]

C: Kubalulekile sisi ukuthi ungaliphosi ixesha into eyenzekayo xa usitya amayeza. Amayeza anqanda intsholongwane ukuba ingaphinda phindani egazini. Okukuqala yiyo leyonto ekuyeye kuthiwa xa umuntu esitya amayeza i-CD 4 count yakhe iyanyuka bese i-viral load iyahla. So into eyenzekayo omnye umntu uthi ngesoqhelo aqonde ukuba hayi suka bendimtyise ngo 8:00 nobandingamtyisa ngo 8:30 uyaqonda?. Ndiyathanda ukuba umntu ndithethe naye ndimxelele ngobungozi balonto. Because intsholongwane iclever indawo yokuqala ijonga ithuba once uba uliphose elaxesha iyatyhudisa ihamba iyokwenza ubugeza kwakhona. Andinothanda mna uba umntana wakho xa esitya itreatment akhawuleze asiwe kwi 2nd line. Ndithanda ukuba ahlale kwi 1st line, uyaqonda mos?. Kuba ugovernment ukhupha only lines eziyi-2 ukhupha 1st, ukhupha i- 2nd line

It is important to make sure that you don't change time intervals. ARVs are there to avoid the virus from replicating itself quickly in your body. Number one, it improves CD4 and decrease viral load. So don't change time intervals because the virus is an opportunist. And when the child is taking ARVs we like him/her to stay on the first line. I would not like it if your child quickly moves to the 2nd line. I would like it if the baby stays with 1st line, do you understand? Because the government only provides two lines, 1st and 2nd lines.

P: Ewe. Yes.

C: so umntana xa esaqala i-first line ngase atye la-1st line for iminyaka emininzi. Ngaphandle kokuba ke izenzekele iyodwa ke indaba yokuzenzekela ibiological changes uyqonda?. But not ukuba into yenzeke ngabom uyaunderstand(a), like umntu alibale, okanye kalouku nibancinci. Hayi bendiyojam(a) netshomi zam.

So if the baby is taking the 1st line I wish she could stay on that for years. Unless it happened and because of biological changes, do you understand? But not because they happen on purpose because someone forgets, you are young so you go out with your friends.

Not listening to the patient so responses are inappropriate to what she's telling her [R188]

C: Mm. ufeele njani ke ngelaxesha nikwi separation ngaye?

How did you feel about him when you were separate?

G: Bendonwabile, hayi bendonwabile bendistress free bendonwabe kakhulu.

I was happy, I was stress free, I was very happy.

C: Mm which means xa anothi atshintshe ningahlala kamnandi?

That means you'd be happy if he changes?

6.17 SUMMARY OF CHAPTER 6 PART 2

This chapter described the communication facilitators and inhibitors identified by the rater team, which complied with the criteria of consensus, substantiation and cross-consultation occurrence.

Communication facilitators included the use of practical examples, analogies, non-mitigation of the issue of ‘cure’ and the use of open questions to aid patient understanding. The inclusion of shared moments (e.g. humour) and non-verbal gestures appeared to facilitate empathy and collaboration with the interactions. Furthermore, non-judgmental counsellor responses and counsellor patient advocacy were considered to contribute towards creating more patient-centered consultations.

A number of barriers to effective communication between counsellors and caregivers were identified. Sessions lacked structure with poor introductions and endings. Questioning tended to be closed-ended and typically comprised of “Do you understand?” with a failure to systematically check *what* patients understood. The presence of medical jargon that was not explained to the patient was felt to impede explanations. Topic shifting and mitigation were common but ineffective responses when difficult to discuss topics were raised. Furthermore, non-verbal skills such as demonstrations were noticeably lacking. In addition to these general facilitators and inhibitors, individual counsellor communication characteristics were described. There is a great deal of variation in communicative competence and style between counsellors. This appears to be unrelated to prior training and probably reflects natural variations in communicative ability. The results in this chapter highlight the value of detailed, turn by turn analysis in contrast to a checklist approach. This is probably best illustrated in Elsie’s consultation K in which her apparently poor non-verbal communication did not impede the patient’s narrative. The patient was able to unburden herself and share her story despite counsellor non-verbals which suggested disinterest. This serves as a reminder to be cautious in making judgments (particularly cross-culturally) without examining the micro (communication) context.

Chapter 7 that follows uses the same form of analysis to examine and to compare the post-training consultations with the results from Chapter 6.

CHAPTER 7

RESULTS OF THE PRE- POST- TRAINING COMPARISON

In this chapter of results, the effect of the training on the counsellors' communication is described by outlining the general characteristics of the post-training consultations, and then describing communication changes relative to the pre-training consultations (as described in Chapter 6) for the counsellors generally and for each counsellor specifically. The last section of this chapter explores the impact of the communication training on four main issues, namely: treatment literacy; communication about psychosocial and lifeworld issues; the counsellor as a mother, patient and woman; and role of the counsellor.

7.1 LENGTH OF THE POST-TRAINING CONSULTATIONS

The post-training sample consisted of 10 consultations: Nokuzola (4), Elsie (1), Babalwa (2) and Lindiwe (3). The consultations were recorded over a 6 month period after training with each counsellor having at least one consultation recorded 6 months post-training to see if the impact of the training on communication diminished over time. Seven of the consultations focused on treatment literacy, one on disclosure [O], one on changing from the first to the second treatment regimen [U] and one on psychosocial support following a traumatic life event [T]. The consultation story lines are summarised in Appendix IX.

Table 7.1 summarises the length of the consultations after training. In the post-training consultations, the average length was 26 minutes, (ranging from 9 min to 47 min), with an average of 196 turns (ranging from 67 to 340) and 2473 words per session (ranging from 1250 to 4873). There was no observable pattern in terms of which counsellors had longer/shorter sessions, with Lindiwe having both the shortest (Consultation S) and the longest (Consultation U) session. In all of the consultations except for two (consultations T and U, with Lindiwe), the counsellors spoke more than the patients (65% of the words on average).

Consultation V was not video-recorded (at the request of counsellor Elsie) so turn and word counts for this consultation could not be calculated. The counsellor and caregiver consented for the researcher to sit in on the consultation and make field notes. The analysis of the communication in this interaction is subsequently limited to the researcher's observational notes and is not as detailed as for the other counsellors. Despite this, consultation V was included as it provides a comparative measure for counsellor Elsie, and because it contrasts quite markedly with the consultations of the other counsellors. Choosing to leave it out would have been an unethical decision as it shows the least impact from training.

Table 7.1 Post-training consultation characteristics summarized by case, language, participants, referral, title, date post-training, turns, word count and the ratio of counsellor: patient words

Case & Language	Participants	Referral & reason	Title/ Quote from transcript	Date Post-training	Turns	Word count	Ratio of words Counsellor:	Ratio of words Patient
Case G, isiXhosa	Counsellor (Nokuzola) & Mother	Doctor-referred child starting ARVs	<i>P: "I would like to know if it is possible for a child to be HIV positive while the parent is negative?"</i>	1 week	214	2176	1724 (79%)	452 (21%)
Case H, isiXhosa	Counsellor (Nokuzola) & Mother	Doctor-referred, 2 nd pre-treatment consultation; Mother learning about ARVs	<i>C: "So the most important thing is that you and I should work together with the doctor to fight for the child's health"</i>	1 month	126	1753	1238 (71%)	515 (29%)
Case I, IsiXhosa	Counsellor (Nokuzola) & Aunt	Doctor-referred caregiver for adherence counselling	<i>C: "I would like to know you"</i>	3 months	259	2619	2218 (85%)	378 (15%)
Case J, isiXhosa	Counsellor (Nokuzola) & Mother	Counsellor-referred caregiver for follow up appointment after starting ARVs at previous consultation	<i>C: "You have told me everything and I am impressed with your work, Keep it up!"</i>	6 months	140	1159	644 (56%)	515 (44%)
			Average for Nokuzola		185	1927	73%	27%
Case N, IsiXhosa	Counsellor (Babalwa) & Grandmother	Probably patient-referred, second counselling appointment re adherence.	<i>P: "I want to know [about ARVs] because most of the time, our children are left with us [grandmother]"</i>	1 month	275	4281	3064 (72%)	1217 (28%)
Case O, IsiXhosa	Counsellor (Babalwa) & Mother	Either counsellor or patient-referred for counselling towards disclosure	<i>C: "The virus is very smart and it can spread. For example, a goat can easily escape if it sees an opening in its stall. Just like the goat, a virus is an opportunist and it multiplies faster."</i>	6 months	185	1819	1203 (66%)	616 (34%)
			Average for Babalwa		230	3050	69%	31%
Case S, English	Counsellor (Lindiwe) & Mother	Doctor-referred for adherence follow up after recently starting treatment	<i>P: "The only problem that I have is when I discuss my future with my kids"</i>	1 week	67	1259	1016 (81%)	243 (19%)
Case T, IsiXhosa	Counsellor (Lindiwe) & Mother	Patient self-referral for psychosocial support following traumatic life event	<i>P: "If I had money, I would go to the traditional healer."</i>	3 months	112	1250	432 (35%)	818 (65%)
Case U, IsiXhosa	Counsellor (Lindiwe) & Mother	Doctor-referral for adherence counselling; transferring child to the 2 nd line regimen.	<i>P: "I'm cursed these days. I don't think white people can cure curses"</i>	6 months	340	4873	1903 (39%)	2970 (61%)
			Average for counsellor 6		173	2460	52%	48%
Case V, English/ Afrikaans	Counsellor (Elsie) & Mother	Patient referred for follow up by doctor after child has started ARVs	Not video-recorded, so qualitative comments only	6 months	NA	NA	NA	NA
			Average across all counsellors		196	2473	65%	35%

In comparing the consultation length, number of turns, number of words, and ratio of words pre- and post-training, it was evident that the training appeared not to impact on these general consultation characteristics. Comparison between pre- and post- training consultations for

other aspects (such as number of questions asked) is possible because of their relative similarity in duration. A slight increase in the amount spoken by the counsellor relative to the patient, was noticeable across all of the post-training interactions. A comparison of the before and after training consultation length is summarized in Appendix X.

There was no change post-training in the terms of address used between the caregivers and the counsellors, with ‘Sisi’ or ‘Mama’ used. Counsellors did, however, use fuller introductions post-training, and so there were more references to counsellor and caregiver origins, and recognition of being ‘homies’ if they came from the same area (both Nokuzola and Babalwa [H, I, N, O]). Nokuzola, Babalwa and Lindiwe all used the child’s name at some point in the post-training consultations, which shows evidence of checking this in the folder beforehand, suggesting a more personalized approach to the counselling [I, J, U].

There was no change in the code-switching pattern pre- and post- training, confirming that this is determined by language style and interactional dynamics and not a product of training. However, Nokuzola and Babalwa encouraged the caregivers more in the post-consultations, and so in addition to many of the same words being code-switched as in the pre-training consultations, a number of English phrases were used as praise and encouragement such as *‘I’m impressed’ ‘That’s good’ ‘Wow!’*.

7.2 CHANGES IN COMMUNICATION AFTER TRAINING

All of the transcript analysts independently identified the ‘post’-training consultations when asked to do so. This contrasted with the pre-consultations, some of which were initially considered by the raters to be ‘post’-training. In rater team discussions after all of the consultations had been analysed, it was clearer for the transcript analysts which consultations were post-training. Table 7.2 lists the communication features identified by the analysis team as having changed post-training.

Table 7.2 Communication features that changed post-training

Inclusion of more detailed introductions
Open questioning and frequent verification
Increased instances of checking patient understanding and more effective methods of doing so
Increased patient topic initiation
Greater explanation of medical jargon
Greater encouragement of patients
Inclusion of demonstrations with explanations

7.2.1 Introductions

After training, the counsellors gave more detailed introductions, outlining their name, role and the aim of counselling [G9]. In those consultations in which an introduction was perhaps less necessary (e.g. consultation H, a follow-up consultation), the counsellor acknowledged this and then outlined the purpose of the consultation [H5], namely to continue discussing treatment in preparation for starting on ARVs. In response to Babalwa's more detailed introduction of herself, her role and where she originated from [N8], the caregivers gave more details about themselves. The post-training consultations thus contrasted with the pre-training consultations in that introductions from *both* the counsellors and the caregivers were fuller.

7.2.2 Questioning

The pattern of questioning was one of the most marked changes in the communication after training as illustrated in Appendix XI. Although counsellors still asked many more questions than the caregivers did, in the consultations recorded after training, caregivers initiated more questions than in the pre-training sessions. The following changes were evident in the counsellor questioning post-training:

- An increase in the number of questions asked by counsellors
- An increase in the number of questions asked by counsellors to check understanding
- A change in the way in which questions to check understanding were asked; More open-ended questions were used instead of just asking '*Do you understand?*'
- An increase in the number of questions asked about caregiver feelings for Nokuzola and Lindiwe

In the post-training consultations, the counsellors asked more open-ended questions. These questions enabled caregivers to lead discussions and to introduce topics that were important to them. An example of a typical open-ended question was when Babalwa asked the patient's reason for attending and in doing so left the consultation agenda up to the patient [O9; N19].

Lindiwe used an open question at the start of all of her consultations and this enabled the patients to take the lead [S16, T1, U1]. The open question used at the start of consultation T, resulted in the patient producing a narrative of a recent traumatic life event, a burglary, which had prompted the caregiver to seek psychosocial and financial support from the clinic. The caregiver had heard from other mothers in the support group that the clinic might be able to offer her financial support through their 'emergency fund' in such cases. The counsellor acted

as a gatekeeper allowing patients to access this fund by referring patients on to the social worker. Patient T stated that from talking about what happened to her, she was able to unburden herself [T84].

In the post-training consultations, counsellors more frequently invited caregivers to ask questions. In consultation U, after being asked whether or not she had questions, the caregiver did initiate a question, *‘Why is it that when they change you like you had a great body structure and the next thing you know you have muscles in the wrong places?’* [U184].

Being invited to ask a question was one of the ways in which caregivers were prompted to ask questions. Other factors which led to caregivers asking questions:

- Caregivers also initiated questions after being praised for doing a good job and after encouragement from their counsellor [N]
- Patients ask questions in silences rather than in responses [S]
- Patients initiated questions during note-taking [S]

Post-training, counsellor questioning was more strategic and very specific in order to check patient understanding [O80; N31]. When the patient did not know something, then the counsellors explored this further [O92]. Lindiwe used specific questioning to find out how the treatment was affecting the patient and the impact of its side-effects [S16], and to check patient understanding [S20].

7.2.3 Checking patient understanding

After training, all of the counsellors frequently checked patient understanding in a number of different ways. In addition to asking *‘Do you understand’* as had been done in the pre-training consultations, counsellors asked patients *what* they understood. They were able to establish patient level of understanding by asking patients:

- To name their medications
- To identify their medication from a selection of ARV pill bottles and pictures
- To demonstrate how to measure the dosages
- To explain their understanding of particular concepts to them
- To rationalize why they needed to adhere to the medication

Unprompted, two of the counsellors adapted the questions used by the researcher to measure patient understanding (See Chapter 5). These were used as a checklist to establish understanding of key information and prompted counsellors to re-explain some information [U163].

In Table 7.3, the various methods of checking patient understanding are broken down into asking if the patient understands, closed questions, open-ended questions, and asking for demonstrations. These have been arranged in ascending order in terms of the degree to which they require patients to demonstrate their understanding, with a closed question (do you understand?) being the simplest and the least reliable method of gauging whether or not the patient understands, and the demonstrations being the most taxing and the strongest indicator of the degree of understanding.

Table 7.3 Incidence of counsellors checking understanding by asking do you understand, closed questions, open-ended questions or inviting demonstrations

Counsellor		NOKUZOLA				ELSIE		BABALWA		LINDIWE	
Method of checking understanding		G	H	I	J	V	N	O	S	T	U
1	(do) you understand?	16	14	19	0	Not counted	9	1	2	4	7
2	Closed set questions: What is the name of / what time do you take it	2	8	23	20	Not counted	30	19	1	0	9
3	Open-ended, asking for an explanation eg How do you... / what are you going to do... / interpretation	3	0	0	9	Not counted	20	7	4	0	18
4	Show me ...(inviting demonstration)	1	0	0	0	Not counted	6	0	0	0	0

In consultations [I] and [J] for example, Nokuzola established patient understanding by asking open questions about the medication. Caregivers responded by demonstrating their own knowledge. Nokuzola asked the patient to state the names of the medicines, dosing and timing, as well as the impact of the side-effects. When one of the caregivers in her counselling session did not know the names of her medication, Babalwa showed the caregiver a selection of medicine bottles and asked the caregiver to point to which ones she thought the child was using. When the caregiver did this, Babalwa praised her and the caregiver repeated the names that the counsellor had used for them. Babalwa went further, explaining that the name on the bottle was not always the name that the clinic used, and she used a thick koki pen to write the common name of the medicine onto the bottle for the caregiver to help her. Caregiver confusion about medicine names supports the proposed additional treatment complexities in paediatric ART proposed in Table 2.2 in Chapter 2.

7.2.4 Topic initiation

By examining which topics were initiated by the counsellor or caregiver post-training, there was evidence that counsellors remained more likely to initiate topics into the discussion than caregivers. When caregivers did initiate topics, it usually followed an open-question from the counsellor and was centered around their primary concern. For example, in consultation N, the caregiver introduced the topics of adherence, medication, role of the grandparent and the timing of medication – all of which were related to her primary concern of not understanding her grandchild's treatment regimen which she needed to administer.

Regardless of the reason for the counselling session, after training all of the counsellors covered the basic issues of medication, ARVs and adherence within the session. In cases in which this was not linked to the patient's primary concern (e.g. disclosing to her sister in Consultation O), this served as a 'recap' or checklist at the end of the consultation. This had its advantages and disadvantages. By routinely checking patient understanding in this way, counsellors were able to identify issues that caregivers did not understand. However, if not explained properly to the caregiver, the transcript analysts felt that the checklist disrupted the flow of conversation between the counsellor and the caregiver, particularly if the counsellor did not explain what she was doing and why.

All of the caregivers initiated topics in the post-training consultations. In the pre-training consultations in comparison, only 4 of the patients had not initiated any topics at all. However, far fewer topics were introduced by caregivers in the pre-training consultations. The increase in number of patient-initiated topics appeared to be due to patients responding to counsellors asking open-ended questions. Topics that were patient-initiated (PI) or counselor-initiated (CI) are listed in Appendix XII.

7.2.5 Use of medical jargon

Counsellors continued to use medical jargon in the post-training consultations. As with the pre-training consultations, regardless of the language of the consultation, this jargon was expressed in English. It is likely that the lack of isiXhosa equivalents for some words, combined with the general understanding of some English medical terms because they are so often used, contributed to the frequent use of medical jargon. In both the pre- and post-training consultations, medical jargon was used by patients and counsellors, but was far more frequently used by counsellors. In the post-training consultations, counsellors were more likely to *explain* the terminology when it was used. This was not done at all in the pre-training consultations.

For example, in consultation I, Nokuzola explained what she meant by triple therapy:

C: *It is called triple therapy, you are a school child mos you know when I talk about triple I talk about three ne? ...*

P Mm, ya...

C: *These medicines are called triple therapy that means he has to eat three of them*

Appendix XIII lists the medical terminology used by the counsellors and whether or not it was explained.

In the post-training consultations, counsellors deciphered some of the medical jargon for patients, explaining what the common names were. For example, in explaining terminology when moving on to the second line of treatment, Lindiwe explained that ‘*Abacavir is what we call ABC*’ [U9].

The clinic counsellors and other first language isiXhosa staff were consulted to determine whether or not there were isiXhosa equivalents for the code-switched jargon words. Staff commented that many of the words do have an isiXhosa equivalent (e.g. isifuba for Asthma), whereas others may have one but it is not known to them (e.g. Antibiotics).

Even within the English consultations [S,V], medical jargon was used and was sometimes explained. Lindiwe for example explained that confidentiality means that “*irrespectively, it [your information] will be kept privately*” [S52].

7.2.6 Encouraging and praising patients

In all of the post-training consultations, the counsellors were judged by the raters to be warmer and more encouraging towards patients. In consultation G for example, Nokuzola praised and encouraged caregiver G for knowing the medication and the dosing [G187]. The analyst team felt that the increased warmth from the counsellors contributed to the sense that the post-training consultations were more supportive. Babalwa praised the caregiver for her correct identification of the medicines and the patient responded by discussing her feelings [O43]. Lindiwe encouraged the patient, praising her for her support of her children and her good adherence, mentioning that, ‘*the doctor is very pleased that you are taking your treatment regularly*’ [S48]. In response to this, the patient initiated a question.

Encouragement was also demonstrated through use of the caregivers’ first names and the choice of pronouns. The counsellor encouraged the caregiver to be strong [T66] and asked her “*Now what would you like **me** to do, sisi?*”. In consultation U, Lindiwe used the patient’s

name and a nickname [U161, U199] and demonstrated empathy by continually using phrases such as, “*I am listening*” [U42] and “*I hear you sister*” [U103].

7.2.7 Demonstrations

After training, the counsellors used demonstrations with pill bottles, showing the medicines, actually measuring the dosages [G], writing the names of the medicines in thick koki pen on the bottles for the patient and writing the dosing down too so it was clear [N]. Gesture was used to explain how the virus works [I]. Babalwa also showed the patient the clinic card and indicated where the relevant information was written. She also requested patient demonstrations of dosing to check understanding [N93; N135].

7.3 Rater perceptions of whether the patients’ needs were met

Interestingly, in the pre-training consultations, only Lindiwe, the most experienced counsellor, was considered by the analyst team to have met the needs of the caregivers. In the post-training consultations, it was felt that she did not meet the needs of her patients although the other counsellors appeared to. This may have been a product of the complexity of her post-training cases and is an important variable in considering the impact of the training programme (discussed in Chapter 8). The analyst team felt that even though she appeared to be the most competent and skilled of all of the counsellors, she did not to have the skills to deal with some of the complex issues raised in her post-training consultations (e.g. the dynamics of couple counselling; a patient wanting to stop ARVs; and consulting traditional healers). Case complexity is an important variable which the study design did not account for, as cases were selected on a walk-in basis. One of the unforeseen challenges with equipping counsellors to ask more patient-centered and open questions, was the increased likelihood that patients would raise complex issues that did not fall within the typical adherence counselling ‘script’. Counsellors may be ill-equipped to deal with these issues. Table 7.4 summarises the rater teams’ perceptions of whether or not patient needs were met after training.

Table 7.4 Analyst team perceptions of whether patients' needs were met after training

Counsellor	Case	Reason patient attended the counselling / needs the patient expresses	Analyst team perception of whether or not the patient's needs were met
Nokuzola	G	The caregiver wants clarity about HIV transmission and needed to learn the names of the medication.	The patient's needs were partially met. There was some lack of clarity about HIV transmission, but there were good explanations of medication and dosing.
Nokuzola	H	Patient needs to be prepared for starting ARVs.	Yes. The counsellor gave clear explanations about medication and clinic procedures.
Nokuzola	I	Patient referred for ARV education.	Yes. The information was tailored to the patient's level, and detailed but clear information supplied.
Nokuzola	J	Counsellor checks patient understanding of ARVs. No patient agenda apparent.	Yes. The caregiver has good understanding and counsellor praises her for that.
Babalwa	N	Grandmother wants to be able to recognize the medication, know the names and measure the dosages.	Yes. The counsellor explained all the medicines very carefully and checks the patient's understanding. The caregiver expresses her appreciation ' <i>Thank you for explaining, I am very happy you explained it to me</i> ' [N154].
Babalwa	O	The patient wanted assistance with disclosing to her sister. Through questioning, the counsellor discovered that the patient did not know her medication, CD4, viral load etc.	No. The counsellor did not help the patient with disclosure, and this was only partially explored. However, she did explain the treatment aspects well.
Lindiwe	S	The patient is concerned about the future of her children without her.	No. The counsellor does not delve deeper into this issue.
Lindiwe	T	The patient would like access to emergency funds provided by the clinic.	Yes. The counsellor refers her to the social worker.
Lindiwe	U	The patient is considering stopping ARVs.	Unclear. The counsellor allows the patient to talk and listens non-judgmentally to her.
Elsie	V	The patient does not express any concerns or needs but as it is a follow up consultation, checking of understanding is an implicit need.	No. Checking patient understanding and adherence is not done.

7.4 Counsellor-specific changes post-training

In addition to the general changes mentioned in the previous section, a number of individual changes were noted for each counsellor. These are described below and summarised in Table 7.8 at the end of this section.

7.4.1 Nokuzola

The training programme appeared to have impacted on Nokuzola's communication as it was more structured (clear introductions, endings and use of the checklist), personalized, empathic and more accessible (through clearer explanations with practical advice). Her discussion of meta communication issues and confidentiality displayed greater respect for the patients and an acknowledgement that they are an important partner in the treatment process.

All four of Nokuzola's post-training consultations differed in terms of level of patient understanding and sophistication. In consultation I for example, Nokuzola was able to tailor the information to the level of the schoolgirl who is the primary caregiver for her deceased sister's child. By referring to her school circumstances and encouraging the caregiver to relate the information to what she has learnt in biology at school, Nokuzola was attempting to make the information more applicable to the young caregiver. In all of her post-consultations, Nokuzola discussed the patient's lifeworld and applied adherence to that context.

Nokuzola made use of the research checklist as a counselling tool for checking patient understanding of key issues. She used this checklist towards the end of her consultations, and when caregivers did not understand concepts, she addressed these misconceptions. The communication analysts had mixed feelings as to whether or not this form detracted from or added to the consultations. It was effective in ensuring that key information was covered and misconceptions were sorted out [J], but on the other hand it did disrupt the flow of the consultation as it was not well integrated within the consultation [I].

Post-training, Nokuzola's consultations ended with a brief summary of what had been discussed, clear procedural instructions for what the caregiver needed to do next, and an invitation for the caregiver to ask questions [I]. At the end of one of her sessions, Nokuzola emphasized caregiver responsibility by including 'Homework' tasks for the caregiver [G193]. By labeling these tasks 'Homework' – she was acknowledging the complexity of the treatment regimen and that adherence is an ongoing learning process rather than a once-off event. Nokuzola appeared to be much more aware of the 'meta' communication issues – in her post-consultations she explained to patients *why* it was necessary to ask certain questions [G33-35]. She discussed confidentiality and the patient's freedom to raise any issues she would like to discuss. This did elicit the caregiver's concerns [G]. Nokuzola verbally empathised with the caregivers: '*I know it's not easy*', '*The names are difficult*' " [G199]. Nokuzola's post-training consultations were more collaborative and efficient and the analysts

felt that the patients and counsellor had matching agendas [J]. Furthermore, there was more discussion about misconceptions [G87].

Nokuzola provided more detailed explanations about the various medical aspects of ARV treatment in her post-training consultations. This included CD4 count, viral load, dosage and cells which she explained rather than just using jargon [G]. She also ‘tested’ the patient’s understanding of these concepts, asking her what she remembered from a previous counselling discussion, and trying to put the caregiver at ease by saying that they were ‘*not in an exam room*’ [H]. In addition Nokuzola gave the caregivers written instructions for reinforcement about follow up appointments [G191, H]. She recommended practical solutions to help caregivers to remember to take their medication e.g. use of phone reminders [I]. When explaining the concept of triple therapy, Nokuzola checked the patient’s prior knowledge and then started her explanation from the beginning to ensure that the patient could follow [I48]. She also used examples more frequently post-training [G9,11]. Table 7.5 provides examples from Nokuzola’s post-training consultations.

