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Mhlongo, Euphemia Mbali

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AN EXPLORATION OF THE EXPERIENCES OF CLIENTS ON ANTIRETROVIRAL THERAPY AND THEIR HEALTH CARE PROVIDERS IN KWAZULU NATAL

Euphemia Mbali Mhlongo (née Dube-Nxumalo)

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, in fulfilment of the requirements for the degree of Doctor of Philosophy

Johannesburg, 2010

DECLARATION

I, Euphemia Mbali Mhlongo, declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

.....

Signed on the .....day of 2010

DEDICATION

This thesis is dedicated with love and gratitude to
Thabani, Nkanyezi and, most of all, my husband Ellie

"The global HIV/AIDS epidemic is an unprecedented crisis that requires an unprecedented response. In particular it requires solidarity-- between the healthy and the sick, between rich and poor, and above all, between richer and poorer nations. We have 30 million orphans already. How many more do we have to get, to wake up?"

Kofi Annan, Former United Nations Secretary General

ABSTRACT

The aim of the study was to explore the practice of antiretroviral (ARV) therapy services, specifically regarding the patients' issues and experiences, as well as the experiences of the health care providers rendering these services. Qualitative research methods were used, including a metasynthesis of qualitative research articles on human immunodeficiency virus (HIV) positive patients on ARV therapy, and phenomenological methods of inquiry.

The study objectives were to conduct a metasynthesis of qualitative research on HIV-positive people on ARV therapy; to investigate the experiences of HIV-positive people who are on ARV therapy; to identify the constraints faced by HIV-positive people receiving ARV therapy; and to explore adherence to ARV therapy.

The study was conducted in eThekwini district in KwaZulu Natal (KZN) province. The district was chosen considering the number of clinics rolling out ARV therapy.

Three institutions initiating ARV therapy participated in the study; one urban, one semi-urban and one rural clinic, to ensure representation of each type. Participants were recruited from two initiating hospitals and one Community Health Centre providing ARV therapy.

The metasynthesis revealed a shared set of four themes viz.:

1. Acceptance of, and coping with, HIV positive status
2. Social support and disclosure
3. Experiences and beliefs about HIV medication and health care
4. Provider relationships and health system factors

Qualitative analyses of interviews with clients indicated their experiences and concerns, and were summarized in these themes:

1. Life before and after knowing HIV status
2. Initiating and continuing ARV therapy
3. Adherence to, and side effects of, the ARV therapy treatment
4. Social support for people on ARV treatment

5. Positive outcomes of being on ARV treatment
6. Improving access to ARV treatment services

Analyses of in-depth interviews with health care providers specified their experiences, and were categorized into three themes viz.:

1. Establishing and maintaining a good client-provider relationship
2. Facilitators of and adherence to ARV treatment
3. Barriers to access to treatment

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	ART
ARV	Antiretroviral
CD4	Cluster of Differentiation 4, a glycoprotein that is found primarily on the surface of helper T cells
CHC	Community Health Centre
CHW	Community Health Workers
DoH	Department of Health
FBC	Full Blood Count Test
HAART	Highly Active ARV Therapy
HBV	Hepatitis B Virus
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
KZN	KwaZulu Natal
LFT	Liver Function test
NGO	Non-Governmental Organizations
PCP	Pneumocystis Pneumonia
PHC	Primary Health Care
PICT	Provider Initiated Counselling and Testing
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PTB	Pulmonary Tuberculosis
TB	Tuberculosis
U&E	Urea and Electrolytes Test
UNAIDS	Joint United Nations Programme Study on HIV and AIDS
UNISA	University of South Africa
VCT	Voluntary Counselling and Testing
VL	Viral Load Test
WHO	World Health Organization
WR	Wasserman' Reaction

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CHAPTER 1

1. INTRODUCTION AND RATIONALE FOR THE STUDY

1.1 BACKGROUND TO THE STUDY

The AIDS epidemic continues to expand globally: in 2005, an estimated 38.6 million people worldwide were living with HIV (Joint United Nations Programme on HIV and AIDS [UNAIDS], 2006:8); an estimated 4.1 million people became newly infected with HIV; and 2.8 million lost their lives to AIDS (UNAIDS, 2006: 8).