Table 7.5 Examples of transcript extracts for Nokuzola’s post-training communication

Caregiver feels free to raise questions about her own misconceptions [G87]

C: Akho mbuzo akukho nto ingenye ofuna ndiikucacisele yona mhlawumbi?
Is there anything else that you would like me to explain to you?

P: (Clears throat) Into endifun’ uyicacelwa iyenzeke into yokuba umntwana ke abe HIV kodwa wena mzali awunanto?
I would like to know if it is possible for a child to be HIV positive while the parent is negative?

Fuller introduction from the caregiver explaining her role [G9-11]

C: Alright ke, (*Mnqa*) NdinguNokuzola ne, Ndiphangela apha, ndiyikhansela apha, ndibonana noomama xa Bezoqal’ itreatment, ndibonane nabo naxa sebeqalisil’ itreatment, ndiqonde ukuba baqhuba njani zintoni iingxaki abanazo, uyaqonda, nokuba benza njani ke ngoku ingaba bayakwazi kakhle kakhle ukwenza lento efanelekileyo ngamayeza uyaqonda, Mhhm. Ndicela ukwazi wena. (**raise hand**)Yima sisi ndizakubiza ‘eva’ (**nods**) ndisebhizi ne (nods)

My name is Nokuzola, I work here, I am a counsellor, I see mothers when they start treatment, I also see them when they have already started treatment and find out how they cope with problems they come across with, do you understand? I also find out whether they really know how to do the right thing with medicine, do you understand? Mhhhm. I would like to know you.

7.4.2 Elsie

As Elsie’s post-training consultation was not video-recorded, the analysis of her communication was made on the basis of the researcher’s observational notes whilst sitting in the room. Although it was anticipated that the consultation would be in Afrikaans (the patient is Afrikaans-speaking and so that was why that specific counsellor had been requested by the

doctor), the consultation was in English. The caregiver and her child had both started on ARVs a few months previously. No side-effects from the medication were reported. The counsellor had good non-verbals – good posture, eye contact and attention towards the patient. She introduced herself and her role *‘I’m an adherence counsellor here at the clinic. This means I help you to understand about the medicine and things and when to take them’*. Elsie started off the consultation with an open question *‘So I want you to tell me how things are going’*. The caregiver’s English appear to be limited and the researcher noted that the counsellor did not give her the choice of speaking in English or Afrikaans. The caregiver was able to name her medication and knew the dosing and timing of the medicines. She had brought the tablets with her and when the counsellor asked if she had any questions, she shook her head.

The most marked difference between this consultation and the previous one recorded for Elsie, was Elsie’s non-verbal behaviour. Instead of slouching in her chair with her eyes closed at times, she appeared to be much more aware of her body positioning; sitting upright, leaning towards the caregiver and maintaining good eye contact. The whole consultation was more energy-filled. Whether the improvement in the counsellor’s non-verbal skills was a result of the researcher’s presence in the room, her energy on that specific day or the training, was unclear. Certainly, she used gesture and asked for the patient’s medication and then checked her understanding of the medication which she had not previously done. However, the lack of change in other aspects (e.g. by discussing lifeworld issues, giving the patient the choice of which language to conduct the consultation in, a summary at the end or explanation of procedures, discussion of deeper issues such as disclosure) suggested that for the most part, the training had had little impact.

7.4.3 Babalwa

Babalwa’s post-training consultations appeared to be characterized by being more personal and practical with clearer explanations. She used props and demonstrations in both of her post-training consultations. Of all four counsellors, Babalwa’s communication was impacted on the most by the training. In consultations N and O, Babalwa counselled a grandmother [N] and a mother [O] about understanding the treatment regimen and disclosure respectively. In comparison to Babalwa’s pre-training consultations, these consultations were slightly shorter, and Babalwa spoke relatively more (69%) in the post- than in the pre-training consultations (48%). The reason for this appeared to be her more detailed and thorough explanations, and more frequent checking of the patient’s understanding.

Babalwa's communication changed in a number of ways after training. Very early on in the consultation, Babalwa created an environment within which the patient could voice her own concerns [N]. She gave clearer explanations of dosing, CD4 count and viral load and the explanation of the terminology used [O12; O125; N119]. In addition, Babalwa deciphered abbreviations for the patients [N119]. Explanations were done in a way that was clear and practical. The caregiver provided back channel responses 'OK' and by repeating the names of the drugs and dosages to show that she was following what the counsellor is saying. Babalwa repeated information and instructions several times and analogies were used to help in explaining concepts [O102]. To help patients to remember the dosing, Babalwa 'personified' the medication by ascribing human qualities and using associations [N115]. Babalwa used the pronoun 'We' to show her solidarity with the patient – that she is not alone and that they are in this together [N119]. In her post-training consultations, there were many more personalized moments and Babalwa appeared totally engaged in the interaction. Practical advice was offered from Babalwa's own experience [N125] and she guided the patient through procedures such as the function of the clinic card and contingency planning. Examples from Babalwa's post-training transcripts are presented in Table 7.6.

Table 7.6 Examples of transcript extracts from Babalwa's post-training communication

Clearer explanations of terminology [O12, 125]

- C: Apha ne? Kufuneka uyazi i-CD 4 count yakho. Kubalulekile ukuba uyazi, ngokuba kalokhu i-CD 4 count yakho ngamajoni akho omzimba, uyaqonda. So kongoku xa isezansi, it means kufuneka ngabe uyaqala izi-ARVs. Oqgirha bazokujonga bakuxelele ukuba kufuneka ukuba uyaqala i-ARVs. Then uma ingaphezulu kwa-200 noko awukazi ukuqala izi-ARVs usasemandleni. Izi-ARVs uziqala xa i-CD 4 count yakho yehle esho ukuba amajoni akho ehlile. Xa ingaphansi kwe-200 i-CD 4 count yehlile, xa ingaphezulu kwe-200 kusho ukuthi awukezi ukuqala izi-ARVs. So kubalulekile nyani ukuba uyazi.

You need to know your CD 4 count. It is very important to know it because those are your white blood cells. So if your CD 4 count is low, it means you need to start taking ARVs. Doctor will assess you and tell you if you need to start taking ARVs. But if your CD 4 count is above 200 you don't need to take ARVs. Your CD 4 count represents your immune system strength. So it is very important to know it.

Practical advice based on her own experience [N125]

- C: Ungasebenzisi kwesi isarenji uyazi ke napha epharmacy xa unikwa amayeza akunikwa ezi zikhulu zonke unikwa ezikhulu ziyaxutywa ukwenzel' uba ezi mils uzifunayo ukwazi ukuzifumana ngokwesarenji sakho ukwenzela yenzela lula into yoba ngaba ukwazi ukuzifumana nokwesarenji sakho.

Do not use this syringe (showing to patient) even at the pharmacy you don't get only big syringes they mix them with the small ones so that you can get all the mls you want according to your syringe.

- P: Mm. Yes.

- C: Yima ke ndiyicime le bendiyenzile uphinde undikopisele undibonise ukuba uzakwazi na ena xa usendlini. Let me remove the one I did so you can show me again if you'll be able to do it when you get home.

7.4.4 Lindiwe

Lindiwe's post-training communication changed in that she showed more solidarity with the caregivers through her use of 'We'. She discussed meta-communication issues showing an awareness of her own communication, and she explored patient motivating factors. In all of her consultations pre- and post-training, Lindiwe was non-judgmental and allowed the caregivers to speak freely and uninterrupted.

Lindiwe's post-training consultations consisted of one English adherence counselling session with a Mozambiquan caregiver S who had recently started ART, and two isiXhosa consultations, one with caregiver T who had recently been robbed and was seeking psychosocial support and financial assistance from the clinic, and the other with caregiver U whose child was being moved from the first to the second regimen.

Consultations T and U were particularly interesting because both caregivers discussed their belief system and expressed a desire to consult a traditional healer. Caregiver U's scepticism about the efficacy of ARVs *"I don't think that white people can cure curses"* [U308], her belief that the doctors did not offer her the choice not to take the ARVs, *"But why are we forced to take them?"* and her dismay at the impact of the side-effects on her body *"Better to die than to lose the shape of your body"*, were particularly challenging for Lindiwe. As in all of her sessions, Lindiwe's non-judgmental and careful exploration of all of these issues in consultation U through sensitive questioning, successfully elicited much about the caregiver's explanatory model and motivating factors in her non-adherence. Lindiwe expressed her empathy towards caregivers through her posture (sitting upright and very still, leaning forward towards the caregivers and maintaining eye contact), open-questions, strategic silences, pausing and tactful questioning, and it was these skills which she already had, that led caregivers to open up to her and speak freely. The raters felt that as with her pre-training consultations, everything about Lindiwe's manner facilitated confidence and the patient's attention.

After training, Lindiwe's communication had not changed as much as Nokuzola and Babalwa's did. The most noticeable changes in her sessions were the increased use of open-ended questions, greater encouragement of the caregiver, more thorough explanations, increased checking of patient understanding and the use of multiple modalities (through drawing, demonstrations and showing of props) to explain how the virus works.

In consultation U, the caregiver expressed her mistrust of a health care system in which doctors do not take the time to explain things to patients, *"what kind of a doctor is always in a*

hurry” [U273]. In this consultation, the initial difficulties in the early stages of the medicine rollout were raised [U210-225]. In particular, the absence of counsellors resulting in patients not understanding the doctors (because of language barriers) or the treatment options available to them (as these were not explained in their home language) was mentioned. Through the caregiver’s voice, we glimpse a system in which strange medications with terrible side effects are dished out by doctors who had no time or ability to explain what was going on to a naïve and largely ignorant public with a contrasting perception of wellness and disease. Viewed through this caregiver’s eyes, it is no wonder that many patients were suspicious and non-compliant. The issue of a doctor-patient divide created in part by communication barriers, is commented on by caregiver U: *“And all of a sudden he [doctor] said he was going to change me... He did not explain... I don’t know whether it is because I don’t understand English”* [U235-239]. This reinforces the need for counsellors to act as interpreters, but ironically, their presence may also be a contributing factor to increasing this doctor patient divide; instead of using counsellors to work alongside them, the doctors appear to consult and make do with communicating with the patient and then to refer them to the counsellor to fill in any bits that weren’t understood.

Lindiwe modified the pace at which she spoke when explaining things to patients (e.g. First and second line treatment in consultation U, or when there is a language barrier such as in consultations S), using increased pausing and shorter utterances. In her post-training consultations, Lindiwe explored which factors motivated caregivers. When Lindiwe checked the patient’s understanding, and the caregiver replies commenting on her motivation for why it is important that she understand *“Yes, because I am the one who looks after my children. I’m the one who must know, Sisi”* [S67].

Lindiwe tried to motivate the caregiver by referring to the future of her child. As the mother clearly held strong beliefs about the importance of traditional medicine, the counsellor referred to the traditional practice of circumcision in an effort to try to make the mother dream about her child’s future [U173]. Lindiwe also strengthened this appeal using the pronoun ‘we’ to show her solidarity with the mother, and makes reference to another child in the clinic who is older and is thriving on ARVS: *‘if you keep the time his virus load will decrease. And then we will be happy... We want this baby to grow and be a man, send him to circumcision school. Even when we are old we want to go to the celebration. Give him the treatment. Do you see kids like Nokuthula?’*

Lindiwe used ‘we’ on many occasions in consultation U e.g. *‘I like it when the virus is undetectable. And if we work together, that is possible. Is there a question you would like to*

ask me?” [U183]. Lindiwe personalised her advice ‘*this is up to you*’ and drew on the caregiver’s knowledge of a shared acquaintance at the clinic [U175] whose compliance has led to positive long term health for her child. The raters felt that this made her advice more ‘*personal, tangible and effective*’ (Rater 2).

As Nokuzola had done, Lindiwe also narrated why she was doing particular actions in her interactions. In consultation S for example, she explained *why* she was writing in the folder, thereby deconstructing the ‘myth’ around the folder. On another occasion, Lindiwe acknowledged that her own communication about a particular issue had been poor and she expressed her concern about this and the need to explain it again for the patient’s benefit [U23]: ‘*Niki, it’s up to you. You should give the baby his medication. I know I’m confusing you and I’m worried.*’ Examples of Lindiwe’s post-training communication are presented in Table 7.7.

Table 7.7 Examples of extracts from Lindiwe’s post-training communication

Explains who different personnel in the clinic are when outlining clinic procedures [S56]	
C:	They didn’t write your weight. (pause) but now your weight is 86.5. So I’m sure next time when you come for your appointment and we’ll watch it from there. They’ve got to do it there by Sylvia.
P:	Who is Sylvia?
C:	The lady who is taking everything for this (motions to folder notes then motions behind her). I’ll show you.
Caregivers not understanding doctor explanations provides motivation for interpreters [U235-239]	
P:	andayazi man ndava lagqirha seyesithi uza kunditshintsha <i>And all of a sudden the doctor said he was going to change me.</i>
C:	akakucacisela? <i>Did he explain?</i>
P:	akazange andicacisele ukuba ngoku uza kunditshintsha <i>He did not explain the change</i>
C:	akakucaciselanga <i>He did not explain</i>
P:	akazange andicacisele ukuba ngoku iCD4 count andazi noba kungasiva isiliungu. Akazange athi iCD4 count yakho ihlile virus inyukile. Wathi unditshintshile kulamayeza kufuneke ndizothatha into ethile nethile echemist. Ndathi ke mna ke okay ndavuma. Nyhani echemest ndinikwa iKaletra ne DTI ndanikwa iD4T. ndatya ndatya ndatya, ndaziva uba yhey yanyuka iCD4 count yaphela ingculaza ndazibukela ndindim ndandikwazi mna ukumnxiba ushorty ongaka (showing that she used to wear very short pants) <i>He did not say anything about my CD4 count I don’t know whether it is because I don’t understand English. He did not say that my CD4 count is low and my virus is high. He just said told me he was changing to a different medication and I should get them from the chemist. I agreed and the chemist gave Kaletra and DTI and D4T, I took them and my CD4 count increased and the virus disappeared and I could feel my old self back and I could wear short pants.</i>

Table 7.8 summarises the counsellor-specific changes after training as described above.

Table 7.8 Summary of counsellor-specific changes post-training

Nokuzola	Elsie	Babalwa	Lindiwe
More personalised communication	More eye contact with the caregiver	Exploration of caregiver feelings	Advocacy for patient rights
Checklist at end of sessions to check understanding	Increased energy level	Personification of the medicines for emphasis	Exploration of patient motivating factors
Fuller endings with better closure	Increased use of gesture	Solidarity expressed through use of the pronoun 'We'	Tailoring communication to individual patient needs
Discussion of meta-communication issues			Solidarity expressed through use of the pronoun 'We'
Creating a 'Safe-space'			Discussion of meta-communication issues
Increased expression of empathy			Increased expression of empathy
Rumours and misconceptions discussed			
Clearer explanations with practical advice			

7.5 WHAT DIDN'T CHANGE?

From the counsellor-specific results, it is evident that changes in counsellor communication varied considerably. This is a product of the training being tailored to each counsellor's individual needs through specific feedback based on their pre-training video recordings rather than a 'one size fits all' approach. Although many changes in communication were evident post-training for all of the counsellors, a number of barriers to effective communicating were not overcome. These also varied from counsellor to counsellor and are summarized in Table 7.9. 'Yes' indicates that this barrier was evident in a specific counsellor's consultations

Table 7.9 Barriers to communication that did not change for each counsellor after training

	Nokuzola	Elsie	Babalwa	Lindiwe
Too much information provided	Yes			
Mitigation of taboo topics		Yes	Yes	Yes
Discussion of disclosure			Yes	
Ambiguity in not 'naming' HIV			Yes	
Appeal to higher authorities / religion			Yes	Yes
Jargon				Yes

In the sub-sections that follow, the impact of training on particular themes that resonated throughout the consultations is discussed. The communication barriers mentioned in Table 7.9 are addressed in the discussion that follows.

7.5.1 Communication about treatment literacy

A large proportion of both the pre- and post-training cases involved discussions aimed at improving treatment literacy. This discussion focuses on treatment literacy as it applies to improving patient knowledge about the medical aspects of HIV, ARVs, adherence and treatment failure. Psychosocial aspects are discussed in section 7.5.2.

Chapter 2 summarises the large amount of content information that counsellors need to cover to achieve patient literacy. Counsellor treatment literacy was not formally measured in this study as this may have been construed by counsellors as testing them or measuring their level of understanding which would have been counterproductive to developing a rapport between the researcher, facilitators and counsellors. However, by examining the counsellor explanations to patients and the content of their interactions with the facilitator (in the individual training) and with the researcher (in the semi-structured interviews), counsellor baseline knowledge appeared to have been both accurate and extensive across topics.

Treatment literacy is dependent on the counsellor being able to effectively explain concepts so that they are understandable to the patient. There was a marked difference in the counsellors' explanations pre- and post- training. This was evident from changes in the use of medical jargon and the inclusion of demonstrations (drawing, use of props).

The use of jargon within any specialist context, is difficult to avoid. Prior to training, the counsellors had stated that they knew what jargon was. After training, they expressed that learning about the extent of what could be regarded as jargon and what could be misunderstood by patients, had been new information for them. In the group training, presenting the clinic data of jargon their own patients did not understand, proved to be a powerful experience for the multidisciplinary team. Counsellors and other members of the multidisciplinary team reported being surprised by patients not understanding concepts that they had not considered to be jargon or which they had assumed were generally understood by patients on treatment (e.g. CD4 count). To some extent, counsellor use of jargon reflects the institutionalizing of counsellors within the clinic. The use of jargon with patients could be viewed as the counsellors asserting their position as professionals with authority within the clinic, or could just be habitual from use in interactions with other staff members. Both the

trained and the untrained counsellors frequently used jargon. This suggests that the use of jargon is not a product of training, but rather of immersion within the clinic.

In addition to expressing a greater awareness of the jargon they were using, counsellors also became more aware of their code-switching from isiXhosa to English. Results suggest the need for a general awareness, among all health professionals, that many commonly used terms are poorly understood by patients and appear to be difficult to explain. Taking the time as a clinic team to practice explaining these terms without using other jargon, is recommended. Table 7.10 lists commonly used terms in adherence counselling that are difficult to explain.

Table 7.10 Commonly used terms in adherence counselling that require explanation and are difficult to explain

- | |
|--|
| <ul style="list-style-type: none"> • CD4 count • Viral load • First line treatment • Second line treatment • Any terms with an abbreviation: (MDR TB, CD4) • Percentage calculations to do with dosing |
|--|

After training, counsellors used demonstrations when giving instructions to patients. All of the trained counsellors had been exposed to demonstrations in their prior training and had found these to be valuable in helping them to understand. Despite this, the routine use of demonstrations had not been assimilated into their own interactions with patients. In the newly developed 5-day paediatric ARV training course at ATICC, counsellors are trained to conduct demonstrations with patients. Findings from this research support the inclusion of this element in counsellor training for a number of reasons. Firstly, giving instructions in a logical order about measuring and dosing proved to be a challenge for counsellors and was not always well done. By combining instruction-giving with a demonstration, the sequence of instructions was more logically ordered. Secondly, the use of demonstrations energized the interactions, breaking the tedium from what can otherwise be a didactic educational session. Making mistakes whilst doing a demonstration is not to be feared, as this led to shared moments that were light-hearted, an opportunity for humour and gave recognition of the difficulty of the mother's task. Appendix XIV illustrates counsellor demonstrations.

One difficulty with demonstrations is that they require the following:

- Access to equipment (which was often found to be lacking).
- Organisation and forward-planning: Equipment needs to be stored somewhere and stocks need to be replenished when running low.
- Dexterity: This is a problem with older counsellors who may struggle with fine motor tasks as well as require glasses for reading print on syringes and bottles (but this is also the case for mothers and grandmothers so provides an opportunity for discussion about these issues too).
- Practice: The HIV positive counsellors who were caregivers themselves, performed much better at the demonstrations than the other counsellors who were not.

Within the clinic, counsellors reported that there were no condoms or dildos for demonstrations, and that sharing rooms and having no base to store equipment made demonstrations challenging. Counsellors welcomed the idea of a ‘goodie-bag’ hanging from a hook on the back of all doors, in which a basic demonstration kit for paediatric adherence could hang.

Counsellors took time to become familiar with the adherence materials and to engage with them through highlighting/ making notes on them. When adopted, this strategy appeared to be particularly helpful. Any toolkit for counselling should include a thick koki pen so that counsellors can write the common names of medications on the pill bottles so that they correspond with leaflets and other materials used within the clinic.

It is necessary to caution that not all change is good. In consultation S, in trying to emphasise the importance of timing in adherence, Lindiwe tried to explain the lifecycle of HIV through drawing and metaphor. What resulted was a confusing account about ‘*soldiers who prevent HIV from making copies in our body*’. Her explanation contained too much jargon and her metaphors could be ambiguous to someone with little understanding of HIV. Furthermore, her sketch faced herself and not the patient, so it was not a tool for aiding understanding.

Treatment literacy is also dependent on the counsellor being able to establish the patient’s level of understanding, his/her explanatory model and checking the patient’s understanding. The results from counselling post-training indicated that open questions were useful to establish patient explanatory models and level of comprehension. However, it is not just open questions that are useful in establishing patient understanding; close-ended questions

targeting strategic information are also effective in establishing patient understanding. The results suggest that there needs to be an explanation of the thought process behind questioning patients about their understanding, otherwise questioning can appear to be judgmental and intrusive. As a general rule, the patients understood less than the counsellors expected them to as reflected on by counsellors. Many of the caregivers of children on antiretrovirals had poor understanding of what the doctors at the study site had considered to be the ‘bare minimum’ amount of information that each patient should know prior to commencing treatment. In order to prevent caregivers from feeling that they are being ‘tested’ by counsellors and to avoid this intruding on the development of good rapport with counsellors, it might be better for a third party to check patient comprehension. If this task is taken on by a counsellor, then a separate counsellor or another team member should provide psychosocial support. Roles could be rotated or tasks between ‘treatment literacy’ and ‘counselling’ could be split. This would fit well with the recommendations for more specialized roles for CHWs from the task-shifting literature reviewed in Chapter 2. An effective strategy circumventing the counsellors being viewed as examiners, was for the counsellors to comment on the ‘meta’ and communication process.

The improvement in counsellor explanations resulted in the analyst team commenting that patient information-needs were more likely to be met after communication skills training. Post-training, there was an increase in the amount of treatment literacy – and at some point in each of the post-training consultations, patient understanding was addressed. There are, however, constraints in focusing solely on information giving to patients and patient understanding. Certainly the counsellor-as-educator role has been criticized within the literature, particularly in studies examining interventions such as brief motivational interviewing. Undoubtedly, ‘*throwing information at a patient*’ (as described by one of the counsellors) is not helpful and will not lead to behavioural change. The limitations in the role of counsellor-as-educator (no matter how skillfully the information is communicated) are apparent in consultation U as described in Table 7.11.

Table 7.11 Researcher reflections on Consultation U: Is understanding enough?**(Is it even the issue?)**

In consultation U, the counsellor used strategic questioning to establish what the mother knows. In response to the counsellor's requests that she names her medications and explains the timing [U24] she can name all her medicines and those of her child, and knows the dosing and timing as well as what CD4 count is and viral load and the importance of timing. It is apparent that the mother knows and understands everything she needs to to adhere to the treatment. But this is not enough. The counsellor acknowledges '*Caregiver U, we always fight about the treatment, and you say that you want to stop giving the baby the treatment because he has worms*' and the caregiver's misgivings about Western medicine and her desire to consult a traditional healer instead, are unleashed. The caregiver states that the sweet taste of the Nevirapine causes worms and the traditional practice of using salt water to induce vomiting is needed to stop this. She explains to the counsellor that she believes in this traditional method because it was how she was brought up. Caregiver U doubts that ARVs will work on her or her baby; the reason given is that their effectiveness will be diminished because she doesn't have enough faith in them. Counsellor Lindiwe explores the reasons why the caregiver wants to consult a traditional healer using open questions in a non-judgmental manner [U63]. She also encourages the caregiver to research the traditional healer to make sure that he works alongside doctors and that he has a good understanding of HIV and how ARVs work. To this, the caregiver states that '*You know a black person, sister Lindiwe, when I ask him whether he works with doctors he is going to say yes even though he doesn't work with doctors because he wants money...*' [U72]

Through empathic listening and open-ended questions, the counsellor is able to elicit the patient's explanatory model. *But then what?* One is left feeling that all of the issues that have been raised by the caregiver are valid and are, in the context of her good understanding of treatment and her child being moved to the second line, definitely impacting on her motivation to adhere. All of this appears to be beyond the capabilities of the counsellor. As a last resort, she tries to force promises from the patient that she will try to adhere '*do you promise that when the baby starts treatment that you will give it to him... give the baby the medication my sister*', and that the patient needs to pray to God for assistance '*Do you know that there is someone who can help you better than the traditional healer? There is someone who can help. Do you know that?... When you believe and you don't have to pay even a cent. You don't have to spend money.*' When the patient asks '*Who is it?*' the counsellor responds that '*It's Jesus*'. The caregivers then responds '*My heart is not close to God yet. But I believe in God and when I ask for something he provides. He gives but I don't have the heart to go to church yet. I don't feel like going to church just because I need help when my heart says otherwise*' [U310-319].

Consultation U illustrates the frequently adopted pattern of counsellors reverting to discussing religion when at a loss with what to do. The extract above demonstrates an excellent rapport between counsellor and patient, evident in patient ability to be open about beliefs even when they contradict the 'Western' medical model. Patient encounters such as these were reported by the counsellors as being demoralising. After doing a good job in teaching the patients about HIV and treatment, and being patient-centered by establishing the patient's explanatory model through open-ended questioning, the counsellors resorted to pleading and encouraging

them to turn to God for support. Releasing counsellors from the burden of feeling responsible for effecting change (Mash et al., 2008) would be useful in such instances.

The role of the counsellor (Appendix III) in such instances is to communicate the patient's explanatory model to the multidisciplinary team. In the current study, this too presented challenges. Counsellors expressed that they did not feel supported within their multidisciplinary team and remained on the fringe of the system. This might be linked to their auxilliary status as described in Chapter 6 and supported by the background literature in Chapter 2, and reinforces the need for counsellors to become acknowledged members of the public sector.

An alternative option is for the counsellors to communicate this information via the patient's folder. However, ethnographic notes indicated that counsellors seldom report in patient folders, and when they do, lacked detail. Whether this is due to time constraints or to counsellor writing skills, needs further exploration. A lack of confidence in their report-writing ability, writing in their second language, and a lack of attention to this in their prior training, appears to warrant additional training in this area.

If one views the cultural mediating role of the counsellor as being bi-directional, one can surmise that this role is only partially filled by the counsellor; in the direction from the health care system to the patient, the counsellor is able to fulfil this role by translating information so that it is accessible to the patient. However, in the other direction, i.e. from the patient to the health care system, the counsellor's fringe status is a barrier to this mediating role, because cultural information shared with the counsellor is then not shared any further with medical colleagues.

There is a mismatch between health worker team expectations and counsellor perceptions in providing access to care. In the focus group with the doctors described in Chapter 6, they expressed that they wanted counsellors to comment on patient readiness to begin treatment, thereby acting in a gate-keeping role, preventing people who were not yet ready to be on treatment from accessing treatment. In contrast, the counsellors viewed themselves as a conduit promoting patient access to care. Given the high degree of LTFU, counsellors have limited opportunities to interact with patients. Counsellors gave anecdotal accounts of pressure placed on them by doctors and nurses to rapidly complete the stipulated three counselling sessions so that a child in need of treatment can start ARVs as soon as possible. This mirrors the finding by Rohleder and Swartz (2005) that counselling success is measured in terms of the number of patients tested, rather than the quality of counselling. Of concern,

this placed the counsellors in a position in which not giving the go-ahead to start treatment, meant that they were a barrier in patients accessing care. This is an unfair burden to place on any individual. In the counsellor interviews, they all reiterated that none of them had ever suggested that a patient was not ready to start treatment, even when the stipulated three sessions had not been completed. Some counsellors reported being asked to reduce the number of counselling sessions prior to starting treatment by some doctors (this was anecdotal and was not verified in any of the observations.) Poor lines of communication between counsellors and doctors was a barrier preventing counsellors from voicing concerns about this.

7.5.2 Communication about psychosocial and lifeworld issues

In all of the pre- and post- training consultations, complex human predicaments were discussed. The psychosocial issues discussed in this section are distinguished from the medical issues discussed within the treatment literacy section prior to this, although there is a great deal of overlap. Case U discussed in the last section, illustrates this overlap; the relatively ‘medical’ topic of treatment literacy for adherence involved a much broader discussion on psychosocial issues leading to non-adherence. In this section, the psychosocial issues of disclosure and stigma are discussed as well as the lifeworld realities of poverty, substance abuse, relationships and fidelity.

These themes have been grouped together in one section, as the impact of the communication training was felt to be similar across these themes. All of these issues were discussed by counsellors and patients in both the pre- and post- training consultations. Post-training, there was no increase in the breadth of topics discussed. However, the depth in which the counsellors explored these topics increased post-training. Despite lifeworld and psychosocial issues being discussed in more depth post-training, the comments from the analyst team indicated that communication about these issues was challenging and the training programme had limited impact on improving communication for these issues. This is explored in more detail within each of the topics below.

a. Disclosure

Disclosure was discussed in a number of cases [C, L, M, O]. Patients openly expressed a desire to disclose to their partner (or a family member) and asked counsellors to advise them on how to do this. In the pre-training consultations, counsellors did not explore patient reasons for wanting to disclose. In the post-training consultations, counsellors spent more

time asking patients about their feelings and the anticipated feelings of family members. The analyst team commented that counsellors appeared to delve into the issue in more depth in the post-training consultations. However, counsellors did not suggest practicing disclosing and did not explore the risks to patients of disclosing in either the pre- or post-training consultations. The patients tended to switch topic away from issues that they felt uncomfortable talking about and the counsellors did not try to readdress such issues or to comment on patient topic changes. In the extract from Case C in Table 7.12, when the counsellor tries to explore why the patient's boyfriend went for HIV testing, the patient laughs appearing to be uncomfortable about the questions, and the counsellor immediately asks another question rather than delving into the issue or waiting for the patient to answer the question. Later in the same extract, the patient laughs and switches topic to avoid discussing this issue any further.

Table 7.12 Transcript extracts illustrating how disclosure was discussed in consultation C which was recorded before training [C23]

P:	eyona nto bendifuna ukuyibuza ingxaki yami ndine-boyfriend iyandithanda futhi nam ndiyayithanda but kunzima ukuyixelela ukuba ndi-positive. And ayinanto yona iyazazi. Andiyazi ndingenza njani.
	<i>The reason why I wanted to see you my sister is, I have a boyfriend that loves me and I love him but it's hard to tell him that I'm HIV positive. My boyfriend is negative and he also knows that. So I don't know what to do.</i>
C:	Uzazelaphi yena, u-testile? <i>How does he know, did he get tested?</i>
P:	Ewe, wandibonisa neResults ebesanda ku-tester. Mna kunzima akatsho kum uba mando-tester. Akukho nto ayithethayo.
	<i>Yes, he showed me the results, he just got tested. It is difficult for me, he does not say that I should get tested.</i>
C:	kwakutheni aze ayo-tester? <i>Why did he get tested?</i>
P:	athini ke. <i>Come again?</i>
C:	kwakutheni aze ayo-tester? <i>Why did he get tested?</i>
	(Patient laughs uncomfortably and looks down)
C:	Nindibane nini? <i>So how long have you been together?</i>
P:	Ndisanda kudibana naye inoba uvele wazicinga nje. <i>We just met, maybe he just thought of doing it.</i>
C:	wazicingela. <i>He thought about it.</i>
P:	ewe, because esaStatus sesalenyanga iphelileyo. Ndisanda kudibana nayo inoba ndinenyanga eneveki.
	<i>Yes, the HIV results that he has shown me were done last month. We just met maybe we have 1 month and a week.</i>

Table 7.12 continued

C:	Niya-condomiser? <i>Do you use condoms?</i>
P:	Ewe siya-condomiser. <i>Yes we do condomise.</i>
C:	Okay, keep on ni-condomise ukwenzala into yokuba xa um-disclosela, aha aha aha abene anger yoba umsulele. Condomise then ufuna ukum-disclosela xanilapha ungeza naye apha or whatever. Xa nincokola nge-HIV uthini? <i>Okay, keep on using a condom so that when you are disclosing your status to him he won't have anger that you have infected him. If you want to disclose your status to him, you can come with him here. When you are talking about HIV what is it that he is saying?</i>
P:	hayi, Uvele athi sistudy eso akukho lo nto akukho nto iyiHIV (says the line laughing. uvele athethe izinto ezi-funny ezingabhadlanga wethu. Ingathi ngumntu ongahoyanga ndiqonde ukuba nam mandimyeke. Nam ndikhe nditry(e) ibengathi ndiyathetha but akahoyi, akabi serious manditsho ukuthetha ngayo. Vele athi hayi suka yinto engekho leyo. <i>He says it's a study. There is no HIV. He just makes jokes about it and I end up not being able to say anything about the topic. He just acts funny about HIV. But I try talking about it without much success. He just says there is nothing like HIV/AIDS in life.</i>
C:	Ebesiyo-testela ntoni kanti yinto engekho? <i>So why was he testing if he knows that HIV/AIDS does not exist?</i>
P:	Andimazi (laughing). Sisi [Counsellor's name] la-form ye-grant iphelelwa emva kwexesha elingakanani? Oh hayi inoba seyiphelelwe le ndandiyinikwe apha. <i>I don't know (laughing). Sister [Counsellor's name], when is the expiry date for the grant form? I think the one I got from here expired long ago.</i>

In both the pre- and post- training consultations, counsellors appeared to lack the skills needed to explore these issues in a meaningful way. Patients were allowed to topic shift without the counsellors commenting on this switch. In some of these cases, the analyst team felt that counsellors and patients were engaged in socially expected dialogues. For example, in case C, the discussion of condom use was considered to be superficial and unrealistic. Counsellors may well feel that there is no point in discussing such issues as patients are unlikely to change their behavior. The analyst team felt that it was positive that counsellors encouraged the patients to invite their family members to come to the clinic with them to learn more about HIV.

Caregivers and counsellors alike appeared to have been well-indoctrinated with the gold standard of 'needing to disclose' one's status. This is evident in the rapid turn-taking in [L521-526] when caregiver and counsellor advocate for disclosure as illustrated in Table 7.13. This is particularly interesting in light of the fact that they are both aware that the caregiver has not disclosed and does not appear to intend to do so.

Table 7.13 An extract from consultation L recorded after training demonstrating the ‘mantra’ of disclosure [L521]**The ‘mantra’ of disclosure**

(overlapping turns, rapidly spoken)

P: omchazeleyo *someone you told*

C: umntu oyaziyo lento *when someone knows*

P: ude ubecool *you feel cool*

C: Ubaright *You feel alright*

P: kufuneka uyichaze *You should tell them*

C: Uchaze ewe ewe (with emphasis) *You should tell, yes, yes*

In case M described below, no practical steps were discussed in terms of how to disclose and no role play for disclosure was practiced. Nonetheless, the patient thanked the counsellor for assisting her in preparing to disclose to her sister. Possibly, the ‘talking cure’ meant that just mentioning that she wanted to disclose and having the counsellor listen to her and encouraging her was helpful to the patient. However, the analyst team was sceptical about this and felt that the patient was just thanking the counsellor as a courtesy but that the session had probably not really been beneficial to the patient. Appendix XV contains extracts illustrating how disclosure was discussed before and after training.

Throughout the post-training interactions in which disclosure was discussed, counsellors were particularly encouraging and commended the patients on the good job they were doing. Counsellors frequently appealed to a higher authority within the hospital team by stating that ‘*the doctor will be very pleased*’ [S33] to further encourage patients. Praising the patients for their adherence and desire to disclose was common throughout all of the post-training consultations. There appeared to be a strong link between counsellor praising and the affirmation showed by the communication skills facilitator to the counsellors in the individual training sessions. This is especially powerful given that patients tended to initiate questions or new topics for discussion after being praised. It suggests that just by encouraging and praising patients (rather than learning complex skills), patients will participate more actively in interactions. Furthermore, facilitators need to model this behavior when training counsellors. The benefit of individualized attention from research in counselling is documented in a number of studies described in Chapter 2.

b. Stigma

Stigma was not openly acknowledged by any of the counsellors or patients in any of the interactions as impacting on adherence. Perceived stigma was alluded to in metaphoric and figurative language by the patients in many of the cases. There appeared to be no difference in how this was addressed in the pre- or post- training consultations.

In consultation L, the caregiver mentioned how difficult it must be to hide ‘*the big bags*’ needed to contain the child’s medication from one’s family. This is interesting in both the literal and the figurative sense. Trying to literally keep the medication out of sight of one’s family would be difficult in a crowded family home; however is only an issue if the family has not been disclosed to. Figuratively, hiding the emotional baggage associated with keeping one’s status and that of one’s child secret from those closest to the caregiver, must be taking an enormous toll on the caregiver. The counsellor did not follow up on this. The same caregiver describes ‘*dirty blood*’ and ‘*cleaning blood*’ [L389]; an indication of the internal stigma she feels.

In case A, the patient relates the child’s TB symptoms to a wet carpet at her house. She states “*I also see the child struggling to breathe with that wet carpet. And I sometimes feel as if I have a big wound in my chest because of this wet carpet.*”

In consultation U, the caregiver’s poor body image as a result of her change in figure from the ARVs makes us aware of the stigma of size. Caregiver U comments on the visual manifestation of HIV, challenging our belief that you can’t see that someone is HIV positive, illustrated in Table 7.14.

Table 7.14 Selected extracts from the caregiver speaking in consultation U

“But we are forced to take it [the medication] knowing that it may change our shape, because it is not nice to lose your shape at all. And it changes people, you see people looking like some unknown thing...”

They can only see when they are facing you that you are a woman by seeing your breasts. You have a bad shape. It is better to die than to lose your shape. I used to be beautiful and they had no idea that I was a patient...

I stood in front of the mirror one day naked and I realized that I have a big stomach full of air and big breasts and my bras do not fit any more and I also have small arms. No, this is not for me...

I would rather die than being teased when walking on the street. People will see that I am sick and there is something wrong with me because of the changes in my shape...

I will take the medication from the doctor and throw them away.”

Table 7.14 continued**The reason why caregiver U wants to consult a traditional healer:**

“I want to hear what he has to say because it has been a long time since I’ve been there. I don’t know what’s going on with myself given that I’m unlucky. I’m cursed these days. I don’t think that white people can cure curses.”

Counsellor Lindiwe tried to balance caregiver arguments by presenting the differing consequences of the caregiver’s choices: the caregiver is concerned about her body shape, and the counsellor spells out very clearly that the other option is dying. This allows the patient to then express the seriousness of the issue for her, namely that quality of life is very important to her. Not looking good and not feeling like a woman, is worse than dying [U204]. This caregiver’s identity seems to be very much tied in with how she perceives herself as a woman, which is informed by how she looks. The counsellor appears to be ill-equipped to deal with this issue and reverts to her mantra *‘but you must promise to take the medication. Give the baby his treatment’*.

Consultation U is particularly powerful as the caregiver expresses her disillusionment with the ARV medication and how it has impacted on how she perceives she will be viewed as a woman. It epitomizes the complexity of the issues that counsellors have to deal with. Given the limited training that counsellors have, it appears to be unrealistic to expect them to deal with cases such as this effectively. Communication training enables counsellors to explore such issues by asking open questions, and the openness and frankness with which patients feel able to raise and discuss these issues indicates that caregivers trust counsellors. However, there is a limit to how helpful communication training can be. The analysis of Consultation U also suggests that communication skills training may place counsellors in a position of having to deal with increasingly complex cases (as patients discuss issues more openly) for which they are ill-prepared.

Death and religion were two other themes that recurred in many of the consultations and were raised by both counsellors and caregivers. All of the counsellors made reference to God and religion in an attempt to give caregivers hope and strength. Caregivers also made reference to God’s punishment and wrath, issues which are referred to in the literature on stigma in Chapter 2. The analyst team felt that whenever the discussion became ‘heavy’, Babalwa for example reverted back to the topic of religion.

c. In exploring the Patient's lifeworld: The emergence of traditional healing beliefs

In both the pre- and post-training consultations, counsellors explored the patient's living circumstances. In the post-training consultations, the increased number of open-ended questions meant that these circumstances were discussed in more detail. Caregiver perceptions about traditional healing practices emerged from their discussions about life-events, rather than from counsellor questions about traditional healers. Patients appeared to feel comfortable self-referring to counsellors to discuss non-medical problems in their lives. In response to an open question at the start of consultation T, the caregiver started a narrative about a recent burglary at home which was a traumatic event for her. Counsellor Lindiwe asked the patient how she reacted. The caregiver responded that if she could afford to, she would invite the traditional healer to tell her who the burglars were [T46]. She expressed doubt about the benefit of police involvement [T57] as she has previously not found them helpful.

Patients openly discussed traditional healing with counsellors in both the pre- and post-training consultations, and counsellors responded non-judgmentally to patients. Patient U expressed her belief that evil spirits had caused HIV [U80]. *'According to isiXhosa custom they say it may happen that a baby has seizures because of evil spirits and one day he may die from it'*. The caregiver expressed her concern that evil spirits may in fact kill her child while she was wrongfully attributing the child's sickness to HIV [U102]. To this, the counsellor acknowledged what the patient said without judging her [U103], *'I hear you sister'* and explored more specifically what the patient *did* in response to these beliefs e.g. *'When you are going to the Eastern Cape taking your baby with you, what do you do?'*

An examination of the counselling file notes for these cases indicated that counsellors did not then formally report patient beliefs about traditional healing practices. Counsellor confidentiality on such issues may be preserving patient trust in the counsellors. However, a lack of communication about these issues to the health care team may impact on treatment decisions. There may be conflict between a medical and a psychosocial model of treatment in such instances, which places the counsellors in a difficult position.

b. Substance abuse

Substance abuse was the main theme of only one consultation, namely that involving counsellor Elsie and caregiver K (pre-training). In what must have been a very frustrating encounter for the counsellor (the patient rambled at length and was very incoherent and emotional, barely understandable at times), the counsellor gave the patient time to talk and

did not interrupt her. The counsellor expressed her sense of futility about the value of counselling a patient who is not motivated to adhere or to change her lifestyle within the Cape Flats environs in which poverty, substance abuse and promiscuity are rife. Communication skills training can have only limited application in such cases as more advanced counselling skills are needed. LTFU, a lack of continuity of care and infrequently scheduled counselling sessions, appeared to be significant barriers to dealing with cases such as these effectively within the current counselling model.

c. Relationships and fidelity

In a number of cases, issues centered around sexual relationships and fidelity were raised. Family planning was not however discussed in any of the consultations. In both pre- and post-training consultations, discussions around condom use appeared to be contrived and followed a socially acceptable 'script'. Counsellors tended to 'preach' what patients should do, and there was no acknowledgement of the difficulty in negotiating condom use. The same could be said for discussions about being faithful to one's sexual partner. Counsellors tended to urge caregivers to be faithful. More developed counselling skills are needed to address discussions about sex and relationships. It may be that given cultural taboos around these topics, a support group platform with a skilled counsellor may be more effective than one on one counselling. Given the limited agency that women have in sexual issues as discussed in Chapter 1, alternative methods to traditional counselling may be needed. There was no discussion of the link between viral load and transmission in any of the consultations, suggesting that counsellors may need to be reminded to address this issue as a preventative measure.

d. The role of the counsellor in discussing psychosocial and lifeworld issues

Undeniably, all of the consultations necessitated the exploration of patient psychosocial and lifeworld issues in order to understand the barriers to adherence for each individual patient. Counsellor knowledge about which lifeworld factors could impact on patient adherence appeared to be adequate; counsellor skills to assist patients in overcoming these barriers were not.

This finding is interesting because it delineates the boundary of communication versus counselling skills. It clearly demonstrates that good communication skills themselves are insufficient for improving an interaction to the extent that behavior change is brought about (which was never the intention of this study). These findings thus illustrate the limitations of communication skills training, possibly particularly so within a South African context.

Many circumstances are beyond the control of vulnerable people. Indeed, many definitions of vulnerable populations specify that they have '*limited choice*'. In South Africa, many women are emotionally and financially dependent on their partners and disclosure within such relationships can put them and their children at risk. There is an underlying awareness of this on the part of both the counsellors and the patient, and so no amount of encouragement or deep exploration of this issue through good communication will effect a behavior change in the patient's life.

Methods such as motivational interviewing which do aim to affect change have had only limited impact on improving counselling skills as described in Chapter 2. In two of the studies on motivational interviewing with counsellors in South Africa, counsellors were only able to attain a below the beginner level of proficiency in a number of MI skills, and the studies caution that there is no research substantiating the effectiveness of motivational interviewing if below the level of beginner proficiency is attained. Furthermore, Baldassini (2006) has suggested that within an androcratic society in which decision-making is male-dominated, the application of MI might be limited as patients may not be agents of their own destiny within such societies, and these findings certainly support this contention.

The common pattern when faced with the difficulty of discussing psychosocial and lifeworld issues with patients, was for counsellors to revert to pleading with them- a tactic which the literature suggests is ineffective. Two main approaches were used; firstly, counsellors placed emphasis on the maternal role and guilt, and secondly, counsellors asked patients to turn to God.

7.5.3 The counsellor as a mother, patient and woman

There were no changes pre- and post- communication skills training in how motherhood and vertical transmission were explored within counselling interactions. 'Mothering; was a common theme across all of the interactions in which the two openly HIV positive counsellors (Nokuzola and Babalwa) who were themselves caregivers of HIV positive children counselled caregivers. In these consultations, Nokuzola and Babalwa expressed empathy for the caregivers that was based on their own personal experiences of motherhood. This varied from commenting on emotions they had felt at various stages, to practical advice such as how they would overcome their child not wishing to take medications for example. These shared anecdotes appeared to strengthen the bond between counsellor and patient. Nokuzola and Babalwa frequently used the pronoun 'we' in their interactions which was felt to promote a shared situation 'we are in this together'.

“There is a sense that the patient comes in with the desire to please, ‘I have not memorized them all but I will’ with the expectation that she will be judged in some way for her actions and I think this initially makes her tentative. Is there a sense of blaming when a child is being treated for HIV especially in light of the fact that the mom’s status is not confirmed? By remaining reassuring and encouraging and finally by probing a question, Nokuzola manages to break through that reserve and I think that it’s at that point that she really establishes trust with the patient. This could potentially form the basis of their relationship and allow the patient to be a more effective carer for her child as she can access the support offered.” (Rater 2 comment on consultation G).

The shared experience between these counsellors and the caregivers was evident from open acknowledgement of maternal guilt about transmission, that HIV is only one of many stressors in their lives, and the burden of adherence.

a. Maternal guilt about transmission

Expressing mutual guilt about transmission was a feature of Nokuzola and Bablawwa’s consultations. As discussed in Chapter 2, stigma has been shown to be worst in families and health care institutions. Commenting on maternal responsibility for a child’s HIV status could be seen as reinforcing this stigma. However, the counsellors as HIV positive women themselves who *‘have infected our children unpurposefully’* appeared to be giving voice to an unsaid truth. Transmission, remains that which lies beneath. In expressing their own feelings of guilt and through the use of the pronoun ‘we’, Nokuzola and Babalwa appeared to be saying to caregivers ‘I too have walked this road’. A careful tension was observed between parental responsibility and placing too much burden on the mother.

Transmission and the role of viral load in transmission, were concepts that were poorly understood by caregivers. There appeared to be an assumption by the counsellors that caregivers understood mother to child transmission. This was not the case; two mothers whose children were on ARV treatment, believed that they were HIV negative. They had drawn this conclusion because they had been told that their *‘soldiers are high’* (i.e. their CD4 count is high and so they did not need to be on treatment yet). This was adding to the confusion about HIV transmission as they then did not understand how their child happened to be HIV positive when they were HIV negative.

As PMCT programmes grow and more women access prophylaxis, the face of paediatric HIV care will change. It is likely that there will be fewer cases resulting from vertical transmission. However maternal guilt may increase as people come to understand how

preventable it is. The recent recognition of the need to close the gap between PMTCT and paediatric services to ensure that LTFU is limited, will hopefully alleviate this problem.

The fact that counsellors with or without training both had good baseline knowledge lends support to the notion of ‘expert patients’ as this counsellor, Babalwa, was the mother of an HIV positive child, and so the knowledge she had gained as a patient herself and as a caregiver, had equipped her in terms of the general knowledge required. However, as there is no guarantee regarding untrained counsellor baseline knowledge, there needs to be caution regarding selection of expert patients to ensure quality control.

b. HIV is only one of many stressors in a woman’s life

That HIV is only one of many stressors in patients’ lives and its chronic nature, meant that it was not always a topic that caregivers wished to discuss. One of the challenges with adherence counselling is that patients have to continue to return to the clinic at regular intervals to collect medication, and may require counselling, especially as the child’s dosing changes or if problems are identified. However, most caregivers may prefer just to get on with life and not to have to think about HIV particularly as it is beyond their control. This is awkward for counsellors who are required to counsel patients who do not feel that they require counselling.

[S 23] P: *I don’t think about it. I just take it and forget about that. Because I was (laughing) The way I was worried about everything so I said let me just forget let me just see what is God what is going on and then I just ... (trails off using hands).*

The counsellors who themselves were caregivers attending the clinic appeared to be very aware of this and more sensitive to patient desires not to discuss HIV.

c. The burden of paediatric adherence is difficult to shoulder

The burden of adherence is apparent in the planning and the logistics of managing the child’s ARV treatment. In instances in which caregivers had not disclosed to other family members and feared what the extended family might think, they felt the need to hide the medication and this created logistical problems when they were travelling to the Eastern Cape [L480]. In case L, the mother expressed how stressed she felt about whether or not to send her child to a crèche, and what this will mean in terms of the times the medicines are given and the logistics of managing this whilst working shifts. A tension appears to exist between the desire to be a good mother and the guilt from infecting their children. As a mother whose own child is HIV

infected, Nkuzola tried to ease the mother's guilt by acknowledging the part that they played in infecting their children, but encouraging her to be strong for her child [A].

Accepting the doctor's recommendation to start on ARV treatment means that the caregiver has some awareness that the virus has infiltrated her body. Understandably, there must be fear associated with the extent to which the virus has done this, as well as fears about what the medication will do to you and its side-effects. Unsurprisingly therefore, in case L, the caregiver misinforms the counsellor about her CD4 count, betraying her fear of starting on ARVs [L344].

7.5.4 Role of the counsellor

In addition to the role of the counsellor as treatment-educator and in providing psychosocial support, the counsellors filled the role of patient advocate, language mediator and multidisciplinary team member. There appeared to be no change in the role of the counsellor pre- and post- communication skills training. Counsellors successfully filled the role of patient advocate and language mediator. Despite this, a number of problems were evident in their role within the multidisciplinary team. Extracts illustrating the role of the counsellor as patient advocate and language mediator can be found in Appendix XVI.

a. The counsellor as patient advocate

The counsellors assisted caregivers with understanding how the hospital works, and provided the caregivers with access to social grants and financial support. In addition, they assisted patients with transfers to other clinics and with allaying patient fears. Some of the children and their caregivers have been managed by the clinic since its inception. With the system of transferring them to outlying clinics, some caregivers experienced heightened anxiety about how this would impact on their care. Others expressed relief that this would be more convenient for them [Q].

b. The counsellor as language mediator

Counsellors serve as language mediators by interpreting for doctors, and by explaining information to patients in their home language. Only one of the consultations in the sample involved interpreting (illustrated in Appendix XVI), so a pre- and post- communication skills training comparison is not possible. However, an analysis of the interpreted interaction showed how the counsellor acted as a patient advocate within that consultation; often softening what the doctor was saying and strengthening the patient's voice.

Appendix XVI illustrates an inaccurate but positive interpretation as the counsellor does not always translate exactly what the doctor or patient has said, but tries to make the information more comprehensible to the listener.

In addition to interpreting, the counsellors filled the role of mediator in explaining information to patients. Whilst this has been discussed in general terms throughout these results, the importance of explaining information to non-South African (foreign language-speaking) patients is worth examining in more detail as the counsellor incorporated a number of the training programme techniques into the interaction.

Caregiver S was a Mozambiquan national, living in Khayelitsha. The South African father of her children was no longer involved in caring for his two children. The counselling was conducted in English which was not the first language of either the counsellor or the patient. Throughout this interaction the caregiver was very softly-spoken. Whether this was because of anxiety due to language proficiency or general shyness, was unclear. At times the counsellor struggled to understand her. Lindiwe modified her own speech rate, making it much slower with more pausing. This appeared to be helpful and resulted in the caregiver also slowing down and becoming more audible. When counselling in English, Lindiwe used particularly formal language. This could be because she does not know some of the lay terms for more technical words. Far more medical jargon was used in this consultation by the counsellor than in any of her others. It was interesting that she was referred for counselling by her doctor, even though the doctor himself can speak English. This does suggest that the doctors value the counsellor's input for more than just crossing the language divide.

All of the communication analysts commented on the unease that counsellor and caregiver seemed to show in consultation S. It is unclear whether this was due to a lack of confidence of speaking their second language on camera, or because of cultural differences between the two, which might have made them slightly less relaxed with each other than the other caregivers.

c. The counsellor as multidisciplinary team member

Any patient in the clinic is seen by the doctor, nursing sister, counsellors and pharmacists as well as possibly the social worker, occupational therapist or physiotherapist. A number of consultations highlighted that working with such a large team, can lead to confusion about diagnoses and medication.

In consultation E, the counsellor was able to adapt to the role of interpreter and patient advocate with ease. The counsellor understood the doctor's medical jargon and use of abbreviations (TBM), and empathised with the mother's distress. It became apparent in this consultation that it was not just medical terminology (TBM is used in its abbreviated form) that can be problematic for patients, but clinic jargon too e.g. 'Brooklyn' for a local TB Hospital. The child was to be admitted for 9 months for treatment. The patient did not understand where the child was being sent, for how long and why. For any parent, a hospitalisation of 9 months would be bewildering; even more so if the diagnosis had not been explained. Within this consultation, the counsellor re-checked her facts with the doctor in response to the patient's earlier query as to whether or not meningitis was treatable. The counsellor encouraged the patient to have an open relationship with the doctor, and the patient voiced her wish for someone to communicate the diagnosis and its implications to her husband. The counsellor was instrumental in setting up a follow up appointment for the doctor to talk to the husband with an interpreter present.

This consultation highlights the difficulty of the counsellor's position as the doctor is expecting her to provide information to the patient, beyond her knowledge and possibly her job description. Surely it is the doctor's responsibility to call an interpreter if needed and to provide information about the diagnosis, where the referral hospital is and when the child will be going? Instead this is left up to the counsellor. Although the counsellor looks uncomfortable in this interaction, she maintains good eye contact between herself and the patient and herself and the doctor. In her role as patient advocate, she is much more animated and encouraging in her dialogue with the caregiver, and more sombre in her exchanges with the doctor. The counsellor does an excellent job in assisting the caregiver in understanding.

One of the analyst team members comments on the role of the counsellor:

'What is required of a counsellor in any given session almost seems too much to manage. The counsellor is expected to relay information, provide reassurance, clarify terms etc... be emotionally supportive, problem solve, administrate on the hospital's behalf, for the child as much as for the caregiver who is presumably as much in need of being a patient in his/ her own right. It's a mammoth task. I would find it totally overwhelming.' (Rater 2)

7.6 CHAPTER SUMMARY

From the pre-post results comparison, it is evident that although the communication training had a different impact on each counsellor, there were a number of common changes across

the four counsellors, as well as across discussions about treatment literacy, disclosure, lifeworld issues and patient advocacy.

Communication training appeared to have the most impact on the quality of the treatment literacy provided to patients. In addition, counsellors explored lifeworld and cultural issues more thoroughly and openly, but appeared unable to manage the information obtained. Communication training had no impact on discussions of disclosure which remained poor, and on patient advocacy which remained good as summarized in Table 7.15.

Table 7.15 Summary of the impact of the communication training across themes

Communication about:	Quality of communication prior to training	Quality of communication post-training
Treatment literacy	Poor	Considerably improved
Disclosure	Poor	Poor
Lifeworld issues	Poor	Mixed: Limited improvement: Exploration of lifeworld issues, but inability to manage the information obtained. Good exploration of cultural issues.
Patient advocacy	Good	Remains good

These consultations highlight the importance of the counsellor's role as a mother, patient advocate and multi-disciplinary team member. Furthermore, the anthology of stories told in this analysis bear testimony to the complexity of the counselling role.

CHAPTER 8

GENERAL DISCUSSION

8.1 INTRODUCTION

This chapter explores the impact of the training on the communication in interactions by describing what changed and what didn't change in relation to the literature. Furthermore, reasons for the change, how lasting this change was and the generalisability of the results are discussed. Variables impacting on the effectiveness of the communication training, the study methodology and ethical considerations for research of this kind are also explored.

8.2 CHANGES IN COMMUNICATION IN COUNSELLOR-PATIENT INTERACTIONS

Prior to training, the consultations analysed in this study reflected many of the problems documented in the counselling and medical literature, specifically: poor exploration of caregiver understanding of concepts (Chopra et al., 2005), limited checking of patient understanding (Maguire & Pitceathly, 2002; Fallowfield & Jenkins, 1999; Chopra et al., 2005), poor questioning of previous experiences (Chopra et al., 2005), frequent use of jargon (Hollenburg, 2006), rapid topic switching (Maguire & Pitceathly, 2002), offering advice and reassurance before patients had the chance to express their main difficulties (Maguire & Pitceathly, 2002), sparse instruction giving (Chopra et al., 2005) and no demonstrations showing how to carry out instructions (Chopra et al., 2005).

All of the above contributed to communication breakdown in interactions between counsellors and patients and support the contention that the counselling format itself negatively impacts on counsellor patient communication (Buskens & Jaffe, 2008). The generally poor communication skills pre-training mirrors the finding by other researchers such as Baldassini (2006) that basic counselling skills are weak.

These findings differ from other studies because the baseline consultations did *not* show evidence of counsellors providing only biomedical information (Ellington et al., 2006) or counsellor non-exploration of cultural issues (Buskens & Jaffe, 2008). On the contrary, prior to training, the content of the counselling reflected counsellor sensitivity to cultural issues, and counsellor exploration of the patient's lifeworld. Cultural attunement to the customs, beliefs and rituals of patients (Hoskins, 1999) was demonstrated by the counsellors. Counsellor familiarity with the patient's lifeworld was evident in references to cultural practices, discussion about common points of reference (e.g. being 'homies' from the Eastern Cape) and in the frequent use of code-switching which as a pattern of social relationships

(McCormick, 1995), suggests a degree of rapport between counsellors and patients. Patients consulting traditional and Western medicine in parallel is well-documented and was evident in many of the consultations. However, an issue which is not often raised, was *what* counsellors should do with this information about cultural practices once patients had shared this with them.

In contrast to Watermeyer's (2008) study in which pharmacists modified their communication strategies to facilitate patient understanding through the use of repetition, reinforcement, summation and repair strategies (Watermeyer & Penn, 2009), there was no evidence of such modifications by the counsellors in baseline consultations in this study. What did characterize all of the interactions by counsellors who themselves were openly HIV positive caregivers, was the sharing of their life experience with patients to assist them with coping. Although self-disclosure is contentious within the counselling literature (Van Dyk, 2004), it was felt to be beneficial within the paediatric HIV context with the associated maternal guilt about vertical transmission. The manner in which self-disclosure occurred, fitted Van Dyk's (2004) criteria of being for the patient's benefit and not burdening the patient. These findings support Van Dyk's (2004) recognition that in the context of HIV in particular, sharing stories is appreciated by patients because it brings them into contact with HIV positive individuals who have worked through many of the same challenges.

The pre-post comparison in Chapter 7, clearly demonstrates that communication training was helpful in improving the treatment literacy in consultations and was noticeable in counsellors asking more open questions; more frequent verification; the increased incidence of checking patient understanding; more effective methods of checking patient understanding; more frequent explanations of medical jargon and the use of demonstrations. The communication training provided counsellors with the tools to tackle information-giving in a more practical, hands-on manner and provided patients with the opportunity to ask questions and to practice what they had learnt.

Furthermore, post-training, communication was more personalized and patient-centered with interactions having fuller introductions in which both the counsellor and patient provided more detailed information about themselves and their cultural background; more personalized communication resulting from better preparation and using the child's name, and more encouragement of caregivers. In response to praise from counsellors, caregivers in turn asked more questions. That caregivers asked questions in response to affirmation and initiated topics in response to open questions, substantiates Street et al.'s (2007) model in which the modification of communication style to one partner impacts on the communication of the

other. Although greater affirmation was not overtly addressed in the training programme itself, it was covertly modeled by the facilitator, and increased patient affirmation was evident across all of the counsellors. Greater affirmation of caregivers post-training has been reported as a success in other studies (Evangelini et al., 2009). In response to counsellor open-ended questions, caregivers initiated more topics and their stories followed a narrative format which is considered to be more culturally appropriate (Penn, 2000). All of the above suggest that the post-training consultations were more client-centered. Improved patient-centeredness after communication skills training has been reported with studies involving medical doctors (Fallowfield et al., 2002) and these findings support those of other researchers involving doctors, nurses and medical students which have dispelled the myth that communication skills reflect personality and talent that cannot be improved (Fallowfield et al., 1998).

The counsellor in the role of *information-giver* is usually negatively portrayed within the counselling literature and is perceived as being at odds with a client-centered approach (Richter et al., 1999). In the literature, much is made of counsellors speaking at length, asking numerous questions, ‘educating’ patients in a didactic manner and focusing on biomedical issues. In brief motivational interviewing studies in which the analysis methods such as the MITI are used for example, providing less information was associated with better scores (Mash et al., 2008). From results such as these, information-giving holds a negative association and the importance of information-giving, whilst clearly stated in counsellor job descriptions (DOH, 2008) and guidelines (NDOH, 2005), is belittled.

This research suggests a need to move away from viewing information-giving as problematic and to move to examining *how* the information was conveyed. It demonstrates that counsellors can follow an informational approach without necessarily being directive, and, if tactfully done, information-giving need not be at odds with a client-centered approach. The balance of open-ended questioning and information-giving achieved in the post-training consultations, suggests that current perceptions of the information driven model may be too narrow.

The value of a patient-centered approach in adherence counselling is debatable for a different reason; namely, that this research suggests that it is more likely that it is the ‘scripted’ (desired) medical outcome which is at odds with a patient-centered approach. By this I mean that counsellors, by asking more open-ended questions, elicited more detailed information from patients about their lifeworld. However, counsellors then appeared at a loss with what to do with the information provided by patients. As the desired medical outcome perceived by counsellors (and possibly other health care workers too) is for adherence counselling to result

in more patients opting for ARV treatment, when patients share lifeworld and personal details which raise warning flags about the likelihood of them being non-adherent, counsellors did not know what to do. So although counsellors start off from a position of *mutual understanding* (when both the clinician and patient use the voice of the lifeworld (Mishler, 1984)), the counsellor then acts in a manner in which it appears as if the *lifeworld is ignored* (Mishler, 1984), as there are no explicit guidelines on managing information which does not fit the scripted dialogue. On a daily basis, counsellors, who have limited training, need to negotiate between Western and African perspectives and manage patient feelings about stigmata (abominations of the body). Such complex human predicaments were sufficiently distressing for the caregivers in this research to cause them to desire cessation of treatment.

The subtext underlying counsellor perceptions and caregiver perceptions may not be conflicting; rather it is the expected ‘good of public health’ at large which contrasts. Many of the counsellors are HIV positive themselves. They are also women and mothers and regardless of their HIV status, are aware of the issues and challenges mothers face in their daily lives. Counsellors are thus tasked with trying to translate medical knowledge into *credible* messages for mothers. This is made more difficult by the futility of the task within a society in which women have little agency. It may be helpful to follow Baldassini’s (2006) recommendation that looking at conceptualizing and holding on to the ‘vision’ may have importance for women. This means that counsellors themselves need to believe that they can affect change, and that mothers can too.

Reflecting on Richter’s (1999) words of caution that counselling runs the risk of being assigned responsibility for all non-medical services in response to the HIV pandemic, I am not convinced that we have progressed any further. I am left feeling that that most difficult job, which nobody else wants to do, is assigned to counsellors. The effects of task-shifting become diluted and task-shifting is merely a means of ‘passing the buck’. Doctors, nurses and pharmacists know that given the language and cultural barriers that still exist, and the mountain of work they need to bear, shifting the task of providing psychosocial support on to others is the easiest option. So of those to whom very little is given, much is expected.

It is unclear what the clinic wants to do with the cultural information that is shared with counsellors. Guidelines need to be drawn up by the multi-disciplinary team for what to do if a patient is consulting traditional healers or is openly non-adherent and wishes not to take ARVs. This is not something the counsellor can decide about in isolation.

There appears to be a need to share these stories so that doctors and the rest of the health care team are aware of some of the ethical dilemmas that counsellors face. An appropriate format may be a multi-disciplinary team discussion group. This could follow a similar format to the Auntie Stella discussion toolkit (TARSC, 2008) developed to guide adolescents in discussing sexual issues. The cases reflecting the stories from this research and summarizing some of the dilemmas counsellors face have been written up for this purpose and will be shared with the research site.

8.3 SHARED CULTURES

Buskens and Jaffe (2008) found that there was too little ‘shared understanding’ between nurse counsellors and patients for them to connect. This was not felt to be the case in the present study as evidenced in the rapport between counsellors and caregivers, and the openness with which caregivers raised a number of issues that traditionally go against the medical model. In contrast with Buskens and Jaffe’s (2005) research, the caregivers in this research were very open with the counsellors. There was no evidence to suggest that these caregivers did not follow instructions or did not tell counsellors the truth. However, there was some evidence of collusion about issues such as disclosure. It may be that counsellors, with their shorter training and by being positioned on the periphery of the clinical context, are less institutionalized than their nursing counterparts and so it is easier for them to achieve this shared understanding. Buskens and Jaffe (2008) found that as a product of the rift between nurse counsellors and patients, each party talked past the other and there was no real meeting of minds, resulting in ritualistic dialogue. Similar ritualistic dialogue was evident in this research in discussions about disclosure and condom use. However it was felt that the rift lay between the expected medical outcome being misaligned with what both counsellors and patients felt was achievable within the context of their lives.

Buskens and Jaffe (2008) proposed that the subtexts between mothers and counsellors are more real than just ritual exchanges and so can be regarded as conflicting agendas. However, in this research, it did not appear that the counsellors were juxtaposed against the caregivers’ reality. The ‘lie’ of the institutional desire or ‘greater good of public health’ is implicit for both counsellors and caregivers. They both appear to be following the same script, responding ritualistically to each other and are equally aware that neither intends changing. In particular, the ritualistic dialogue about condom use appeared to mimic prayer rituals with set responses.

There was also no evidence to suggest that poor medical knowledge at the baseline as found by other researchers (Mash et al., 2008), existed in this group of counsellors. While it is likely that counsellors do have less medical knowledge due to their training being more limited than

other health professionals, this knowledge appeared to be comprehensive and accurate. This is a credit to the institutions that trained them pre-service and to the clinic in which they are currently working. Counsellor knowledge about core messages to be conveyed in this study thus contrasts with the PMTCT context in which counsellors are reported as being confused about these core messages (Chopra et al., 2005).

The raters in this study generally did not perceive the caregivers to be judged by the counsellors as reported by Buskens and Jaffe (2008). The low uptake of counselling could be considered to be an indicator of this. Evidence of a good rapport can be found in the openness with which caregivers discussed a myriad of issues with counsellors. Adherence counselling does not have the same difficulty as PMTCT counselling of mixed messages and difficult choices regarding feeding. Poor continuity of care leading to mixed messages as reported in the PMTCT literature (Buskens & Jaffe, 2008) was not evident in the adherence counselling context. However, a product of poor continuity of care was that information did appear to slip through the cracks and information shared within one counselling session was not passed on to the rest of the multi-disciplinary team.

Similarly to Delva et al. (2006) in Kenya, the frequency and duration of counselling in this clinic were low (although there was a great deal of individual counsellor variation and it is not fair to generalise across counsellors as some counsellors appeared to be more productive than others). In contrast to studies which have made general comments about communication skills being 'good' (Chopra et al., 2005; Delva et al., 2006), this study provides detailed analysis of which aspects of communication facilitated or inhibited the interaction. Similarly to Delva et al. (2006), information provided by counsellors was seldom summarized. In addition, the limited time available to counsellors made it difficult for them to cover the large amount of treatment literacy required. However as the counsellors within this context chose the length of time they spent with patients, and as there appeared to be considerable spare time in which no counselling was happening, counsellors have more time available to them and so need to learn to structure and manage that time better.

Generally, the counselling style in this research differs from that most commonly reported in genetic counselling by Ellington et al. (2006) in which the client-focused biomedical pattern (both the counsellor and the client are involved in exchanging biomedical information and there is an equal proportion of counsellor:client discussion) predominates. Counsellors in this study fell somewhere between the *counsellor driven psychosocial* pattern (in which the counsellor dominates with discussion of issues and the client's voice is largely absent, suggesting that the counsellor is exercising verbal control and presenting or teaching

information) and the *client-focused psychosocial* encounters (counsellors facilitate the client opening up and sharing psychosocial information). Certainly, after training, counsellor communication style tended to be more *client-focused psychosocial*.

8.4 COMMUNICATION BARRIERS THAT WERE NOT OVERCOME BY TRAINING

Despite the improvement in treatment literacy and the more patient-centered approach after training, a number of communication barriers were not overcome by the communication training. Specifically, counsellors still struggled with correcting misbeliefs, mutual goal setting (also found by Baldassini, 2006), discussions about difficult-to-discuss topics and ensuring continuity of care through adequate note-taking in folders. Other researchers such as Epstein et al. (1998) have noted that there are still significant barriers between patients and health professionals who have received advanced training in doctor-patient communication.

Communication training alone also had no impact on the motivational interviewing desired outcome of guided conversations to empower mothers to make changes. Although this was not a desired outcome of this study, it is useful as a measure of comparison with other counselling studies. These findings support those by Van der Walt (2000) that add on counselling in its existing form remains insufficient to meet the emotional needs of patients or have the desired effect of behavior change.

Difficulty in correcting patient misbeliefs was also found by Chopra et al. (2005). Agenda-setting, namely coming to a mutual understanding of the topics for discussion, was also reported by Baldassini (2006). Inability to achieve mutual goal setting is even more problematic in an adherence counselling session than in one such as PMTCT feeding counselling where the session is far more focused on a particular outcome, namely a feeding choice.

In comparing the pre- and post-training topic initiation, it is evident that certain topics were never caregiver initiated. This is interesting as it could mean that caregivers do not think that it is necessary to discuss those topics, that those topics are not important to them, that they feel uncomfortable raising them, or that the counsellors initiate them before they have a chance to. Given the asymmetry that exists between doctors and patient, this is not surprising (Maynard & Heritage, 1984). Table 8.1 lists topics that were not raised by caregivers in the recorded consultations.

Table 8.1 Topics which caregivers did not initiate in any of the consultations

Clan names/ cultural origins
Grants
How the virus progresses: CD4 counts, viral load
Medical procedures
Nutrition
Patient advocacy, rights, responsibilities
Partner involvement
Role of the counselor
Role of the doctor
Role of the parent/ patient responsibilities
Sexual activity
Substance abuse
TB/HIV

Because caregivers appear unlikely to raise the issues listed in Table 8.1, and if it is felt that they need to be discussed, then the counsellors need to know to raise these issues themselves. In the context of adherence counselling, the topics of disclosure, partner involvement, termination of treatment and condom use appeared to be most problematic for counsellors to discuss. This finding reiterates those in numerous studies that taboo topics are seldom addressed or are poorly discussed (Chopra et al., 2005; Fallowfield & Jenkins, 1999; Klitzman, 2006; Nulty & Edwards, 2005; Delva et al., 2006). In the VCT context, Nulty and Edwards (2005) reported that counsellors found it difficult to discuss issues cross-generationally. This could not be determined from my results. Two issues linked to disclosure stood out in this research: Firstly, unlike Chopra et al.'s (2005) PMTCT research, counsellors in this research did encourage caregivers to disclose when this topic was initiated by caregivers. However, what was found to be lacking, was advice on *how* this can be done, and practicing doing so using role play or brainstorming possible scenarios. Secondly, disclosing a positive diagnosis to the caregiver herself was also found to be problematic in my research, as evident in the circumlocutive way in which mothers were inadvertently diagnosed by virtue of their child's status. Despite the communication training, a number of topics were not addressed in the counselling, namely formula or breast-feeding and disclosure to children. It may well be that counsellors feel that discussion of these issues falls outside of their area of expertise. Indeed, discussing them is difficult for anyone. Nonetheless, it is important for the multidisciplinary team to be aware of this so that discussion of these issues is not neglected.

Nulty and Edwards (2005) propose that in their personal lives, counsellors may not be able to enact the advice they give to others. The findings in this study support their view, and it is likely that this is the root cause of counsellor difficulty in discussions about disclosure,

partner involvement and safer sexual practices. At the centre of all of this, lies the agency of women. My findings support Baldassini's (2006) contention that within an androcratic society, only limited change is possible. In particular, the ability of counsellors to hold an unconditional positive regard (Carl Rogers in Baldassini, 2006) appeared problematic. The lifeworld of mothers and counsellors and women generally presents a significant obstacle to developing a genuine belief by counsellors that mothers are capable of change against circumstances. It is very likely that counsellors are unable to make these same changes within their own lives particularly as the issues in their and their patients' lives are the same. It has been shown for example that very few counsellors have themselves had an HIV test (Desmond Tutu HIV Foundation, 2009). If the counsellors can not affect these changes within their own lives, it is unlikely that they can begin to convince others to make these changes. To overcome the lack of agency which women in South Africa have, there may be merit in heeding Jewkes's (2009) recommendation that what is needed is a change in how women are perceived in South Africa and their status in society.

In the shorter term, there may also be benefits in following an expert patient or mentor mum approach such as that used by Mothers to Mothers to Be (M2M2B), so that the individuals selected for counselling within a clinic have demonstrated role model behavior within their community.

The findings in this research suggest that counsellor understanding of confidentiality is a barrier to effective multidisciplinary teamwork and the continuum of care. Communication training helped significantly in obtaining information from patients. Counsellors asked more open questions, and patients shared more information. Counsellors appear to be non-judgmental as evidenced by patients sharing beliefs and personal information. However, counsellors did not appear to pass this information on. Potentially the weekly debriefing meetings with an outsider to the clinic whilst serving the role of boosting counsellor morale and debriefing counsellors, may in fact hinder communication within the clinic. Paradoxically, reporting in patient folders might in fact discourage patients from sharing information with counsellors if they know that this information is passed on. Ethically, the concept of confidentiality presents a barrier as counsellors do not pass on information; nonetheless it might contribute to patient openness so shouldn't be discouraged.

Unfortunately, these results suggest that it is unlikely that information will be passed on verbally to team members. Competence in teamwork requires speaking up against an authority gradient, clarity in assuring the sequence of messages-sent-message-received, attentiveness to roles and relationships, monitoring and backup (Duffy et al., 2004). Without

improved counsellor self-esteem, counsellors are unlikely to participate as equal team members.

The issue of confidentiality permeated all discussions about HIV. Counsellors reported that confidentiality was emphasized in their pre-service training. However, confidentiality was a source of internal ethical dilemma for counsellors and appeared to be a barrier to effective continuity of care. There needs to be greater dialogue within the multidisciplinary team and a deeper understanding not only of what confidentiality is and what the patients' rights are, but of the place of confidentiality within patient treatment. Confidentiality in this sense differs from the stress which counsellors experienced regarding whether or not to disclose to discordant couples and spouses (Nulty & Edwards, 2005). There needs to be a call for ongoing ethical 'training' through facilitated discussions within the multidisciplinary team regarding:

- The boundaries of counsellor-client confidentiality
- What counsellors should practically do if they feel that information that patients have told them will seriously impact on treatment and how to handle this information without losing patient trust
- The impact of poor continuity of care and limited provision for follow up which means that it is impossible to determine the effectiveness of counselling (Nulty & Edwards, 2005).

Consideration for counsellor note-taking ability, and literacy levels is needed and should be investigated prior to the employment of counsellors in clinical posts. Note-taking in my study suggests that this is an area of weakness in which counsellors need to be supported and that an intervention aimed at improving record-making needs to be implemented. These findings echo those of Richter et al. (1999) in which accurate record-keeping was found to be lacking.

The whole multidisciplinary team might also benefit from discussing the tension that exists between *quality counselling* and the amount of counselling being offered for the sake of record-keeping. Fieldnotes suggest that increased pressure on counsellors to keep accurate records may in fact lead to inaccurate reporting by counsellors in order to please authorities. Ill-established lines of reporting and hiding behind the "confidentiality" of counsellor-patient encounters, means that it is difficult to verify counsellor day sheets.

8.5 ROLE OF THE COUNSELLOR

After training, in considering the counsellor's role as defined within the DOH job description (described as key performance indicators (C1 – C7) in Appendix III), counsellors appeared most successful in the role of preparing patients for treatment readiness (C1) and in communicating (C7). However, counsellors need more assistance to provide ongoing support (C2) tailored to the needs of patients at various stages and they specifically need assistance with identifying resources available to them to assist support groups. Counsellor record keeping (C3) and multi-disciplinary team case management (C4) are areas of significant weakness that need specific interventions to address. The degree to which counsellors fulfilled the roles of defaulter tracing (C5) and ongoing district management (C6) could not be ascertained from this research. The omissions from the DOH list of key performance indicators should not necessarily be judged as positive or negative, but serve as a reminder of the breadth and complexity of the counselling role.

The use of adherence counsellors as interpreters is a break from the established ad hoc interpreting involving nurses or family members, which has become the norm in South Africa and other health care contexts (Crawford, 1994; Flores et al., 2003; Penn, 2007; Anthonissen, 2008). In the research clinic, counsellors were well-positioned to act as language and cultural mediators as they match the language, cultural and gender group of the caregivers requiring their assistance. This study supports Richer et al.'s (2001) finding that counselling in South Africa extends far beyond the traditional role concept. Consultation E for example demonstrated the value of the adherence counsellor adopting the role of patient advocate within an interpreting role. In health care generally, there is a need for demanding patients. Counsellors acting as patient advocates can serve to overcome the traditionally passive patient 'sick role' which is attributed to the information gap between patients and clinicians, and the intimidating medical environment (Allshouse, 1993). As evident in Consultation D in which the counsellor encouraged the caregiver to allow her to address the issue of announcing the child's diagnosis in a space that did not protect her privacy, the caregiver responded well to this show of solidarity for her patient rights. Furthermore, the doctor at fault in Consultation D was receptive to being approached about this issue. Addressing it timeously could prevent patient dissatisfaction and promote retention in care. With the notable exception of Richter et al. (1999), this positive extension of the counsellor's role remains unacknowledged in the literature.

Studies show that interpreters are seldom neutral in interactions and tend to side with clinicians rather than the patient in conflict situations (Bolden, 2000 in Hsieh, 2006). It is

evident from helpful mistranslations in Consultation E that some errors in translation were beneficial in aiding patient understanding and contribute to interpreters playing a cultural mediating role (Evans, 2000).

The counsellor's interpreting role is not emphasized within the clinic context and the researcher felt that it could be extended further. Given the counsellor's extensive knowledge of medical terminology, negative mistranslations are less likely to occur. Pairing the counsellors up with doctors on a more long term basis might have far-reaching benefits for both patient care and for relationships within the multidisciplinary team. This could further minimize the opportunity for information to be lost.

In this study, counsellor access to privileged and confidential information appeared to give them status in the eyes of the patients. Interestingly, the patient's folder served as a physical symbol of the counsellor's clinical status. Caregivers often requested that counsellors report to them what had been written about them in the folders. Counsellors in turn held folders out of sight of caregivers, thereby appearing to maintain their clinical distance and status. This is probably unsurprising given the importance of a folder within the health care system; without the folder medicines, transfers and appointments can't be accessed. The fact that caregivers feel comfortable requesting folder information from the counsellors and not the other health professionals, might indicate that caregivers feel closest to counsellors.

The findings from this study suggest that counsellors are limited in the degree to which they manage to tailor their message to unique patient circumstances. With current levels of training, counsellors appear unable to serve the art of healing; instead, they fill a technician role. The counselling by the adherence counsellors in the research clinic can not be equated to 'counselling' in Western contexts. It may be better to conceptualise our adherence counsellors as adherence monitors. Labeling them counsellors is to set them up for failure if there is an expectation that they will provide individualised patient care.

8.6 AFFECTING CHANGE

Both training programme and participant variables impacted on the degree to which the training programme was successful.

In the implementation of the training programme, it was felt to be particularly beneficial to have had the support of the chief medical officer at the clinic, as well as the manager of the counselling NGO in encouraging counsellors to participate in this study. Mash et al. (2008) emphasise the support of facility management in any in-service intervention, and counsellor

attendance at training has been reported by other researchers as being problematic (Baldassini, 2006). The support of the head of the clinic was useful in overcoming this.

Other facilitators in the implementation of the training programme were the involvement of the multidisciplinary team, and the combination of group and individual training sessions. Baldassini (2006) acknowledged that he had limited success with affecting change with the hospital and clinic management in his study. By including the multidisciplinary team in the counsellor training, the whole health care team was oriented to what the counsellors were doing. Furthermore, the importance of establishing a language policy that had ownership by all clinic participants could be emphasised. This study thus mirrored Mash et al.'s (2008) finding that a combination of initial training workshops, ongoing action reflections, small group meetings and individual mentoring is effective and essential given the poor correlation between clinician self-reports and what is observed in practice. Furthermore, this research confirms that Mash et al.'s (2008) recommendation that after initial training, learning should be based on audio or video data of actual counselling sessions, has merit.

Difficulties have been experienced in implementing communication training in some studies. In the university context, factors contributing to this are competing curricular priorities, decreased faculty time for teaching, and students' resistance to change in general and the content in particular (Kalet et al., 2004). In this research, like Evangeli et al. (2009), there was evidence of health system, counsellor, intervention and patient factors on the success of implementing the training programme. Although health system constraints such as time, space and organizational support were overcome through the motivation of the head of the clinic for the group training, these were definitely factors that impacted on the overall implementation. The group training programme was squeezed into two afternoon sessions, but more time was needed. Realistically within a busy clinic, this is likely to be the most amount of time available. The individual training was more severely impacted on by health system constraints, as it was difficult to find time and space to train each counsellor within the confines of a busy clinic. Creativity and resourcefulness on the part of the facilitator was necessary in order for the training to happen.

The importance of rapport being established between the facilitator and the counsellors can not be emphasized enough. As described in other studies (Nulty & Edwards, 2005), the counsellors felt energized by talking to the facilitator. A characteristic of the facilitator's style that stood out, was her encouraging and affirming attitude in working with the counsellors. The value of this was evident as counsellors were not overtly taught to be more encouraging. However, the facilitator encouraged the counsellors and was very encouraging in her role

plays. Counsellors in turn were more encouraging to caregivers after training than beforehand. Another reason for the increased encouragement by counsellors, was that from having individualized one on one attention and a feeling that they were being taken seriously, might have motivated them to give what Rollnick (2009) refers to as a ‘gift’ – a piece of themselves for free.

Regardless of the reason for why counsellors were more encouraging, an analysis of the transcripts showed that almost immediately after encouraging patients, patients asked a question. And if we are aiming to provide more patient-centered care in which eliciting patient needs and explanatory models is highly desirable, then it appears that we should be aiming to develop counsellors who are more encouraging. And to do this, we need to be more encouraging of them. So instead of teaching individual communication skills or following complex models, we should be simplifying the message by encouraging counsellors and giving them individualized attention. This should then reflect in the work they do with patients.

Facilitator selection was another important variable; this study shows the benefit of the researcher not being the facilitator too. The facilitator just came in to do her job – and the researcher then organized all other aspects of the training and research including motivating the counsellors to participate in the study.

The counsellor variables that impacted on the degree to which the training was effective, included baseline skill level, whether they were naturally good or poor communicators, prior training, whether or not they were openly HIV positive mothers themselves and their motivation. Counsellors varied greatly in their baseline communication skill level, and this level appeared unconnected to prior training. This suggests that natural communication skills developed over time are important to consider. Variations in health professional information-giving, the use of emotionally-centered comments, psychosocial discussions, partnership-building statements, facilitation of patient involvement and understanding and addressing client distress (Ford et al., 1996 in Ellington et al., 2006) were anticipated. Similarly, it was expected that there would be variations in the degree to which change could be affected in individual counsellors.

Individual counsellor variations in ability as reported by Evangeli et al. (2009) definitely played a role in determining the success of the training programme. One of the counsellors in particular was sometimes resistant to participating. Of all four counsellors, she showed the least improvement. Evangeli et al. (2009) recommend that individual variations impact on

training selection criteria. Certainly, in this study, the counsellors who on observation were doing the most counselling, interacted the most with the researcher and were keen to improve their own skills for their own sake rather than for financial remuneration, improved the most after training.

Training should boost self-confidence, and in line with AUM theory, should decrease anxiety and uncertainty thereby increasing the effectiveness of communication (Gudykunst & Nishida, 2001). The three counsellors who demonstrated the most change, namely Nokuzola, Babalwa and Lindiwe, were most confident about the effects of the training. This was evident from their requests to be video-recorded and the ease with which the researcher was able to obtain the necessary post-training video recordings. In contrast, Elsie, who was the most anxious and did not wish to be video-recorded, demonstrated the least impact from training.

Results from studies indicate that those with the lowest pre-course results improve the most (Chan et al., 2003). Although all of the counsellors in this study appeared to have good baseline paediatric HIV knowledge, Babalwa (who had no formal counselling training) improved the most from the intervention. This suggests that pre-course training rather than pre-course performance as suggested by Chan et al. (2003) is a factor in determining degree of improvement. Both Babalwa and Nokuzola, as openly HIV positive mothers themselves, brought their own experience to consultations and used self-disclosure to good advantage within consultations.

Of the reasons proposed by Mash et al. (2008) for the lack of success of their intervention with lay counsellors in the South African context (commitment to the profession, motivation and poor baseline communication skills), motivation appeared to be a significant factor in my study. Elsie's motivation to participate in the training programme appeared to wane towards the end of the study. Combined with performance anxiety, this could account for her desire not to be video-recorded after training. Interestingly, at the end of the data collection period, Elsie approached the researcher with a request that counselling colleagues of hers at another nearby hospital receive the same training as she had felt it was beneficial. The success of the training programme in the eyes of the counsellors was evident from counsellor recommendations to other counselling colleagues at other clinics to request the training, requests for copies of the DVDs in which they were recorded, and requests for additional video-feedback at a later point.

It appeared that matching counsellors with caregivers of the same gender may be necessary as gender issues are likely to play a role in the communication in the interaction. Richter et al.

(1999) reported on the difficulty that female counsellors have in discussing disclosure, communication with partners about sexual risk and use of condoms. In this study, there were definitely benefits to matching the gender of counsellors to the caregivers with whom they were working. This was felt to be beneficial as counsellors shared their own experiences of motherhood. Nonetheless, in this study it was not so much client *gender* as *sensitivity of the topic* which appeared to impact on how counsellors discussed issues. Even with female clients, sexual issues and disclosure remain very difficult to discuss.

Counselling in its narrowest sense refers to one on one planned interpersonal encounters aimed at influencing the counselee in a particular way for their intended benefit (directive counselling) or to assist the counselee to explore personalized alternatives and responses to their condition (client-centered) (Richter et al., 2001). In reality, in South Africa, ‘counselling’ can refer to any number of encounters. Counselling needs to be seen as a process, and should thus be viewed as a series of interactions. Counsellors comprise only one component of these interactions because patients receive input from doctors, nurses, support groups and pharmacies etc too. It is thus methodologically challenging to isolate the impact of counselling from outside influences.

8.7 WHEN THERE WAS NO CHANGE, WHY?

It is likely that a combination of macro- and meso- contextual factors impacted on the micro-context analysed in the counsellor-caregiver interactions. This is aligned within Chick’s (1995) belief that communication breakdown can be traced to social relations within communities that are constrained by ideologies and values of broader society. Contextual and environmental factors, including culture, economy, media, politics and organization influence communication (Street, 2002, 2003). The meso-contextual (institutional) factors impacted on the implementation of the training programme as well as the nature of the communication in interactions within the clinic. These institutional factors included the pressure on counsellors to fit too much information into a short session due to fear of patient LTFU; not developing an ongoing relationship with the care provider; the practice of off-loading the most hopeless cases onto the counsellors; and a lack of appreciation for counsellors by other staff members.

It is well-documented that fear of LTFU leads to counsellors attempting to cram too much into one session (Buskens & Jaffe, 2008). This was mentioned in interviews with counsellors. Rushing through too much information was visible in many of the consultations. Despite encouraging counsellors not to include too much information, this is unlikely to have any impact unless the clinic as a whole comes to an agreement about the limitations of what can

be covered per session as counsellors experience enormous pressure to impart information to patients because they have limited contact time with caregivers.

As with genetic counsellors (Ellington et al., 2006), caregivers typically did not develop an ongoing relationship of care with counsellors as that same client might do with a primary care doctor. Repetition that results in caregivers having to give personal information to different counsellors, as well as the accompanying duplication of information-receiving in sessions, was probably a source of frustration for caregivers. This is a barrier to developing a relationship between counsellors and caregivers.

Evidence of off-loading of difficult patients by health professionals to counsellors as reported by Baldassini (2006) was found in this research in two forms; Firstly, health professionals referred patients to counsellors without telling patients why. Although the cause was usually a need to change the regimen due to virologic failure, this was usually left to counsellors to explain to patients. Secondly, 'difficult' patients, such as the substance abuse case (K) in which it was perceived that there was nothing that could be medically done to help the patient, were also referred to counsellors. This made counselling particularly challenging.

My findings mirror those by Rohleder and Swartz (2005) that a perceived lack of appreciation by counsellors and teamwork problems impact on the quality of counselling. The findings thus reflect the marginalization of community health workers over the last two decades (Schneider et al., 2008). To some extent, these findings supported those by Nulty and Edwards (2005) and Buskens and Jaffe (2008) regarding burnout and poor continuity of care. It is also likely that counsellors in this research were unable to determine the effectiveness of their sessions which may have led to general demotivation. The research process of watching and analysing their own counselling was beneficial in helping counsellors assess their own counselling skills. Furthermore, the data from patient interviews afforded counsellors some insight into which issues patients do or do not easily understand. This would have assisted them in gauging their own effectiveness.

Communication training for *adherence* counselling, was impacted on by the nature of adherence counselling itself. Unlike infant feeding counselling and VCT which are both of limited duration and have a definite outcome (feeding choice and deciding whether or not to have an HIV test), adherence counselling is ongoing and has no clearly defined goal. This places a different demand on adherence counsellors in comparison to counsellors in PMTCT. This is critical as it appears that what defines 'good' adherence counselling, despite the job descriptions and established training programmes, remains intangible for counsellors.

8.8 HOW LASTING WAS THE CHANGE? PROGRESSION OVER TIME

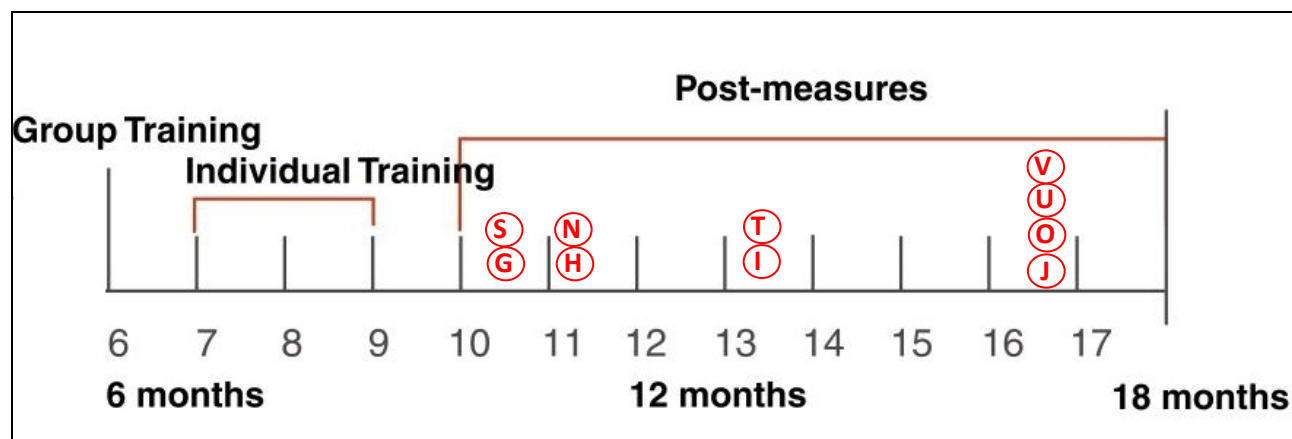


Figure 8.1 Timeline plotting month after training when video recordings of post consultations were recorded (videos indicated by red letter in a circle)

The cases recorded after training were collected over a six month period as illustrated in Figure 8.1. Although it was anticipated that the effect of the training programme might diminish over time, there was no evidence to suggest this. However, consultation V which was analysed to obtain a post-training measure for Elsie, was collected six months after training and showed the least impact from training. I feel that instead of this demonstrating the diminished effect of the training programme with the progression of time (which was not evident for the other counsellors), it demonstrated the value of sustained and continued data collection over time which was a reminder to the counsellors about the training. This does suggest that without follow up, the impact of an intervention will be minimized, even if the follow up is only in the form of continued data collection without additional support.

8.9 HOW GENERALISABLE ARE THE RESULTS?

When interpreting the results from this thesis, it needs to be acknowledged that the counsellors who participated in this study did so voluntarily and so are likely to represent the most motivated of the counsellors within the clinic. With their increased motivation, the results from this study may be positively skewed showing a greater change from training than if all of the counsellors had been obligated to participate.

The sample of consultations recorded in this study can be considered to be a representative sample of the type of consultations referred for counselling. However, they probably reflect the more hopeless cases within the clinic, as there was usually a reason (such as regimen failure) why the caregivers were referred for counselling. As such, the stories told by the caregivers in this research, whilst representative of the group of caregivers referred for counselling, are not likely to be representative across caregivers within the clinic.

The institutional tensions created by the position of counsellors within the hospital hierarchy and the impact that this meso context has on interactions, makes it unlikely that these results are generaliseable across other professions. Change as a result of communication training needs to be interpreted within the relationship between counsellor and caregiver. These findings therefore support Ellington's (2006) suggestion that there may be unique characteristics in interactions involving different professions.

The sample size in this research was very small. Although there were a number of constants across counsellors suggesting that the results are generalisable to other counsellors in the clinic, the variations by complexity of case suggests that there needs to be detailed analysis with consideration for the patient's communication in an interaction prior to forming a judgment on the communication of the counsellor in an interaction.

8.10 REFLECTIONS ON THE METHODOLOGY

Triangulation of both multiple types of data and multiple methods of analysis proved useful in this research for substantiating findings and creating detailed descriptions. The use of actual counselling consultation video data and transcripts enabled the researcher to move beyond just demonstrating participant awareness of change (Baldassini, 2006), and to measure actual change. Evidence of counsellors asking more open-ended questions and asking about patient feelings after training demonstrates the impact of the training in practice.

This research demonstrates the value of examining the process of communication from both members of the communication dyad as recommended by Hall and Visser (2000). In examining this process, this study is able to address the issue of how communication does and does not work and to gain insight into how contextual variables (patient background, disease and site) influence communication in interactions (Ong et al., 1995). This research demonstrates that finely-tuned qualitative research methods can provide greater insight into medical interactions. By not being limited to a predetermined checklist, this research enters the world of the participants. Not all aspects of communication behavior which appear in other assessment methods (especially in some of the checklists) as 'No-No's' seem to have an inhibitory effect. On the contrary, what we (as observers) judge as inappropriate behaviour may turn out (in this cultural context) to have a facilitatory effect aligning the patient and care-provider. This means of course that we must suspend judgment and look to interactional evidence for their effect (as a basic CA principle).

The structured approach of the hybridized form of linguistic analysis based on CA provided a system that can be replicated and could be followed independently by the rater team. As

found by Chopra et al. (2005), the discrepancy between global ratings and ratings of individual skills provides motivation for video-recording sessions so that they could be analysed and re-visited.

This study is limited by potential pitfalls in the translation, transcription, form and content of the analysis and the position of the researcher. Nonetheless, the final analysis produced a “coherent, persuasive, theoretically sophisticated and pragmatic account” (Brandt, 2007).

8.11 EVALUATING THE PARTICIPATORY ELEMENTS IN THIS RESEARCH

As described in Chapter 4, participatory action research has its own evaluation criteria, namely alignment with purpose, ownership of the process, development of reflexivity, democratic and collaborative group dynamics, commitment to action and experience, documentation of the process, transferability and construction of practical knowledge (Mash et al., 2008; Buskens et al., 2007).

The degree to which the research participants were aligned with the purpose of this study varied. The counsellors who volunteered for the individual training were more aligned than the other participants. The inclusion of the whole multidisciplinary team in the group training was felt to be only partially successful in aligning the other health professionals with the training. An overarching scepticism of the importance of communication and of the potential of counsellors to improve, appeared to underlie this. General health professional burnout, training fatigue and disharmony within the multidisciplinary team, would all need to be addressed to overcome this.

True Participatory Action Research should involve the research participants setting the aims of the research themselves. This was not possible for the overall study, however was achieved within the group and individual training sessions. The use of actual examples from their own clinic, made the didactic training component more relevant to all of the participants. Counsellor reflexivity was developed in the analysis of the individual feedback sessions. In reviewing the videos of these feedback sessions the counsellors initially required guidance from the facilitator on how to analyse and reflect on their own practice. However, they grew in confidence with practice. For this to be developed further, regular viewing of their own videos will be necessary. All of the participants made use of the opportunity to verbally reflect on their own practice and that of the clinic in the interviews after the consultations. Given the poor English literacy skills of the counsellors, journaling in English would not have been appropriate but could be taught in isiXhosa.

Within the multidisciplinary group training, there was full participation in the discussions and role-plays. The groupings were pre-selected in an attempt to achieve a balance of participants known to be more or less outspoken in the clinic. Despite dividing the group into smaller sub-groups, feedback within the group training may have been intimidating for some of the participants. It is recommended that when the case scenario feedback is given to the clinic, smaller groups working in separate spaces are formed. In the individual feedback sessions, facilitator and counsellor dynamics were characterized by engagement and much discussion, and were energy-filled.

The communication changes evident in the pre- and post- comparison and the counsellors' inclusion of new skills learnt in practice is evidence of their commitment to action. The whole multidisciplinary team's attendance at training, and counsellor attendance at the individual training, also shows this commitment.

The research process was well-documented through the triangulation of video recordings and transcripts, interview transcripts and questionnaires, journal reflections and video recordings of both the group and individual training. This documentation was necessary for the research process itself and for evaluating the impact of the training programme. However it proved beneficial for the research participants too which was evident in their requests for continued access to their own video data.

The improvement in the counsellor communication skills after training suggests that the transferability and construction of practical knowledge was a strength of this research. Although there are individual variations in the degree to which counsellors changed, this is to be expected in any training programme and suggests that a further strength was that the training programme was individualized to each counsellor's personal needs. As discussed earlier in this section, as the post-training measures were recorded up to six months after training and as no tapering off of results was noticed, this also suggests that there is a lasting effect from the training in the short to medium term.

8.12 ETHICAL CONCERNS RAISED BY THIS RESEARCH

This study has confirmed the invasive nature of qualitative research in the workplace (and ethnography in particular), and the vulnerability of not only patients but all participants and non-participants in an HIV context. As a result, a discussion of ethical issues is imperative. In this research, the NGOs, clinic, myself as researcher and the income-generating project are all vulnerable.

Contrary to my prior expectations, the patients in the clinic welcomed the intervention study and were keen to participate in the research despite no financial incentives to do so. I had made provisions to only focus the video tape on the counsellors (the main focus of my study), but a number of patients requested that they also be filmed and included in the footage. It was refreshing that the anticipated stigma and privacy, was not a preoccupation of this population group. The receptiveness of the patients to improving the skills of the health care workers in this study, makes a strong case for involving patients in developing and measuring quality care. If patients can be made to step up and demand quality care and to complain about care should it be sub-standard, it is far more likely that health care workers will receive the training and support that they themselves recognize is needed.

Prior to starting this research, my expectation had been that patients are vulnerable and that the counsellors participating in the study would be vulnerable as their work would be scrutinized. As the study progressed, I realized that the operational research underway meant that there was only a very fine line between participant and non-participant. Through my ethnographic field notes, it became apparent that both participant and non-participant health care workers (i.e. those who had chosen not to participate in the study) were being described in my field notes, and that an explanation for how the clinic functioned was incomplete without commenting on this whole picture. However, this was rendering those who were not participating in my study equally as vulnerable as the participants. Furthermore, as the study sample was very small and in-depth, this created difficulties in providing feedback to the clinic of the results I had obtained, as it would be very clear to others working in the clinic about whom I was referring.

Interestingly, in ethics guidelines, much is made of protecting the study participants, but not the non-participants. Although I accept that my ethnographic field notes were invaluable in adding to my understanding of the study context and some of the underlying tensions and dynamics between the different health care workers in particular, I have come to doubt the ethic of ethnography within a workplace setting. This study shows that an ethnography of the workplace is unintentionally invasive and has the potential to be damaging to interpersonal relations within the study setting.

Furthermore, I was insufficiently prepared for contingencies such as what to do if illegal activities were uncovered or if someone was not doing their job. Glimpses into the reality of hospital life made me question the role of the researcher. I had never expected to be completely objective and was well aware that the role of the researcher would impact on the interpretation and analysis of the data.

As the data collection process in this research unfolded, it became apparent that there were problems with the counselling in the clinic, related to counsellor motivation and mistrust in their abilities by other staff members. Some of the counsellors were not seen to be performing any counselling duties. As my sample size dwindled due to counsellor fear of exposing their lack of actual working, I was faced with the dilemma of whether or not to proceed with the research within that context. Surely my sample size would be too small? Certainly the counsellors who opted to participate in the study were very motivated to do so. I thought that this would be enough. Only when I started analysing and writing up the results, did I realize how exposed they, their profession, their trainers and the clinic were by my analysis. I needed to include details about their prior training and experience in order for my results to be accurately interpreted. Prior to starting the research I had considered the counsellors themselves to be vulnerable, but the extent of this vulnerability was more far-reaching than I had anticipated. I was also uncertain of the ethics of including ethnographic notes about those counsellors who were not performing their duties in the clinic – to what extent did the hospital ethics committee and the head of the clinic have jurisdiction over whether or not I could describe their activities in my research? At the same time, failure to report on this skews my data in an overly positive light – it suggests that all counsellors are motivated to change and will improve their skills by undergoing communication training. I do not believe this to be true; I believe that it is likely that some individuals can attend training but will not be motivated to make changes to their practice. Training techniques such as motivational interviewing for example might be more likely to succeed in such instances than communication skills training.

Ironically, the data collection method that I had assumed to be most invasive (video-recordings) invaded privacy the least. I feel confident that the caregivers and counsellors consented to the video-recording process and had ample opportunity to opt out were they to feel uncomfortable. This was not the case with the ethnographic field notes I took. How much more invasive was the pen than the video-camera! In sitting unobtrusively and taking notes on the comings and goings of hundred of patients and hospital workers, most of whom had no idea of what I was doing, I felt increasingly like a spy, a judge, an inspector.

Counsellors earn relatively little in comparison to other health care workers. By virtue of being female, black and living in South Africa, it is probable that they will be HIV affected (and possibly infected). Job security is more tenuous for people infected/ affected by HIV, as they may miss more work days due to sickness or increased care burden. By commenting on their lack of motivation and lack of visible occupation whilst at work, is to provide a glimpse

of only one facet of their lives. This is not something on which one feels comfortable sitting in judgment. We all have bad days; we might even have bad weeks or months. Would I want someone watching me all day?

I am left with a sense that ethnography is inherently unethical in its violation of individual human rights. Certainly it was useful and necessary to produce rich data of what was actually happening in the clinic. But does this good outweigh the damage, and if not, I am left wondering whether or not ethnography should be allowed in a working environment.

CHAPTER NINE

CONCLUSION AND RECOMMENDATIONS

This research shows that communication in HIV adherence counselling interactions can be modified through training. Furthermore, changing counsellor communicative behaviours can change patient communicative behaviours. In paediatric HIV, communication training for adherence counsellors is particularly effective in improving counselling towards improved patient treatment literacy.

Despite this success, we need to be cognisant of the impact of context on any communication training programme. Communication training has limitations because it is affected by contextual issues and women's issues. Evidence of this is found in the difficulty that counsellors had in discussing disclosure and sex, even after training. Findings from this study certainly support caregiver fear of stigma as being the primary reason for non-disclosure.

The complexity of paediatric ART as outlined in Chapter 2, is reflected in the content and the interactional dynamics of the consultation transcripts. The findings from this limited sample of four HIV counsellors in one context, support the contention that baseline communication skills of HIV counsellors is poor. Within the context of this study, it can be concluded that counselling, if envisaged through traditional Western lenses, is largely ineffectual. However, the extent to which this can be attributed to the counsellor or the disease-context, is difficult to surmise. These results do suggest that the paediatric-specific complexities proposed in Table 2.2 of Chapter 2 do contribute towards making adherence to paediatric regimens difficult for counsellors to explain. However, communication skills training countered this problem to some extent. After training, counsellors initiated the use of demonstrations and props to assist patient understanding. Counsellors also asked more open-ended questions, encouraged caregivers more, provided simpler explanations of treatment regimens and checked understanding more effectively.

My results provide testimony to the hardships faced by women as described in Chapter 2. In particular, narratives of financial difficulties, crime and changing household dynamics (sometimes but not always linked to HIV status) were all prominent issues that were openly discussed with counsellors. Furthermore, discussions of cultural practices were frank and open, suggesting patient ease in confiding with counsellors. Counsellors and caregivers appeared to identify with each other as women in poverty and they shared common stories. Furthermore, counsellors appear to be able to maintain an air of non-medical non-institutionalism about them despite their positioning in a clinical context.

Caregivers' stories were marked by resilience. Many of the caregivers were organized and showed forward planning in decisions about transfers, trips to the Eastern Cape and in their selection of which clinic to attend. Caregivers also made good use of the services available to them such as the clinic's income generating project and in accessing social support. These findings concur with others which show that in contexts such as PMTCT, women receive good support. This suggests that through paediatric HIV care, in addition to women themselves benefitting, paediatric services become a point of access into the system which is beneficial for whole families.

Some caregiver lifeworld concerns described in Chapter 2 were not discussed in any of the consultations, in particular, maternal mental health, partner involvement and stigma. Even when caregivers were openly emotional and wanted to stop taking ARVs, there was no evidence of counsellors referring caregivers on to a more skilled counsellor to assist the caregiver. Both physically and in discussions, male partners were ominous in their absence. Consultation transcripts appeared to reinforce the notion of clinics being perceived as the domain of women and children with little space in them for men. The dominant discourse was of absent fathers/ male partners. Whilst this does not negate findings that we are locked into our stereotypes of men as irresponsible neglectful, abusive and irremediable, the experiences of the women in this particular clinic support the commonly held view of male partners being disengaged. In the limited cases in which male partner involvement was mentioned in consultations, some had died and others had disappeared from their lives. In the only consultation in which a male partner was present, his relationship was being severely impacted on by his own substance misuse. Whilst no comment can be made on the extent to which brothers, male heads of households etc were involved in these women's lives, the children's fathers were absent. It is quite likely that counsellor reluctance to raise the issue of partner involvement, may be steeped in counsellor expectations that men are not likely to be involved. A belief in the potential benefits of male involvement may need to be engendered in both caregivers and counsellors. There was also limited discussion of other adults and children living in the home as recommended in the guidelines. So although the clinic offers a family-centered approach (all treated under one roof; 24 hour walk-in policy etc), this is compromised by counselling still being centered on the individual. There is a need for counsellors to conceptualise each caregiver as existing within a community and a family.

Although stigma was never overtly discussed, there was evidence of fear and stigma in caregivers' reluctance to discuss disclosure, as well as in the collusion and mitigation by the counsellors. Stigmata, 'abominations of the body', were evident in caregiver descriptions of

how the side-effects of the drugs made them feel and this resonated in a number of caregiver accounts of their illness. These stigmata appeared to be the primary reason for caregivers wishing to cease taking ARVs. Contrary to some of the literature which has depicted nurse counsellors as being particularly judgmental, no prejudice or judgmentalism was shown by any of the adherence counsellors in this study. However, counsellor avoidance of delving deeper into caregivers' lies and omissions, reinforces 'that which lies beneath' and may in fact be reinforcing stigma.

These findings support others in which metaphors are used to describe HIV. Metaphors used in this study conjured images of weighty baggage that is difficult to conceal. That the word HIV is unsayable was evident in only a few of the consultations. Counsellors generally used the word HIV and did name the disease in most consultations. This was a sign of counsellor openness and fits recommendations that health care workers should use factual references for HIV to prevent stigma from being reinforced. Caregiver internal stigma was evident in a case in which the caregiver denied transactional sex for example. Cases such as this provide further substantiation of the vulnerability of women in South Africa.

Counselling in paediatric HIV is highly complex and the counsellors tasked with this job have poor working conditions and self-esteem. Nevertheless they play a very positive role in bridging the doctor-caregiver divide. This is evident in the successful patient advocacy, interpreting and cultural brokerage roles they fill. These under-acknowledged roles need to be recognized and applauded because they are instrumental in improving patient access to services and in promoting patient retention in care.

This research appears to contradict suggestions that patient-centered and educational models are necessarily at odds with one another. In addition to improving treatment literacy, after communication training, consultations became more patient-centered with counsellors asking more open-ended questions. As counsellors became more patient-centered, caregivers shared more information. However, counsellors appeared to be at a loss in terms of knowing what to do with this information. In contrast with other research which suggests that caregivers and counsellors may have agendas that are at odds with one another, a major finding from this research is that the caregivers and counsellors share the same agendas, but there may be a schism between this and the perceived expected medical outcome. Thus the public health 'script' appears to be misaligned with the patient-centered model. The health care team's desire to put patients on treatment and moral/ ethical obligations to prevent infection and sustain life, may be incompatible with what the patient desires at that stage in their life or feels able to achieve with the limited resources available to them. One is left wondering

whether the clinic actually wants patients to share their stories and to find out what patient beliefs are, or whether the clinic covertly desires that patient conform to the ‘Western’/scientific way. If the former is true, and the healthcare team genuinely does want to find out what patient beliefs are, then it appears that counsellors may not be aware of this.

Systemic challenges were most evident in health care worker expressions of anxiety regarding the need to speed up the time taken to get patients on to treatment because of fears of LTFU. In this study, counsellors appeared to be underproductive. Counselling mothers at routine visits as recommended in the guidelines did not occur. Referrals to counsellors usually came from doctors, occasionally from the patients themselves or even less frequently, from the counsellors. Certainly, the varied caseload and complexity of cases lends support to their role being taxing. Ethnographic notes suggest that minimal counselling is happening, and this supported doctor and nurse frustrations about the lack of counselling. Of particular concern, appeared to be the fabricated lists of which patients had attended counselling that appeared to have been submitted to the NGO employing the counsellors.

Counselling in its present form is not an effective means of task-shifting and is not a solution to the human resource crisis. There is no comprehensive ‘plan to support adherence’ tailored to the individual’s needs. Rather, a one size fits all approach is being followed; this is a product of health system deficiencies and resource constraints. Counselling may in fact be compromising the quality of care in some instances. This is, however, largely dependent on the individual conducting the counselling. A negative experience with a counsellor could seriously jeopardize caregiver motivation. As described by Steinberg (2008, p.97), “The magic must light up the whole system at once. All is connected. One dark corner can short-circuit the whole.” The role of the counsellors, their motivation and the quality of their service needs to be prioritized and taken very seriously so that it does not taint perceptions of overall quality care. However, not all of the counsellors are doing a bad job. The study methods strongly showed the value in research that examines individual counsellors in detail as there are individual variances.

This study responds to this identified need for an evaluation of counselling services. The methods used in this study appeared to get to the heart of the issue and were more sensitive than checklist approaches. This is evident in the detailed verbal and non-verbal information elicited from the hybridized analysis approach. The qualitative methodology allowed for new and complex dynamics to emerge. This study thus questions the validity of checklist approaches as they do not allow for consideration of micro, meso or macro contextual influences. Resting on the premise that communication is a dynamic process, and what and

how it is said by one partner, impacts on the other partner's response, this study is a departure from many other counselling studies that have examined the communication of only the counsellor within interactions. The hybridized analysis approach elicited highly individualized results for each counsellor. This fits within a constructivist approach in which individual modes of learning are encouraged. Averaging out these results using a more quantitative methodology would dilute the individuality of each participant's communication and the richness of each unique case would be lost. Intervention studies, despite their design complexity, are needed to measure the impact of intervention in practice. Small studies such as this one, although limited in their generalisability, provide depth and detail that are lacking in larger studies. This is beneficial for making practical recommendations.

This research aimed to improve the communication in counselling interactions, in order to improve the quality of the interactions. Good communication is viewed as an absolute necessity for any counselling interaction, and this study demonstrates that effective communication can be taught. The purpose of this study is not to add to an already burgeoning array of guidelines on HIV counselling, but to make recommendations with regards to barriers and facilitators to communication in-service, that can or cannot be overcome with communication skills training. The identified facilitators and barriers have practical application which should assist in a clinical context.

Overall, results from this study add to the existing body of knowledge on how to achieve the best possible standards of care for people living with HIV/AIDS within the limited resources available to us in South Africa. Most importantly, this study addressed issues relating to quality of life of both people living with HIV/AIDS and that of their care providers. Findings from this research should improve the quality of care in HIV/AIDS counselling and should contribute to the body of knowledge of best practice in HIV/AIDS.

9.1 RECOMMENDATIONS

The counselling provided by Nokuzola, Elsie, Babalwa and Lindiwe at Lady Evelina Clinic reflects a fairly typical counselling service in a paediatric ARV clinic. At the time of data collection, the clinic was involved in transferring patients out from the central service to outlying clinics in accordance with the expansion of the national ART programme. The counselling service being offered at Lady Evelina clinic was most often utilized pre-initiation of ART, or in response to the call for 'intensified counselling with sub-optimal adherence' as specified in guidelines. Of the other types of counselling recommended in the guidelines, the adherence counsellors in the study clinic did not cover infant feeding, nutritional support (patients are referred to the social worker or nutritionist) or support for counselling towards

disclosure in children. They did provide support for TB, diarrhoea, palliative care, pre-initiation of ART and some limited 'on treatment' support. Pre- and post- test counselling were provided as requested. The counselling at Lady Evelina Clinic does differ from many services as it is not based in the community. This needs to be kept in mind when transferring findings and recommendations from this research to other settings.

This study has implications for the multidisciplinary team and the role of communication training in these teams, counsellor selection criteria and working conditions, as well as research in this field. The results from this undertaking suggest that site specificity needs to be accommodated within research and clinical interventions. Furthermore, language experts are needed in both clinical and research contexts to ensure that language complexities are taken into account.

There is a need for communication skills training of adherence counsellors working in the field of paediatric HIV. This is unsurprising given the limited training and supervision of this cadre of health care worker and the demands of their job which requires extensive knowledge and skill which in other countries might involve lengthy preparation and training. With the increasing emphasis on the need for task-shifting given the dire health care worker shortages in Africa and the large population group needing ARVs, this will be a growing problem in years to come. Given that many women are HIV positive, vulnerable and will want to have children, coupled with a moral obligation to prevent vertical transmission (because HIV is a preventable disease), this is a population group that needs quality intervention by skilled workers.

In South Africa, the current counselling enterprise appears to pay lip-service to the task-shifting called upon in UNAIDS and WHO releases. Existing health care system constraints suggest that counselling is unlikely to improve in the near future, unless there is drastic re-thinking of the stop-gap solution that is currently operating in which lay persons with limited training, earning minimal pay and receiving little support, are performing this role. The current emphasis on task-shifting means that in all likelihood, the number of counsellors may increase exponentially over a short period, resulting in even larger numbers of poorly trained, poorly paid, demotivated counsellors; a shoddy response to a critical need. Both political and personal will are needed to improve this situation. This may well mean substantial more investment in training and recruitment of the right people for the job. Integrating this large body of lower cadre health care workers without appropriate career advancement into the formal health sector may compromise quality resulting in mediocrity.

The solution may lie in communities of women and a team-based approach. Greater economic empowerment of women is needed and health workers need to be supported to follow a team-based approach. To make counsellors part of the health care worker team, we may need to revisit the traditionally impartial, external de-briefing sessions and look at ways for the health care team to be debriefed together.

There is a strong case for caregivers who themselves are HIV positive and are coping well with treatment, being more involved in clinics. A mentor model in which counsellors are matched to doctors full-time, so that they are better supervised, are required to be accountable at all times and are more engaged in patient care, might need to be created. The lack of career advancement and job stagnation also needs to be addressed. The length of counselling contracts should also be reviewed. Models such as the Mothers to Mothers to Be model in which mentor mothers work for a limited time period (approximately 13 months rather than indefinitely) on specific tasks, should be investigated; this can prevent fatigue, boredom from the repetitive job and institutionalisation. Furthermore, it may create competition and demand which may improve quality. It will mean more training, more frequently, but may also result in better trained and skilled counsellors who with more developed skills, may be more employable at the end of their contract term. Such an approach is likely to place enormous strain on supervisors in the clinical context, so steps need to be taken to develop a cadre of mid-level supervisors to manage such an approach. Substantial investment is needed for this to succeed.

The lack of supervisory frameworks and support for counsellors remains a problem in this particular clinic. As with all cadres of ad hoc health care workers, if the counsellor is to be a respected and accepted part of a multidisciplinary team, their line of reporting needs to be to the clinic head (as with all other staff) and rules of the clinic need to apply equally to them. As discussed in Chapter 2, researchers have recommended that counsellors be provided with external support from someone independent of the hospital. This is a common counselling recommendation that merits closer examination. External support is obviously useful in terms of preventing counsellor burnout, however in the current context, creates a number of additional problems. There is greater separation from the multidisciplinary team which detracts from continuity of care. This is noticeable in counsellors sharing stories with each other and with the psychologist debriefing them, but not with other members of the multi-disciplinary team. Furthermore, in the study clinic, the blurred lines of reporting and the creation of a ‘mystique’ surrounding what counsellors actually do and health professional scepticism regarding their productivity appeared to be a product of this external support. External de-briefing sessions enabled counsellors to cloak all

that they were (or were not) doing within the term ‘confidentiality’ to justify all actions. This was contributing to mistrust within the multidisciplinary team.

This research supports the need for ongoing debriefing and counsellor in-service training. However to avoid some of the divide that this external debriefing is creating within the multidisciplinary team, the involvement of a neutral (probably external) figure to facilitate mixed discussions with counsellors and other multidisciplinary team members, may be more beneficial to teamwork and harmony. Using a facilitated workshop approach in working through counselling case studies may be an appropriate method of addressing communication issues in a clinic.

There is a need to revise models and to better understand the role counsellors fill. I question the value of the existing model of adherence counselling in which counsellors are responsible for providing psychosocial (and other) support with very little training. In the study context, the title of ‘counsellor’ appeared misleading. In this study, adherence counsellors fill the role of interpreter, patient advocate and treatment literacy supporter admirably. Tasks that are goal-specific and do not require flexibility or innovation, are well-performed and the communication skills required to take on those tasks can be easily taught. However, the title of ‘counsellor’ implies far more than this. This study demonstrates that the wide range of complex issues with which adherence counsellors are expected to deal, is unrealistic given their existing capacity. Training counsellors in communication skills is insufficient to prepare them for the complex human predicaments they need to manage. In fact, training may just add to their confusion as it taught them to be more patient-centered and to follow the patients’ lead, which only served to expose counsellors to new complexities which they were ill-equipped to manage.

Given the resource constraints and the limited training and supervision available to adherence counsellors, it is unlikely that they can succeed at the tasks set for them. With the increasing push for task-shifting given limited human resources, much clearer role definitions are needed. Appointment of ‘adherence counsellors’ appears to be little more than just lip service to what has to be the most critical role in ARV treatment. Rather than setting these counsellors an impossible task, it may be more beneficial to divide the role into more specific responsibilities and train them well for these tasks as recommended in the task-shifting literature.

Literacy skills need to be a consideration in counsellor selection. Once employed, counsellors need to be supported in providing accurate record-keeping. This would assist in

demonstrating changing caregiver needs over time, in listing which factors have been discussed including which terms were explained at each session, recording whether caregivers had practiced implementing new knowledge (e.g. measuring of medication) and documenting psychosocial needs including transport and changing home circumstances. This study shows great variation in individual counsellor ability and motivation. In-service, regular re-assessment of counsellor motivation is needed. Equally important, there needs to be recognition that not everyone can be a good counsellor.

A bottleneck to carrying out research in this field is the mistrust of research held by counsellors with their relatively limited education. The development of a research culture will be important for furthering advances in this field. Advocacy for an attitude shift in both counsellors and in patients is also needed. We need counsellors who are more giving and less demanding (of their right to tea breaks, to working hours and to maintaining confidentiality at the detriment to patients); and we need patients who are more demanding, and less accepting of mediocrity in service.

Finally, we need to revisit and rewrite the current counselling script: Do we want patients to be on ARVs who do not want to be on them? And if the answer is no, how then do we deal with the ethical concerns over children's rights to be on ARVs if their parents do not want them to be on them? Counsellors need to be relieved of all perceived responsibility that their role is to persuade patients onto ARVs. They need to maintain neutrality and non-judgmentalism of counselling and there needs to be acceptance from the health care team, that although this will not produce the statistics they may need, that those patients that do choose to be on treatment, truly want to be and thrive on the first line regimen. Quality and not quantity needs to be emphasized: Counsellors need to be told again and again to slow down; take pride in a job well done, and to document thoroughly.

9.2 FINAL REFLECTIONS

When this study began, I started from a viewpoint of research observer. As an outsider to the clinic, what struck me most was the sitting around, eating and counsellor inactivity amidst the bustle of a busy clinic. I had an overwhelming sense of frustration that so little counselling was happening. And this frustration resonated and was echoed in the comments from doctors, nurses and some of the counsellors themselves. My prior reading and experience with other community health workers such as interpreters has prepared me for this scenario and had shaped my judgments. As I became immersed in the counselling transcripts and videotapes and was exposed to layers of stories - counsellor stories, caregiver stories, systemic stories

and children's stories - I realized how misdirected this frustration was and how my perspective had become biased from my prior research experience.

As the study unfolded, I progressed from despair at a lack of energy, motivation and activity in the study population, to an appreciation that the same social circumstances that beset the patients in this study, also applied to the counsellors. They too were women, vulnerable, desperate enough for work to take on a job for which they may not have felt particularly motivated and for which they were not well remunerated. For the majority, the poor pay, monotony of the job, seeming futility of discussing unresolvable issues, lack of career path, lack of appreciation from fellow health care workers and bizarre system of separate lines of reporting, meant that within the 'system', as with other cadres of ad hoc community health workers, counselling truly was a thankless task.

If you feel angst for the children, mothers and families affected by HIV in South Africa as evidenced in the consultation extracts in this thesis, then feel this for the counsellors too. For their stories are actually one and the same. Who was I to be judging them? And how ludicrous is this system that passes the most difficult and most important job in HIV adherence management on to those whose resources are already so strained? And then to criticize this! As replicated at the start of this thesis, in one of their newsletters, the Women's Public Health Network published a linocut by Austin Helza depicting six women holding pots above their heads and children on their arms on either side of a rondawel. The caption "Women hold up half the sky" keeps returning to me. Again and again. I love this linocut. It feels very true, and yet not true enough. *Half* the sky? *Only half*? What about the sky above their children's heads too? We need a portrait of counsellors, holding up women, holding up children, holding up the sky, whilst treading water.

The burden of paediatric AIDS falls on women. They shoulder a heavy burden as do the counsellors working with them. It is imperative that we improve the lives of women. This thesis has shown that interventions will have limited impact until this can be achieved.

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APPENDIX I

A summary of the types of counselling recommended in managing children on ART that are recommended within the NDOH (2005) guidelines and are relevant to caregivers of children on ART

Infant feeding choice for pregnant women (p26)	Pregnant HIV positive women need to be counselled regarding feeding options. The guide recommends that HIV negative women and women of unknown status are not counselled on infant feeding options, but should be supported to exclusively breastfeed for 6 months, and should continue to do so for at least 2 years.
Nutritional support counselling (p28)	This needs to recognize cultural and financial constraints and information should be provided on food preparation, hygiene, improving energy and nutrient density of meals and examples of nutritious low-cost foods as well as stressing the susceptibility of HIV-infected infants to gut infections.
Support for children with TB (p45, 85-86)	The caregivers of children with TB need to receive accurate and detailed information about the diagnosis, the need to complete the full course of treatment and the possibility of other household members having TB. There are different treatment scenarios to consider depending on whether the child presents with TB prior to starting ART or if the child develops TB whilst on ART, which need to be communicated to caregivers.
Support for children with diarrhoea (p48)	This involves counselling mothers on recommendations for managing feeding, how to mix oral rehydration salts safely and management of dehydration at home, which needs to include a discussion of giving extra fluid, continuing feeding and knowing when to return to the clinic.
Palliative counselling (p74)	Palliative care is defined in the guide as ' <i>The active, comprehensive care for the physical, emotional and psychosocial needs of the child and the family</i> ' (DOH, 2005: 68) rather than just care for children for whom no cure is possible. In addition to relieving pain, in the management of children who are imminently terminally ill, counselling needs to be individualized in order to provide emotional support to the dying child and to the grieving family. For home-based palliative care, caregivers need to be reassured that the child has not been abandoned by the health service.
Pre-treatment adherence counselling (p100)	Counselling as part of adherence monitoring is specified pre-treatment, and should include information and education as per visit schedule, caregiver and patient are introduced to counsellors and patient advocates, home visit is arranged, monitoring of co-trimoxazole for one month.
On-treatment adherence counselling (p100)	Counselling for adherence once treatment has started, should include ART pill/ syrup counts, routine discussions about adherence which is open-ended with time for repetitions and questions and encouragement of support group participation. A monthly visit for three months is recommended, followed by quarterly counselling sessions.
Step up adherence counselling for non-adherent patients (p100)	This is recommended for people with reduced adherence or virological failure. It should include re-education to the patient and caregiver and their 'buddy' with emphasis on the long-term benefits, evaluation of the support structures in place, considering the use of adherence aids, insistence on support group participation, checking the family situation, increased home visits and consideration of directly observed therapy for a given period.
Pre-test counselling (p112)	This should be conducted in a private area, and should include a discussion about confidentiality, the reasons for HIV testing, offer information about HIV/AIDS, the implications of a positive/ negative result, information about the HIV antibody test and window period, how the test is done and when the results will be ready and informed consent.
Post-test counselling (p113)	This needs to be conducted irrespective of the result and should occur as soon as possible in a quiet and private room and should include giving the result, an explanation of the window period, discussions about safe sex, providing information and emotional support and a discussion of how the recipient plans to cope and identification of support. If the test is positive, patients should discuss with whom they want to share the results, ways they need to take care of their own health, the implications for pregnancy if relevant, the implications for feeding if relevant, trouble-shooting, referral to appropriate support in the community, plans to return for a follow up session and what to expect if the child is HIV-infected.
Counselling towards disclosure to children (p116)	This is recommended prior to adolescence and is a process, not a once off event which is dependent on the child and the caregiver's readiness.

Appendix II Recommendations from Philips et al. (2008), Schneider et al. (2008) and Zachariah et al. (2008) for effective task-shifting

Appropriate remuneration	Health workers must receive a decent salary that constitutes a living wage and that is commensurate with their responsibilities. This will sustain outputs over time, without the need to make patients pay for their care. A change in remuneration and other retention measures are indicated as studies show that retention of professional health staff and lay workers in active clinical work is hard. Staff losses carry repetitive costs linked to training and supervision of new personnel in the medium and long term.
Improving working conditions	Leave and complaints mechanisms should be improved beyond the existing provision of stipends. This may benefit staff-retention efforts.
Limit the number of tasks per role	These workers should not be expected to do many different tasks because quality of care is compromised by excess work load and complexity. Once tasks have been clearly defined, clear job description and remuneration packages need to be established. Clear delineation of boundaries and responsibilities are needed to ensure good team work.
Training for CHWs	Like all other health care workers, lower cadres of workers also need adequate training. Inappropriate curricula, poor supervision and weak regulatory mechanisms affect the quality of care provided by any cadre.
Provision of support and supervision	Supervision and support are needed to avoid stress and burn-out. In particular, nurses need to develop the capacity and confidence to cope with the increased workload for supervision.
Training for health professionals	Professionals need to be trained to engage with and support CHWs.
Developing the role of NGO intermediaries	This will facilitate ongoing training and support of CHWs and professionals.
Viewing the CHW role as a means to an end	Not viewing the CHW as an end-point, but rather as a means to an end, and accepting a high degree of turnover
Creation of formal sector mid-level categories	Counsellors would fall within this category and would have skills and experience in specific domains which would allow for fairness in the opportunity to enter the formal health sector.
Developing expanded models	Integrating prevention with care and promoting community-based roles without fixing a single identity or job description to CHWs.
Avoiding over-regulation	Maintaining balance between regulation and flexibility. Care must be taken to avoid banning initiatives that may occur outside of regulatory frameworks and that contribute to delivering effective care. Granting 'temporary pilot status' to programmes engaged in task-shifting may be a way to get around this.
Application of easy-to use technologies	Detection of treatment failures by lower cadres of CHWs could be improved by increasing the availability of technology.
Not cutting down on staff	Task shifting does not equal a need for fewer staff.
Participant involvement in target-setting	Patients, health staff and policy makers should be involved in setting measurable targets and indicators to an acceptable level of quality.
Accreditation and registration	This will ensure that health workers have the necessary skills and capacity for specific interventions and legitimises them, and ensures institutional responsibility for the performance of that cadre.

Appendix III

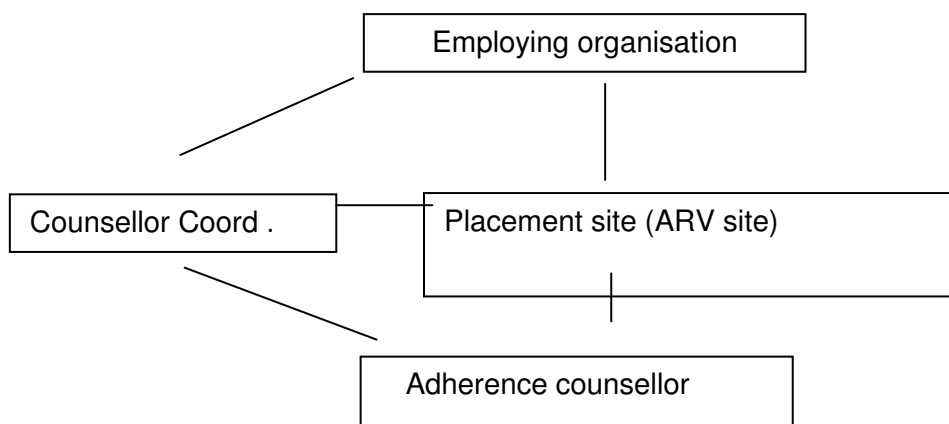
ADHERENCE COUNSELLOR JOB DESCRIPTION

Job Information Summary

Name and Surname	:	
Job Title	:	Adherence lay counsellor
Date	:	
Location	:	ARV Treatment Centres
Component	:	Post reports to:

ORGANOGRAM

▪



B. Job purpose

To be part of the broader comprehensive care and treatment counselling initiatives of National, Provincial /Regional / District Aids Plan as it is implemented.

C. Key Performance areas

C1 Treatment Readiness

- Facilitate structured ARV treatment readiness group sessions for prospective clients
- Conduct individual counselling for prospective clients to ensure treatment readiness

- Conduct individual or family counselling (identified family treatment supporter) during enrolment process to ARV for those clients eligible to initiate treatment
 - To provide pre and post-test counselling at ARV sites when requested (this is not a major activity, since most have already been diagnosed in other services)
- C2 Ongoing Support
- To provide ongoing supportive counselling to enrolled clients and follow up on their needs
 - To provide access and/or conduct psycho-educational support groups for clients on treatment
- C3 Record Keeping
- Accurate client record keeping, data collection and compilation of monthly report forms as determined by the site
- C4 Multi Disciplinary Team Case Management
- Discuss problematic cases with team and co-ordinate management strategies
 - Detect and report barriers to adherence
- C5 Defaulter Tracing
- Defaulter tracing and other trouble shooting home visits or arrange for this as needed.
- C6 Ongoing training and District Management
- Participation in counselling co-ordination meetings and any appropriate training workshops arranged or organised by the ARV site
 - Compulsory fortnightly supervision and debriefing sessions preferably at the site (will be negotiated with the employing NGO)
- C7 Communication
- To provide education and information on HIV/STI/TB and ART related issues in the waiting rooms of the ARV site
 - Assist as language/communication mediator between patient and doctor

D. Key Performance areas/Outputs required (results)/Performance Standards and Indicators.

Key Performance areas	Job Outputs	Performance Standards	Performance Indicators
C1. Treatment Readiness			
Facilitate structured ARV treatment readiness group sessions for prospective clients (each prospective client to attend 3 compulsory treatment	1hr 30 min Group-health education session on: -how ARVs work -criteria for admission -Importance of compliance	-In line with treatment readiness counselling guidelines (will be made available) -Batho Pele. -group sessions of not more than 10	-Patient/client informed decision-making. -No of clients attending each group session

readiness educational sessions)	- alcohol effect on treatment - importance of support - safe sex		
Conduct individual counselling for prospective clients to ensure treatment readiness	Recapping on Information given in group session: - Determine and ensure good client understanding around ARVs -deal with concerns -pick up any issue that might impact on treatment	-Privacy -confidentiality Batho Pele	-Recording of assessment
Conduct individual or family counselling (identified family treatment supporter) during enrolment process to ARV for those clients eligible to initiate treatment	-Good communication skills (Greet, Eye contact, body language, non-judgemental) -Determine support systems -Determine and ensure good client knowledge level around ARVs -Client consent -Take client/family through process -Discuss safe sex - Arrange for follow up counselling (whether on day of treatment initiation or 2 weeks after treatment initiation to re-inforce adherence)	-Privacy -Confidentiality -Batho Pele -ARV Protocol	-ARV Treatment Uptake -Recorded treatment support with contact details
To provide pre and post-test counselling at ARV sites when requested (this is not a	-Good communication -Reasons for testing, coping skills, support systems	-Confidentiality	- no of VCT done at treatment site

major activity, since most have already been diagnosed in other services)	-consent -preparation for rapid test		
C2. Ongoing Support			
To provide ongoing supportive counselling to enrolled clients and follow up on their needs	-Active listening -Advice on positive living and referral networks -Encourage disclosure to partner/family if not done -Motivate for partner testing if not done -Re-inforce importance of treatment compliance	-Confidentiality -Privacy	-Number of clients coming for follow up support and attending the support group/s -Number of clients who continue to have family treatment supporters
To provide access and/or conduct psycho-educational support groups for clients on treatment	-Run compulsory monthly support groups in line with client's appointment for medication refills. Support groups to be run according to length of time on treatment e.g. 0-3/12, 3-6/12, 6-1yr and one for over 1 year -Know resources available that could assist with the support groups	-Batho Pele -Confidentiality	-No of clients attending support groups -Ability to disclose/discuss treatment issues with partner/family
C3. Record Keeping			
Accurate client record keeping, data collection and compilation of monthly report forms as determined by the site	-Collate monthly data on records used and/or as requested by site -Feedback to service point supervisor and lay counsellor co-ordinator	-Data collection as determined by site	

C4. Multi Disciplinary Case Management			
Discuss problematic cases with team and co-ordinate management strategies	-Fill in compliance assessment form for each new clients for at least the first 3 months of treatment (will be made available) -Ability to explain treatment side effects and their management -Operate as first line contact for client/s experiencing problems	-Accurate information sharing within the Multi-Disciplinary Team (MDT) context - Confidentiality of all matters discussed within the MDT	Recording in client's folder problems and actions taken
Detect and report barriers to adherence	-Determine reasons for treatment non-compliance	- Accurate information sharing - Confidentiality	-Report to team on barriers to adherence
C5. Defaulter Tracing			
Defaulter Tracing & other trouble shooting home visits or arrange for this where needed	This will depend on treatment readiness assessment and request by doctor -Arrange for home visit either self or by treatment support service if there is one linked to the site. If hospital based liaise with ARV treatment site in district where client comes from (with client consent to this) or team to make alternative arrangements	-Risk assessment -Confidentiality -Empathy	-No of clients needing trouble shooting home visits and number not accessed because of logistical problems

C6. Ongoing Training & District Management			
Participation in counselling co-ordination meetings and any appropriate training workshops arranged or organised by the ARV site	-Any other relevant training not organised by the site to negotiated with site supervisor		
Compulsory fortnightly supervision and debriefing sessions preferably at the site (will be negotiated with employing NGO)	- Debriefing sessions to be arranged with site and to be on the days that suit the service		
C7. Communication			
To provide education and information on HIV/STI/TB and ART related issues in the waiting rooms of the ARV site	Information on: -How ARVs work -Drug classes -Side effects -Resistance	-Accurate information in line with guiding protocols	- Topics covered
Assist as language/communication mediator between patient and doctor	-Required to assist in interpretation	-Good communication skills	-Well informed clients

E. Inherent requirements of the job

1. Senior certificate or equivalent
2. 3 years experience as a VCT/PMTCT lay counsellor.
3. Emotional stability
4. Good interpersonal communication skills
5. Basic administrative and time management skills

Learning field

In-service training / learning on a continuous basis.

F. Career Pathing

Not applicable – contract post.

G. Job Agreement

SIGNATURE OF POSTHOLDER

SIGNATURE OF SUPERVISOR

DATE

DATE

**A discussion of communication in the key performance areas in the DOH adherence counsellor job
description: The researcher's interpretation of how communication relates to C1 – C7**

C1: Treatment readiness:

Treatment readiness sessions occur individually or in groups. A decision about treatment readiness involves establishing the client's motivation to be on ARVs, whether they have considered disclosure and if so to whom, and finding out what they know about HIV and ARV. Counsellors are required to have good communication, which is specified as including '*Greeting, eye contact, body language, non-judgmental*) and obtain client consent. As counsellors are expected '*to determine and ensure good patient understanding around ARVs*' and '*to pick up on any issue that might impact on treatment,*' conversations need to be extremely broad and cover many areas.

Discussions about treatment readiness presuppose the ability to question the patient about their *social circumstances* (Risk factors for adherence such as poverty, unemployment, family structure, substance abuse and the interaction of alcohol and ARVs, and support at home, relationship with sexual partner and cultural practices) as well as communicating *medical information* (TB, STIs, ARVs – how ARVs work, timing and dosing commitment, names of medicines including generics, common names and abbreviations, the importance of adherence, family planning, HIV transmission) and *information about how the clinic works*, to the patient. As not all HIV positive patients in South Africa are eligible to be on ARVs from the state, a discussion of criteria for admission (which will include CD4 counts and viral load testing) needs to occur. In addition, the procedural aspects related to medication – such as how the clinic works, how often appointments are scheduled, who does what in the clinic, what social welfare and support groups are available, clinic layout such as where the pharmacy is and how the folder system works, as well as troubleshooting what to do if problems occur. Clients requiring treatment readiness have usually already been through the process of pre- and post-test counselling, however, if this has not been done, then adherence counsellors provide pre and post-test counselling. Information provided in pre- and post- test counselling includes establishing the reason(s) why the patient wants to be tested, a discussion of sex and transmission of HIV, support systems, consent, confidentiality and preparation for a rapid test.

As the primary aim of C1 is the assessment of patient treatment readiness, the counsellor needs to make a recommendation to the multidisciplinary team on the patient's understanding of all of the above, and so is required to be sufficiently skilled to determine patient level of understanding. It is recommended that each prospective client attends 3 compulsory treatment readiness educational sessions.

C2: Ongoing support:

Counsellors are expected to provide ongoing support by questioning how clients are coping with adherence and following up on their needs. These needs may be related to medical and treatment related concerns (side-effects, adherence, dosing queries, drug classes, resistance and first and second line regimens), how the patient is coping psychologically (disclosure, motivate for partner testing if not done, family support, feelings about death and dying, stress), the patient's social circumstances (income generation, referral for social grants, financial situation, changes to the family, family planning) and continued discussions on living positively and the importance of adherence. As part of the provision of ongoing support, counsellors provide access to psycho-educational support groups for clients on treatment and to know which resources are available that can assist the support groups. Counsellors are expected to demonstrate active listening skills.

C3: Record Keeping:

Counsellor's are expected to keep accurate records, collect data and compile monthly report forms as determined by the site. To do this, the counsellors have to have adequate literacy and report writing skills to be able to report on the many issues discussed within sessions.

C4: Multidisciplinary Team Case Management:

Counsellors are expected to discuss problematic cases with teams, co-ordinate management strategies and '*to detect and report barriers to adherence*'. This presupposes that counsellors have knowledge about risk factors for adherence, and that they are sufficiently skilled to be able to question the patient about sensitive issues such as sex, condom use, cultural practices such as consulting traditional healers and other alternative medical practices and substance abuse. An understanding about women and agency within the South African context is necessary so that counsellors are alert for indicators of intimate partner violence, sex within the partnership, transactional sex and the risks of disclosure. '*Compliance assessment forms*' need to be filled in for the first three months of treatment.

C5: Defaulter tracing:

Counsellors need to arrange for defaulter tracing and other trouble shooting home visits as needed. Counsellors need to have collected sufficient contact details and information on the patient's family circumstances to enable them to do this, and to have kept records of this accordingly. Counsellors will also need to have an understanding of issues around LTFU and have communicated to patients the importance of continuity in treatment.

C6: Ongoing and district Management:

Counsellors are required to participate in coordination meetings and any appropriate training workshops arranged or organized by the ARV site. Compulsory fortnightly supervision and debriefing meetings should be held on site, preferably, but are negotiated with the employing NGO.

C7: Communication:

Counsellors provide education and information on HIV/STIs/TB and ART related issues in the waiting rooms of the ARV site, and are required to assist as language/communication mediator between patient and doctor. This presupposes an understanding of the role of an interpreter and the ability of the counsellor to switch between two languages, as well as being able to translate the meaning of the information to a level that is accessible to the patient's level of understanding. This entails needing to be able to gauge the patient's level of understanding and question them about their language preferences.

Appendix IV Content covered in ATICC counsellor training

Course	10 day HIV/AIDs Information course	20 day HIV/AIDS Intensive counselling course	10 day ARV therapeutic counsellor course	5 day paediatric ARV counselling course
Accreditation	SETA accredited	SETA accredited	SETA accredited; introduced 2004	Introduced 2008
Topics covered	Module 1: Myths & attitudes Medical facts The link between HIV and TB HIV testing The PMTCT programme Introduction to HIV/AIDS counselling The link between HIV and other STIs Legal and ethical issues HIV advocacy Infection control Resources Living with HIV Caring for the carer Module 2 Opportunistic infections Antiretroviral therapy: (Benefits of the ARV programme, Selection criteria, Drug classes, How ARVs function, ARV treatment lines) Taking ARVs: (How to take them, Side effects, Adherence, Drug interaction) Safer sex: Condom demonstration	Module 1: Personal growth Who am I? World view and attitudes Relationships Gender, sexuality and HIV HIV and loss Importance of balance Psychosocial resources Medical facts recap Effective communication Understanding counselling Relaxation exercise Module 2: General counselling skills Egan's model theory & practical Counselling for infant feeding Module 3: Pre and post-test counselling for HIV/AIDS Pre-test counselling theory Breaking bad news Post-test counselling theory: Positive diagnosis/ Negative diagnosis VCT/PMTCT register Pre-and post-test counselling practical	The ARV programme How the body works (the CD4 cell, immune functioning, the virus particle) Recap medical facts The effect of HIV on immune functioning The lifecycle of HIV How ARVs work in the CD4 cell Introduction to ARVs Nutrition and ARVs Substance abuse Adherence Group presentation skills Group information sessions Counselling skills recap	Overview of Paediatric ARV programme (stats, lay counsellor role) Attitudes and beliefs about children starting ARVs (counsellor, barriers in the community, caregivers) Medical facts: (How children get HIV infection, What HIV does to the body, Differences between HIV infection and AIDS in children, Testing for HIV infection in children, Diagnosis and clinical follow up, Clinical staging in children, CD4 count in children, Viral load in children, HIV/TB co-infection, Criteria for ART eligibility, When ARVs are started in children, How ARVs work against the virus, Treatment regimens, Dosage, Food requirements, Fridge requirements, Problems after starting ARVs and changing treatment regimens) Adherence: (What adherence means and why it is important, Things that help adherence, Things that interfere with good adherence, Difficulties associated with each age, group: infant, toddler, school going children, adolescents) Disclosure to children

Appendix IV continued

Course	10 day HIV/AIDs Information course	20 day HIV/AIDS Intensive counselling course	10 day ARV therapeutic counsellor course	5 day paediatric ARV counselling course
Topics covered	How to design a poster & poster demonstration skills Factors contributing to the spread of HIV and AIDS: (Culture, Religion, Social, Economic) Vulnerable groups within our country Impact of HIV on society The importance of positive living: (Taking care of the mind, Taking care of the body, Support, Safer sex) Support options: (Support groups, Grants)	Module 4: Supplementary counselling skills Support groups Follow up counselling for HIV + client HIV/AIDS and children HIV and nutrition HIV/AIDS, depression and suicide Legal and ethical issues HIV/AIDS and adolescents Grief counselling Dealing with difficult situations Supervision and mentoring Stress management	The ARV programme How the body works (the CD4 cell, immune functioning, the virus particle) Recap medical facts The effect of HIV on immune functioning The lifecycle of HIV How ARVs work in the CD4 cell Introduction to ARVs Nutrition and ARVs Substance abuse Adherence Group presentation skills Group information sessions Counselling skills recap	Paediatric ARVs: (Drug regimen recap, Drug interactions: TB, traditional medicines) Practical demonstrations: Opening of a child proof medicine bottle, Using a syringe, Mixing of capsules with water, Swallowing of capsules, Crushing tablets

Appendix V: Summary of the communication skills training programme

Day 1 Programme and activities

The first afternoon was focused on developing communication skills to increase patient understanding and to develop the following:

Knowledge:

- A definition of communication and what it encompasses
- Barriers and facilitators to patient understanding
- Consequences of poor communication in a health care setting
- A systematic format for identifying good and bad communication strategies
- The Bus Model of Communication in mediated consultations and exposure to communication vocabulary

Skills:

- To analyse communication interactions according to a structured framework of verbal, non-verbal and other factors

Outcomes:

- Increased ability to identify essential elements of communication and an understanding of a framework of facilitators and barriers in a health communication context

Activities that support the development of the above were:

Exploring language diversity and definitions of communication	Marshmallow game Didactic presentation of communication in interactions based on the mini-ethnography and baseline measures (Chapters 5 and Chapter 6) Group brainstorming Paired case scenarios & Framework for analyzing communication
Identification of communication problems in recorded interactions	Video vignettes based on consultation transcripts from Lady Evelina Clinic
Communication Model for Mediated Consultations	Presentation of the communication bus Magical moments from consultations in their clinic

Day 2 Programme and activities

The second afternoon of group training was focused on Exploring the link between communication with patients and communication in the health care team in order to develop the following:

Knowledge:

- The importance of team communication and developing partnerships
- The impact of context/ systemic barriers on communication

Skills:

- Practising effective communication skills
- Team communication

Outcomes:

- Prioritise a list of core clinic information to be communicated per session
- Develop a list of concepts that are difficult to communicate
- Set clinic goals regarding what patients should understand prior to going on to treatment
- Planning the way forward from systemic/ contextual barriers through compilation of communication strengths, weaknesses, opportunities and threats (SWOT)

Activities used to develop the above included:

Review and giving constructive feedback	Optical illusions; everyone sees things differently: Dorcas and old woman/ young woman illusion
Practising communication strategies	Brainstorming identification of key information to be communicated to patients Brainstorming difficult to explain concepts
Communication within the healthcare team	Murder mystery game
Systemic/ contextual factors impacting on communication	SWOT analysis

Appendix VI Transcription coding conventions used

Transcriptions were not coded in the same degree of detail as used by ten Have (2000) or Watermeyer (2008). The following conventions were used:

Turns were numbered sequentially in square brackets []

Italic script indicates translated version of the dialogue

Roman script indicates the original dialogue

(non-verbals) written in brackets

----- indicates a section of the transcript has been skipped

C = Counsellor's dialogue

P = Caregiver/ Patient's dialogue

D = Doctor's dialogue

Appendix VII Verbal and Non-verbal Communication strategies presented to participants

	Communication Strategies
Verbal	Introductions : Yourself, aim of the session, language history. Remember the patient's name – look it up in the folder before you see them and use their name Overt discussion of language issues : Level of understanding, offer an interpreter, ask if they want anyone in particular – see if another interpreter has been used before, introduction of interpreter, OK your choice with the patient Roles : Patient advocacy role of interpreter, cultural mediator, Acknowledgement of difficulties : Complexity of what needs to be communicated, complexity of dosing, difficult to discuss topics, communication difficulties Simplifying the message : No medical jargon – patients do not know what a CD4 count is, do not use this unless you explain it, Short sentences, Simple language, Use of examples/ analogies, Explanations of terms, Small chunks of info at a time Beyond the biomedical : Introduce new topics rather than just shifting the topic, Discussion of non-medical factors i.e. biopsychosocial factors + procedural factors (when they last went for counselling, who it was with, role of the counsellor), Non-mitigation – truth telling even when it is difficult – staying away from euphemisms Checking patient understanding : Confirmation of the message in another modality, ask for their understanding of what they have been told. Use closed-ended questions to confirm details you are unsure about. Structure : Offering rest and toilet breaks. Telling the patient why you might be leaving the room if collecting results etc, Discussion of referral i.e. to counselling etc Non-judgmental questioning : Making it easy for them to answer negatively, Open-ended questioning, Aim to elicit the patient's explanatory model i.e. their explanation for what has caused the problem, Avoid scolding, praise for small accomplishments Summarising : Opportunity to confirm information and avoid misunderstandings, Main topics of discussion, Test results, Procedures to be followed up on, Ask if there are any questions
Non-verbal	Seating Gesture Eye contact Note-taking Use of props Tone Respect
Other	Multiple modalities to get the message across Continuity of care – patient records, returning to the doctor/ counsellor/ nurse, speaking to colleagues, booking next appointment

Appendix VIII Teaching methods in adult education

Adult learners come from diverse backgrounds, aptitudes and learning styles (Makoul, Curry & Thompson, 2000). Adult education models embrace this breadth of varied experience and provide a framework for continuous self-directed learning that extends beyond formal curricula. Interactive, discussion-based small-group activities and peer observation and feedback are suitable formats for adult learners (Makoul et al., 2000).

Effective methods of training in communication skills exist (Maguire & Pitceathly, 2002). Maguire and Pitceathly (2002) state that it is essential to practise key skills and to receive constructive feedback on performance. Maguire and Pitceathly (2002) recommend that all training programmes encompass a balance of cognitive input, modelling and the opportunity to practice key skills. Furthermore, evidence should be provided of current deficiencies in communication, reasons for these, and the consequences for patients and doctors. An evidence base for the skills needed to improve on these deficiencies should be offered (Maguire & Pitceathly, 2002). The skills to be learnt need to be demonstrated and reactions to these need to be elicited (Maguire & Pitceathly, 2002). An opportunity to practice these skills within a safe environment needs to be provided and feedback needs to be constructive and reflect on the reasons for any blocking behaviour (Maguire & Pitceathly, 2002).

The majority of the training programmes used a combination of techniques. A didactic component was used by Byrne et al. (2006). Kalet et al., (1994), Byrne et al. (2006 and Fallowfield et al. (2002) used interactive workshops with a combination of discussions and small and large group work. Both Kalet et al. (1994) and Maguire and Pitceathly (2002) used role modeling, and role play and skills practice were used in studies by Byrne et al. (2006), Kalet et al. (1994) and Fallowfield et al. (2002). Maguire and Pitceathly also used simulated patients and provided participants with the opportunity to practice and receive feedback. Baldassini (2006) and others incorporated reflection into their training programmes.

A didactic component is considered necessary as adult learners should be told about the communication skills and changes in attitude that combat these difficulties and be given evidence of their clinical usefulness (Maguire & Pitceathly, 2002).

However, it is generally accepted that experiential learning is more meaningful than didactic learning. From Byrne et al's (2006) intervention into MI, one participant remarked that they learnt that change comes from a person and is not just about 'throwing information' at a person. Another

participant felt that they learnt to help people change their behaviour by weighing up the pros and cons of their behaviour which is viewed as one of the major tenets of the MI approach and is a prerequisite for change (Byrne et al., 2006). MI intervention is regarded as being successful when an individual is able to appraise the pros and cons of change. This is referred to as raising their level of cognitive dissonance (Byrne et al., 2006). The counsellors participating in this study have already been exposed to some MI techniques through in-service presentations, so the training programme hoped to build on these techniques and engage the participants in debate weighing up the options.

Fallowfield et al. (1998) recommend developing simultaneous rather than sequential skills as well as knowledge and acquisition, and personal awareness of how these impact on both patient and physician. Furthermore, each participant needs to be allowed to define and direct his or her own learning needs and difficulties. Working on specific skills in small groups with standardized patients (trained actors), video review of interviews and group critique create a safe and constructive environment when led by highly trained facilitators. Interactive group demonstrations, small group discussions and selected key readings produce significant gains in conceptual framework and knowledge of the literature. Au (1998 in Baldesari & Pope, 2008) recommends instructor evaluation as an important part of constructivist²⁴ teaching processes.

Kalet et al. (2004) provide a description of the structure of a workshop in which the difficult topics of sex and sexuality were explored through the viewing and discussing of video tapes. Checklists of communication behaviors were used as the basis for reflection of communication skills in role plays with simulated patients which were conducted after the video viewing process. This approach was shown to be successful in working on dealing with angry patients and in multicultural patient encounters in which observation of peer role plays also proved useful.

Modelling can be done through tapes or demonstrations and participants should be invited to discuss the impact of these skills on the patient and doctor (Maguire & Pitceathly, 2002). Maguire and Pitceathly (2002) recommend using the facilitator with a simulated patient. The group is asked to suggest strategies to begin the consultation. Competing strategies are tried out for a few minutes then the group are asked for their views and feelings on the strategies used (Maguire & Pitceathly, 2002). They are asked to predict the impact on the patient (Maguire & Pitceathly, 2002). This has the advantage of allowing the patient to give their feedback too, whereas this can not happen in

²⁴ The primary assumption of constructivism according to Licktieg (2004 in Baldesari & Pope, 2008, p. 143) is that 'learning is a framework of social interactions where knowledge is constructed rather than transmitted'. Personal connections allow for the exchange of ideas and facts and individual modes of learning are encouraged.

audiotaped consultations and the group's suggestions can be confirmed or refuted. This process is repeated to work through a consultation so that key skills are learnt by the group (Maguire & Pitceathly, 2002). An advantage to using simulated patients is that intensity and complexity of case can be controlled and a 'time-out' can be called when a participant gets stuck and the group can decide how best to proceed. However, asking a participant to repeat an interview can result in a loss of confidence as errors are repeated (Maguire & Pitceathly, 2002).

Offering participants feedback on real consultations should ensure more effective transfer of skills (Maguire & Pitceathly, 2002). Practising with simulated patients leads to the acquisition of skills but does not necessarily lead to the transfer of these skills to clinical practise as comprehensively as it should (Heaven, 2001 in Maguire & Pitceathly, 2002). When participants simulate known patients it makes more realistic scenarios and gives insight into how patients are affected by different communication strategies (Maguire & Pitceathly, 2002).

Formative feedback aims to engender individual feedback and remediation students but may be perceived as having evaluative consequences (Epstein & Hundert, 2002). The risk of distressing and deskilling participants in training programmes must be minimised and Maguire and Pitceathly (2002) recommend the following ground rules to prevent deskilling:

- Positive comments about strategies (oral and non-oral) and why
- Constructive criticism should be allowed only after all positive comments are exhausted
- Participants offering constructive criticism should suggest alternative strategies and give reasons for suggestions
- Blocking behaviour should be highlighted and the interviewer should be asked to consider why it was used, including underlying attitudes and fears
- The group should be asked to acknowledge if they have used similar blocking behaviour and why
- To reinforce learning, the doctor should be asked to reflect on what he has learnt, what went well, and what might have been done differently

Fallowfield et al. (2002) compared a variety of feedback methods to participants in a study examining the impact of communication skills training on oncologists in the UK. Written feedback

followed by a course, the course alone, written feedback and no intervention were compared (Fallowfield et al., 2002). The trial showed the training course significantly improved communication skills (Fallowfield et al., 2002), however there was little evidence for the effectiveness of written feedback (Fallowfield et al., 2002). Written feedback would be ideal as it is less expensive to run as it is less-resource intensive (Fallowfield et al., 2002), however was shown to be ineffectual as a communication skill intervention (Fallowfield et al., 2002).

Appendix IX Summary of consultation storylines post-training

Transcript G: Nokuzola counsels the mother about transmission, diagnosis and adherence

The counsellor introduces herself and her role at the clinic, and tells the caregiver that she would like to get to know her. They discuss her living circumstances and the case history. The caregiver can not name the medication, so the counsellor shows them to her, writes down their names and demonstrates the dosing. The caregiver asks if an HIV positive child can have an HIV negative mother, and it emerges that there is confusion surrounding the caregiver's diagnosis. She had interpreted the doctor saying her cells were high and her not needing ARVs, as being HIV negative. The counsellor explains the difference between CD4 counts, cells, viral load and how the virus works. The counsellor gives the caregiver the 'homework' of learning the names of the medicines and writes down her follow up appointment date.

Transcript H: Nokuzola counsels the mother in preparation for the child starting ARVs

The caregiver is new to the clinic and is attending her second counselling session of three in preparation for her child starting on ARVs. The counsellor checks her understanding of adherence and reassures the caregiver that they will work together with the doctor to support her. The counsellor raises the issue of her possibly being retrenched, that had been discussed at her last consultation. The patient informs her that she disclosed to a colleague at work whose daughter is HIV positive, and that she now feels supported by her colleagues as they are understanding of her missing work. The counsellor explains adherence, timing and dosing, as well as the clinic's 24 hour walk-in policy. A date is made for the next appointment.

Transcript I: Nokuzola counsels the aunt about adherence

The caregiver is the school-going aunt of the patient. She has been referred by the doctor for adherence counselling. The counsellor checks her knowledge of HIV and adherence and explains the medication, dosing and how the virus works. She stresses the importance of adherence and the consequences of poor adherence. She then goes through a checklist of questions to check the caregiver's understanding, and discusses any misconceptions that arise.

Transcript J: Nokuzola counsels the mother about adherence

The caregiver started treatment after her previous consultation with the counsellor, and the counsellor referred her back for counselling to follow up on how the treatment is progressing. The counsellor checks that the caregiver knows the names and dosing of her medication and those of her baby, and whether or not there have been any side-effects. The caregiver reports that she is coping well and has no problems at that stage. The counsellor encourages her to keep up the good work. She then goes through a checklist of questions to check the caregiver's understanding and discusses any misconceptions that arise.

Transcript N: Babalwa counsels the grandmother about adherence

The counsellor introduces herself, explaining to the grandmother where she lives, where she is from and her role in the hospital. The grandmother explains where she is from and they establish that they are from the same area. The grandmother requests that the counsellor explains the child's medication and dosing. The counsellor checks the grandmother's understanding by asking her to select which medications the child takes

from a box containing many different medication bottles. She explains the abbreviations of the medication and relates them to the names on the bottles. Using a syringe, she demonstrates how to measure the medication giving the grandmother an opportunity to practice too. She uses a checklist of questions at the end of the consultation to check the grandmother's understanding of some of the terminology used, and she explains the importance of timing, adherence, knowing the child's CD4 count and viral load, and planning for a holiday to the Eastern Cape.

Transcript O: Babalwa counsels the mother about disclosure

Caregiver O would like Babalwa to give her advice on how to disclose to her sister. They discuss how the caregiver feels when she watches programmes on TV about HIV, and establish that her family are non-judgmental when they watch TV programmes about HIV. Caregiver O thinks it is necessary to disclose because her husband is often away and she needs someone to look after her when she is sick. They discuss the child's health and the counsellor reminds the caregiver about the importance of adhering to the medication. She checks the caregiver's understanding of the medication and the importance of adherence.

Consultation S: Lindiwe counsels the mother about adherence after recently starting ARVs

Caregiver S is not a South African citizen, so her consultation is conducted in English, which is neither the first language of the patient (Portuguese) or the counsellor (isiXhosa). Unfortunately the caregiver speaks very softly so some of the content of the discussion is lost. It is evident from the counsellor's responses that she also finds the caregiver difficult to hear.

The patient has recently started ARVs and the caregiver has been referred for counselling to check that everything is going well. The doctor is pleased with the progress she has made. The counsellor asks how the patient feels and is told that she has not experienced any side-effects from the medication. The counsellor checks her understanding of the importance of timing, and explains CD4 counts, viral load and the lifecycle of the virus. The counsellor asks about psychosocial support at home, and the caregiver responds that she is concerned about the future for her children and that (contrary to what the doctor has recorded in the folder), her partner is not living with her and does not support her. The caregiver expresses a wish to see what weight was recorded in her folder on a previous visit. The counsellor outlines the procedures she needs to follow.

Consultation T: Lindiwe counsels the mother following a traumatic event at home

Caregiver T has gone to the counsellor for support following a burglary in her home. She expresses despair at the loss of her belongings and wishes that she had money so that she can consult a traditional healer to assist her. The counsellor encourages her to report the incident to the police and to get a case number. The caregiver believes that there is nothing that the police in her area (Delft) will do as she has found them incompetent on a previous occasion. She requests emergency money from the counsellor that she has heard of in the support group, and the counsellor refers her to the social worker to fill in an application for financial assistance.

Consultation U: Lindiwe counsels the mother about moving to second line treatment

The patient had been referred for adherence counselling following treatment failure in the child, and the doctor's decision to move the child to second line treatment. The counsellor checks that the patient knows

her medications and the importance of adherence, and explains that the second line is the last resort. The caregiver expresses her doubts about the effectiveness of the medication and that she wishes to consult a traditional healer. She believes that the sweet taste of Nevirapine aggravates worms in the child. She has been told by one of the doctors that if she does consult a traditional healer, she should tell the clinic. The counsellor advises her to make sure that she chooses a traditional healer who works with clinics and has knowledge of ARVs. The patient expresses that it is likely that the traditional healer will lie to her and say that he does even if he does not, as he will benefit from it financially.

The counsellor checks the patient's understanding and then the caregiver explains that she is disillusioned about the medication as it has resulted in side-effects which have left her feeling disfigured and unattractive. She feels that it would be better to die than to look how she does. She feels that she is cursed. The counsellor urges her to pray to God for guidance, and the caregiver states that her heart is no longer close to God. The counsellor reiterates how important it is to adhere to the second line treatment for the child's sake and urges her to come back to talk to her again.

Consultation V: Elsie counsels the mother on adherence

The caregiver has been referred to the counsellor because her child recently started ARVs and the counsellor has been asked to follow up on how she is coping. The caregiver reports that she is not experiencing any difficulties and that she is managing the medication well. The caregiver reports that she has disclosed to her sister with whom she lives, and that the child's father is no longer involved in her life.

Appendix X Comparison of average consultation length pre- and post-training for each counsellor

	Turns	Word Count	Counsellor % contribution	Patient % contribution
Nokuzola (Pre)	84	1406	60	40
Nokuzola (Post)	185	1927	73	27
Babalwa (Pre)	340	628	48	52
Babalwa (Post)	230	3050	69	31
Lindiwe (Pre)	159	1871	49	51
Lindiwe (Post)	173	2460	52	48

Appendix XI A comparison of the pre- and post- training counsellor questioning categorized according to counsellor questions, questions for checking understanding, questions about feelings and patient questions

	Nokuzola Average		Elsie Average		Babalwa Average		Lindiwe Average	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Questions asked by counsellors	27	52	19	Not recorded	37	57	24	33
Counsellor questions checking understanding	4	28	0	Not recorded	3	33	3	15
Open questions to check understanding	1	14	0	Not recorded	0	28	1	10
Questions about patient feelings	1	2	0	Not recorded	1	0	2	3
Questions asked by patients	3	7	0	Not recorded	2	8	3	2

Post-training counsellor questioning

	Questions	Counsellor	Counsellor	Counsellor	Counsellor	Patient	
	Total	Total	To check understanding	Understanding checked with open-ended Q	Asking about feelings	Total	Comments
G	58	54	20	3	1	4	
H	30	22	14	8	0	8	
I	89	84	59	23	0	5	Of the 59 questions, , 17 were discourse markers (ne)
J	55	46	20	20	5	9	All of the questions related to understanding were open questions
	Average Nokuzola	52	28 (55%)	14 (50%)	2	7	
N	80	65	45	36	0	15	Patient initiates a question after encouragement
O	48	48	20	19	0	0	
	Average Babalwa	57	33 (58%)	28 (85%)	0	8	
S	26	24	7	4	2	2	
T	19	17	4	0	2	2	
U	60	58	34	27	4	2	Many interpretive questions and asking for the patient's explanatory model
	Average Lindiwe	33	15 (45%)	10 (66%)	3	2	

Appendix XII Topic-initiation by patients (PI) and counsellors (CI) in the post-training consultations for each counsellor and consultation

	Nokuzola				Elsie	Babalwa		Lindiwe		
Topics	G	H	I	J	V	N	O	S	T	U
1st 2nd line treatment, non-adherence		PI	CI		Not counted					CI
Adherence		CI	CI		Not counted	PI	CI	CI		CI
Care for the carer					Not counted		PI			
Case History	CI				Not counted		CI			PI
Cause of HIV	PI				Not counted					PI
Child's health		CI			Not counted		CI			PI
Clan names/ cultural origins		CI	CI		Not counted	CI				
Confidentiality	CI				Not counted			CI		
Death					Not counted					PI
Disclosure of HIV status, stigma	CI	PI			Not counted		PI	CI		
Discussion of WHY issues are discussed	CI	CI			Not counted					
Follow up, transfer & referral		CI			Not counted			CI	CI	CI
Grants, emergency money					Not counted			CI	CI	
HIV , CD4, viral load and progression of virus	CI	CI	CI		Not counted	CI	CI	CI		CI
Infection, side-effects			CI	PI	Not counted	CI	CI	CI		PI
Lifeworld: Small talk home/ family / work, living circumstances	CI	CI			Not counted	CI	PI	CI	PI	PI
Medication, tablets, starting ARVs	CI	CI	CI	CI	Not counted	PI	CI	CI		CI
Patient advocacy & rights, confidentiality	CI				Not counted					
Preparing for the future & Hope					Not counted		PI	PI		
Problem solving		PI	CI		Not counted					
Relationship difficulties					Not counted			PI		
Religion & Faith					Not counted	CI				CI
Role of the counsellor	CI	CI			Not counted					
Role of the doctor		CI			Not counted					
Role of the parent & patient responsibilities	CI	CI	CI		Not counted	PI				CI
Socio-economic status, finances, work		CI			Not counted					
Stress		CI			Not counted					
Support from family & friends & support group	CI	PI		CI	Not counted		CI	CI		CI
Timing of medication	CI	CI	PI	PI	Not counted	PI	CI	CI		CI
Traditional medicine and traditional practices, circumcision					Not counted				PI	PI

Key: 'No' indicates that it was used but not explained; 'Yes' indicates that it was used and explained; 'Patient' indicates that it was also used by the patient; NA indicates that it was not applicable to that consultation as it was not video-recorded; [-] indicates that it was not used within that consultation.

Appendix XIII Medical terminology used and whether or not the terminology was explained post-training

Counsellor	NOKUZOLA				ELSIE	BABALWA		LINDIWE		
Medical terminology/ Consultation	G	H	I	J	V	N	O	S	T	U
Antibiotics	-	-	-	-	NA	-	-	-	No	-
ARVs	Yes	Yes	Yes	-	NA	No	No	-	-	No
Asthma	No	-	-	-	NA	-	-	-	-	-
Biological changes/ biology	-	-	Yes	-	NA	-	-	-	-	-
Capsules	-	-	-	-	NA	-	Patient	-	-	-
CD4 count	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	-	Yes
Cells	Yes	Yes	Yes	-	NA	-	-	-	-	Yes
Confidentiality	-	-	-	-	NA	-	-	Yes	-	-
Dosages	Yes	No	-	-	NA	-	-	-	-	-
First line, second line	-	-	-	-	NA	-	-	-	-	Yes
Gastro	No	-	-	-	NA	-	-	-	-	-
HIV positive / Negative	-	-	-	-	NA	No	No	-	-	-
Immune system ('booster')	-	-	-	-	NA	-	-	No	-	Yes
Infectious diseases	-	-	-	-	NA	-	-	No	-	-
LDLL	-	-	-	-	NA	-	Yes	-	-	-
Lifecycle of HIV	-	-	-	-	NA	-	-	No	-	-
Measurement	-	-	-	-	NA	-	Patient	-	-	-
Medicine names: D4T, 3TC, Kaletra , AZT, Nevirapine, Bactrim	Yes	Yes	-	Patient	NA	Yes	Patient	-	-	Yes
Million copies	-	-	-	-	NA	-	-	-	-	Yes
Multivit	No	-	-	-	NA	-	-	-	-	-
Percentages	-	No	Yes	-	NA	-	-	-	-	-
Pneumonia	No	-	-	-	NA	-	-	-	-	-
Side-effects	-	-	-	-	NA	-	-	No	-	Yes
Specialist	-	-	-	-	NA	-	-	-	-	-
Syringe	-	-	-	-	NA	-	No	-	-	-
TB	No	No	-	-	NA	-	-	-	-	-
TBM/ TB Meningitis	No	-	-	-	NA	-	-	-	-	-
Triple therapy	-	-	Yes	-	NA	-	-	-	-	-
Undetectable/ detectable	-	-	-	-	NA	-	No	Yes	-	-
Viral load	Yes	Yes	Yes	Yes	NA	Yes	Yes	Yes	-	Yes

Appendix XIV Extracts illustrating counsellor demonstrations post-training (Consultation N)

Counsellor demonstration [N87-92]

C: Ok. Masikubonise ke masiqale apha kwi 3TC le ino4mils si- kusetyenziswa isarenji. I3TC lena ingu 4mils, siyazikorekisha zonke esesizigqibile. I3TC lena ingu4mils uyatsala apha (show patient) isarenji masithi nali iyeza nali liyeza lakho eli.

Ok let us show you with 3TC the one that has 4mls we- a syringe is used.(holds up syringe) In 3TC you pull 4mls.(points to 4 ml line) Let's say here is you medicine (Shows the patient the bottle)

P: Mm (Yes)

C: Utsale pha, utsale u4mils nantsi nanku u4mils wakho kodwa ke uyakwazi into yokuba ngaba-awunyanzelekanga into yokuba ngaba tsala apha phakathi uthi 4mils. Uyakwazi ukutsala uyaqonda

You pull there, you pull 4mls here is your 4mls but you don't have to- you don't have to pull 4mls from inside. You can pull-(demonstrates drawing liquid)

P: Mm (Yes)

C: Uyibeke apha ku6mils ukwenza sure into yokuba ngaba ingaba ingenile uthi wakugqiba uthathe ibhotile ubuyisele kakuhle kakuhle uyakubani kengoku ku4mils uyibone, uyabona kengoku u4mils nankuya uzenzile (Showing patient)

6ml to make sure it is in. when you finish take the bottle and take the medicine back to the bottle careful to go back to 4ml. you see now it is 4ml (points)

P: Mm (Yes)

Counsellor asking patient to demonstrate [N93-97]:

C: Khawundibonise u4mils we 3TC lena ibhotile ukuba ungenza njani na

Show me how you would get 4mls of 3TC from this bottle

P: Ibhotile ne ndiyatsala. I pull from the bottle ne. (patient demonstrates)

C: Heke Heke heke 4mils kawume khendibone u4mils wakho. Uyabona ke ugqithile ayinguye lo lona ngu3,5mils

Yes! Yes! Yes! 4mls wait let me see you 4mls. You see now you have passed this is 3,5mls.

P: Ok

C: Nanku u 4 kufuneka uthi- ubelapha (showing). Here is 4 you have to- be here.

Counsellor encourages patient and patient initiates a question [N117-118]

C: Ime kakuhle pha kulamgca. Nantso ke iright le yona. Heke yiAZT, nantsi ke iAZT (Showing) yi 3TC lena (showing). Ndiwagqibile amayeza amabini akhe awaselayo.

It stopped nicely on that line. That's it that one is right. Yes! This one is AZT (showing to the patient) and this one is 3TC(showing to the patient.) I have finished two medicines that he drinks.

P: Aba AZ babhalwe phi, lamagama abhalwe phi?
Where are these AZ's written, where are these names written?

Counsellor deciphers abbreviations for patient [N109-114]

C: IAZT uyofumanisa into yokuba kubhalwe uzidofordine uzidofordine syrup.
You will find that AZT is written zidorfodine syrup. (Counsellor writes AZT in khoki pen on the bottle)

P: Ewe. Yes.

C: Kubhalwe apha u Lamivudine. *The other one is written lamivudine.*

P: Ewe. Yes

C: Yi3TC ke lena. Uyawuzohlula enye imbhoxo imhlophe.
This one is 3TC. You will differentiate them the other bottle is big and white

P: Ewe. Yes

Gives each medicine qualities so that the patient can easily remember them [N115]

C: Enye ibumbhoxo kodwa ingathi ibutswebhana imnyama usuke uvel' uthi ngushorty lo umnyama umncinci.

The other one is bigish but smallish and black, you can say it is black small shorty.

Counsellor suggests to the patient that she does not have to use her way of remembering medicines, that this is optional [N117]

C: Kodwa ke akubalulekanga ukuba wenze ngolohlobo.

But it is not important to do it that way.

Explanation of complexity of different dosing and use of 'we' do show that she also finds it complex [N119]

C: Ndizakuxelela kufunek' uthini . Masize kenngoku apha kwiKalitra ne. IKalitra eli lokugqibela ke ngoku iyeza lona asilimejarishi ngalena into kuba kaloku lona lithi bani 1,2 so xa ingu1,2 ingakubhida kuba kaloku yabona eli lena ithi ithi 1mil,, 1,5mil, 2mils 2,5 mils 3mils so ingakubhida kufuneka kufuneka sikhangele isarenji esingathi sizasibonisa kakuhle . Heke nantsi, uthi ke xa uyitsala lena nayo itsalwa kwangohlobo olunye nalena.

I will show you what you have to do. Now let's come to Kalitra ne. We do not use the same syringe to measure Kalitra because it is 1,2 mls so if you use the big one you'll get confused because it has 1ml, 1,5ml, 2ml, 2,5ml and 3ml. We have to get a syringe that will show you properly. Yes! Here it is, you pull this one the way you pull others.

Practical advice re syringes [N125]

C: Ungasebenzisi kwesi isarenji uyazi ke napha epharmacy xa unikwa amayeza akunikwa ezi zikhulu zonke unikwa ezikhulu ziyaxutywa ukwenzel' uba ezi mils uzifunayo ukwazi ukuzifumana

ngokwesarenji sakho ukwenzela yenzela lula into yoba ngaba ukwazi ukuzifumana nokwesarenji sakho.

Do not use this syringe (showing to patient) even at the pharmacy you don't get only big syringes they mix them with the small ones so that you can get all the mils you want according to your syringe.

Asking patient to demonstrate her understanding [N127]

C: Yima ke ndiyicime le bendiyenzile uphinde undikopisele undibonise ukuba uzakwazi na ena xa usendlini.

Let me remove the one I did so you can show me again if you'll be able to do it when you get home.

Appendix XV Discussions of disclosure and how it was addressed pre- and post- training

Extracts from consultation M recorded before training illustrating how disclosure was discussed

C: Okay, mna ke sisi ndinguBabalwa nhe ndihlala emakhaza ekhayelitsha ndingicounsellor wakho ndingumntu ozakunceda xa unengxaki. Ndingakunceda ke sis wam?

Okay, I am Babalwa and live in Makhaza in Khayelitsha. I am your counsellor and I will help you. So how can I help you my sister?

P: Ewe ungandinceda ndinosister wam endihlala naye andingekamxeleli ukuba ndiphila nentsholongwane ndiyoyika ukumxelela kodwa sendidecide ukumxelela

Yes you can help, I am living my sister and I have not told her that I am living with HIV because I'm scared but I have decided to tell her

P: Ndingcinga ukufumana amacebiso kuwe counsellor wam ukuba ndenze njani ndenze njani and then ndiye kuye ke ngoku ndiyofaceana naye ndimxelele

I need some advice from you my counsellor on what to do and then I can go face her

C: Ungakhe uhlale phantsi nosister wakho uzame ukumxelela ukuba sisi kunjena nanjena then ke ngoku ubone pha kuye usisi ukuba uzakuba ngumntu onjani na

Why don't you sit down with your sister and tell her your situation and see how she will react

C: Okay hayi ke kubalulekile ke sisi ukuba umxelele kuba kaloku nyhani xa kufuneka ugula apha kofuneka ujongwe nguye usisi wakho. Kuyabaluleka ukuba usisi wakho akwazi ukuba uphila nentsholongwane akukho nto iwongo ngalonto leyo.

Okay it is important that you tell her because she will look after you when you are sick. It is important that she know about your status, there is nothing wrong with that.

P: Enkosi ngengcebiso yakho sisi ndiyabonga ndiziva ndikhulekile kakhulu. Ngoba ibiyeyona ngxaki endityayo ngoba kaloku ndizakuqalisa netreatment ngubani ozakundikhumbuza ngubani ozakundinakekela

Thank you, I appreciate your advice I feel better now. Because it has been troubling me especially now that I'm going to start treatment, I have been asking myself who will remind me and take care of me when I'm sick.

Extracts from consultation O recorded after training illustrating how disclosure was discussed

C: Okay, sisi Nokwandisa ndingakunceda namhlanje sisi?

Okay, sister Nokwandisa how can I help you today?

P: Ewe sisi ndifuna undicacisela ukuba ndingaDisclosure njani kwifamily yam njengokuba ndiHIV positive. Ndiyafuna ukudisclosure but ndisenoloyiko ndingenza njani?

Yes sister I want you to help me find a way to disclose my HIV status to my family. I want to but I'm scared

- P: Waye wayamkela yena, but mna ndiyazama ukuyamkela but xana ndibukele iTV kukho lento idlala eTV(ini) ithi siyanqoba. Xana ndibukele iTV kuye kube buhlungu kum ndifeel(e) ipain kube buhlungu kum.

He accepted it but I'm still struggling especially when I see that TV show called Siyanqoba. When I'm watching it I feel sad and in pain.

- C: Yintoni ekwenza buhlungu xa ubukele usiyanqoba?

Why do you feel sad when watching the show?

- P: Ndiye ndizicingele ukuba ndiyagula uyabona njengokubana. Njengokuba ndiyagula ndizofa uyabona izinto ezinjalo.

I think because I'm sick I am going to die and things like that.

- C: Ayikho nto izakubulala kuba kaloku uthi uyamkele and kudala noko uzazi ukuba upositive. Ngoku into oyifunayo ufuna umntu wokuba ukwazi ukudisclosure kuye

You are not going to die especially now that you have accepted it and it's been long since you had it. And now what you need is someone you can disclose to.

- C: Ingaba pha efamily(ini) ngubani umntu ongathi ubhetele kunomnye senditsho into yokuba xa uhleli nabo uyabazi mos abantu bakokwenu ukuba ngabantu abanjani so ngowuphi umntu noko xa ebukele eTV(ini) ureact(a) njani kubantu abaHIV positive.

When you are with your family who do you think will be more understanding. You know your family you know how they react to people that are HIV positive on TV.

- C: Okay, so ucinga ukuba angathini ukuze abe kanti uyayazi ukuba uHIV positive? Ucinga wena ungenza njani ukwenzele ukuba uyayazi ukuba uHIV positive?

Okay, so what do you think you have to do to make sure that she knows. How are you going to tell her about your status?

- P: Ndinga uba mna ndimazise ngoba xa ndigula akukho mntu ozakundisupporta. Without umyeni wam ngoba umyeni wam yena uyaphangele.

I think I need to tell her because when I'm sick no one will be help me. Besides my husband who is working.

- C: Usister wakho yena ukhe umfundise ngeHIV umbonise ukuba abantu abaHIV baphila njani. Okanye babangabantu abanjani ubangumntu onjani yena xa kuthethwa ngeHIV.

Do you teach your sister about HIV and show her how people with AIDS live? How does she react when you are talking about HIV.

- P: Umzekelo yena wayesithi ukuba angaHIV positive okanye kubekho umntu oHIV positive angayamkela lento ngoba sisifo esiphila nomntu esiya.

For example she said if she would be HIV positive or someone she know she would accept it because it's a people's disease.

C: Ngoku uzakwenzani ukwenzela ukuba usister wakho ayazi ukuba une HIV. Kuba enye into abalulekileyo yinto yoba umbize usister wakho umxelele uhlale naye phantsi umxelele. Kubhetele ngokuba usister wakho uyakwazi kwaba athi angamamkela.

So what are you going to do to make sure that your sister knows? The most important thing is to sit down with your sister and tell her, its better because she will accept it.

P: Ndinga nyhani ukuba ndimxelele

I think I should tell her

C: Ucinga ukuba ungayenza nini lo nto leyo

So when do you think you can do this?

P: Andiva?

Pardon?

C: Ucinga ukuba ungayenza nini lo nto leyo

So when do you think you can do this?

P: Andikaqiniseki ke ngethuba kuba ndisagula umyeni wam abe engekho kuba uhlala emsebenzini isikakhulu ubuya ngolwezihlanu emsebenzini. Ngoku akukho mntu uzakundisupporter ndibe ndingakhange ndidisclosure(e) mntwini without umyeni.

I'm not sure about the time, but one day I will be sick when my husband is away because he only comes back on Friday from work. And now no one will be there to support me and given that I did not disclose my status to anyone besides him.

C: Okay ucinga ukuba yiyona nto ibalulekileyo xa udisclosure kuba xa udisclosure(zile) kungona uzakutsho uphile kamnandi. Ngoba xa udisclosure(zile) like xa ugula ulapha endlini uyayazi ukuba ungabiza udade wenu. Ugule ngolwesibini umyeni engekho udade wenu eze azakunceda and ngelinye ixesha kwababantu befamaly yethu uyakwazi into yoba ngaba athi gqi seyesithi ke ngoku hayi masikuse andaweni ethile ufumanise ke ngoku izobangathi uyathwasa but xa udisclozile ibalulekile waziwe into yokuba awuthwasi zizinto nje zokuba uHIV positive unganxiliselwa ngamayeza esixhosa.

Okay do you think disclosing is a good idea and that if you do that you will be better off. Like when you tell your sister you know you can count on her. Like if you get sick on Tuesday when your husband is not around your sister can help. And sometimes your family may misdiagnose your problem and think you have a calling but when you disclose they will know and not use traditional medicine on you.

P: Injalo sisi kangakuba ndiye ndinantuke nalapha kwi weight yam ndiye ndisehla kwiweight ngoba kaloku ndiye ndicinge xa ndihleli ndodwa ndicinge ukuba kanene ndiyagula ndine HIV ndibe ndingakhange ndidisclose mntwini.

You are right I'm also losing weight because I think a lot when I'm alone, thinking that I'm sick and I have not told anyone about it.

C: Intle lento uyicingileyo sisi intle. *What you are doing is great.*

P: Unqwa nomntana wam xana egula ndibanayo lapain xa engaphilanga ndiva buhlungu uba hey umntana wam uyagula and futhi I wonder ukuba uzakuphatheka njani yena.

It's the same when my baby is sick I feel the pain thinking that he is sick and how he must be feeling.

Appendix XVI Extracts illustrating the role of the counsellor as patient advocate and language mediator

Patient advocacy: Emphasising the benefits of the establishment: The counsellor torn between the institution and the patient

- C: Jonga mama kaKuhle, kaloku sana kunyanzelekile ukuba oogqirha bakuxelele ne, into yokuba umtwana unale.ubungazuthanda naxana oogqirha bengakuxeleli ukuba kwenzeka ntoni emntwaneni wakho.Lilungelo lakho ukuba uve ukuba kuqhebeka ntoni emtwanen uyaqonda. Kodwa yonke lento, unentlantla wena ngoba usesibhedlela and yonke lento ivela apha uya-understanda. Bazom-treater oogqirha. Bazothi make it a point ukuba umtana nakho uya-treateka, and uzoba-right umtana nakho akhule afane nabanye abantwana. Kuyanyanzeleka into yokuba oogqirha bakuxelele, uyaqonda sisi. Ngoba xabezokufihlela, mhlawumbe umtana uyagula kakhulu bakufihlele ayikho-right lonto leyo, and yonke into iyedlula akukhonto ingedluliyo. Akukho nto imayo endaweni eyi-one, yonke into iyadlula and umtanakho uyambona ukuba seye-strong kanjani. Kuqhele ukuvuka abantwana ebebe-weak begula babaphakamise oogqirha. Uyaqonda sisi? Uyewenza njani, uye wade wamxelela utata womntwana wakho okanye uye wathini?

Look Kuhle's mom, it is important for the doctors to tell you about your child's condition. It was not going to be nice to you if the doctors did not tell you what is going with the child. It is your right to be told of what is happening with the child. However, you are so lucky that you are in hospital because the services are available here. The doctors here will treat your child, they will make sure that the child is well treated and she will grow up like other children. It is compulsory for the doctors to tell you, it's not right if they don't tell you because the child might get very sick. You should also know that everything passes there is nothing that remains forever. Every thing passes and you can see how strong your child is now. The doctors usually treat very weak children and they survive. Do you understand sisi? Have you told your child's father about the child's sickness?

Interpreting: Counsellor able to adapt to the role of interpreter with ease

- D: Why did she feel embarrassed I don't understand?

- C: I don't know.

Ucinga ukuba ngeyenze njani ugqirha mhlawumbi athini akubizele ecaleni?

What do you think the doctor should have done? Do you think she should have called you aside?

- P: Hayi andibizele ecaleni andibizele umntu endizothetha naye ngoba andikwazi ukhumsha.

I think she should have called me aside and called someone to interpret for me because I do not understand English.

C: Okay, you should have called her aside in private.

Counsellor acts in a patient advocacy role – she also understands the doctor’s medical jargon and use of abbreviations (TBM)

D: We don’t usually call mothers aside to talk to them about TBM. We only call the child to discuss TBM. I don’t understand why I should call her and discuss the child’s TBM and that’s how we deal with this with the entire mums. Most of the times we discuss issues about children in the ward next to the bedside. If it’s something highly confidential then it’s treated differently. Most of the mum’s in the ward of the child who are HIV positive and the whole idea is to point to them where it’s like TB and how comfortable to deal with it. That is why it was inappropriate to call them aside.

C: I do understand what you are saying doctor but I mean she was just telling her feelings.

C: Okay, kaloku sisi nibothetha xa kukho into engakwanelisiyo. Kufuneka uthethe mama uyeva?

Okay, you must talk when you are not satisfied. You must talk mama, you understand?

Doctor has not explained to the patient fully and she doesn’t understand the hospital language e.g. ‘Brooklyn’. We are left unsure of whether or not she knows what TB is, let alone TBM and where her child is being sent for 9 months and why

P: Uhamba nini umtana?

I want to know where and when the child is going?

C: Abe uhamba nini ukuya e-When is the child going (speaking to the doctor)?

D: We don’t know until Brooklyn say confirmed.

C: Okay she’s going to Brooklyn. So we don’t know when?

D: Ja, until then she’s going to stay here.

C: She’s gonna go from here to Brooklyn chest; okay (speaking to the doctor). Akayazi uqgirha uba uhamba nini basalindele ibhedi ne. Kodwa ke xa kubakhona ibhedi phaya E-Brooklane chest, uzohamba ke ngoku umntwana abheke phaya (speaking to the mum).

The doctor doesn’t know, they are still waiting for an available bed but if there is space in Brooklyn, she will go there (speaking to the mum).

Counsellor re-checks her facts with the doctor

C: Yes, she said she spoke to the husband yesterday about her HIV status of the child. He just asked about cure. Is it curable?

D: Yes.

Encourages open relationship with doctor, and this encourages the patient to voice what she wants ie for someone to communicate this to her husband

D: Tell her that I’m Kuhle’s doctor so if she wants to ask me anything she can do so.

C: Uthi uqgirha xa unemibuzo- nguqgirha kaKuhle lona ne. Nantoni ofuna ukuyibuza mhlawumbi noba sewuhleli pha kunento ofuna ukuyibuza yiya kuye uzakucela umntu ozokutolikela ubuze lento ofuna ukuyibuza, ungamonqeni sisi.

My sister this is Kuhle's doctor, when you have a question you must ask her. Whatever you want to ask- Even if you are sitting there and you want to ask something go to her she will ask someone to interpret for you. So don't be shy to ask her. Do you understand sisi?

D: If she feels that something is private, she must let me know and than we will go to the room.

C: Xana mhlawumbi kukhona into oyiqondayo ukuba ufuna niyithethe ecaleni, mxelele ni hambe niyoyithetha ecaleni.

If you feel that something is private tell her so that you can speak in private.

D: Let her know that we try to deal with this as sensitive as possible. The idea was not to embarrass her.

P: Kodwa ke ndifuna uqgirha amxelele utata yena ngokwakhe.

I want the doctor to tell my husband about this.