South Africa's AIDS epidemic, one of the worst in the world, shows no evidence of decline. Based on an extensive antenatal clinic surveillance system, as well as national surveys with HIV-testing and mortality-data from its civil registration system, an estimated 5.5 million people were living with HIV in 2005, and an estimated 18.8% of adults (aged 15-49 years) were living with HIV in 2005 (UNAIDS, 2006:17).

Almost one in three pregnant women attending public antenatal clinics were living with HIV in 2004, and trends over time show a steady increase in HIV prevalence (UNAIDS, 2006:11).

While the KwaZulu-Natal province has the highest HIV preponderance in South Africa, the national antenatal HIV prevalence has steadily increased from 32.5% in 1999 to a peak of 40.7% in 2004. A similar HIV prevalence trend is shown in KZN, where the clinics serving urban communities showed a constant prevalence rate from 2006 to 2007. The districts that had a prevalence of more than 40% in 2006 have remained constant, or have shown a decrease, in 2007. A slight decline from 40.7% to 39, 8% was noticed in 2007 which was a 1.1% decline **(**National Department of Health South Africa, 2008:16)**.**

The citizens of South Africa had reason to hope for a good quality of life for people living with HIV and AIDS (PLWHA) when the Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (2003) came into existence. The pillars of this are: prevention, treatment, care and support. In 2004, in meeting the objectives of the plan, the South African government rolled out the ARV programme to provide free therapy to South Africans whose cluster of differentiation 4, a glycoprotein that is found primarily on the surface of helper T cells (CD4), count was below 200cells/mm3. However, the latest clinical guidelines for the management of HIV and AIDS in adults and adolescents, approved in 2010, stated that patients co-infected with HIV and tuberculosis (TB); pregnant women; and patients with multi-

drug resistant and extreme drug resistant TB can be initiated on ARV therapy when their CD4 count falls below 350 cells/mm3 (NDoH 2010:8).

The plan was implemented in the first quarter of 2004 in South Africa, and, although ARV treatment is not a cure for AIDS and does not eradicate the virus, ARV therapy does slow down HIV replication, allowing for the regeneration of the immune system. However, the medication does need to be taken every day for the rest of the person's life for maximum suppression of the virus, and non-adherence can lead to the development of resistance in the virus to treatment. Ensuring compliance and reducing the number of defaulters is of critical importance in combating HIV and AIDS.

In KZN 17, 264 patients were assessed and 1, 556 were on treatment by September 2004 (NDoH, 2004:1). Stewart, Padarath and Bamford (2004:3) state that the provision of ARV therapy has been credited with having a significantly positive effect on the lives of PLWHA. Where it was widely provided, it had been responsible for emptying wards for PLWHAs in the hospitals, for dramatic falls in AIDS related mortality and morbidity and for people returning to their homes, families and jobs. However, provision of ARV treatment in developing countries had been limited due to a number of factors, most importantly the high costs of ARVs and inadequate infrastructure. It is of importance to note that, although ARVs are provided free to South African citizens with CD4 counts less than 200 cells/mm3 or to those with clinical AIDS, the service is costly to clients because of repeated visits, transport costs to and from the ARV sites, and the long waiting times for access to treatment -it is also a prerequisite that clients attend three ARV literacy sessions before being initiated on therapy.

The chronic shortage of health care providers is recognized as one of the major bottlenecks to health care provision, including the scaling up of ARV therapy. The impact is most devastating in rural areas where the human resource crisis is most acute.

The issue of stigma, and the subsequent fear of disclosure of HIV status, have also been hindering factors in the accessing of ARV therapy by the people that need it -people preferred not to be seen utilizing the ARV services, as utilization confirmed one's HIV status. The process of accreditation of health care facilities began in South Africa with the introduction of ARV therapy, and this entailed assessment of facilities for both the availability of resources and the sustainability to provide ARV therapy services. The assessment criteria of potential sites included infrastructure, personnel and data capability.

1.2 MOTIVATION FOR THE STUDY

I conducted ARV training for professional nurses in the KZN province, and also provided support to sites initiating ARV treatment in the eThekwini district from 2004 to 2006, and this piqued my interest in the subject, and helped make my decision to embark on this research study. As a result of transferring knowledge and skills to professional nurses on the comprehensive management of HIV and AIDS, I developed an interest in working closely with PLWHA, taking ARV treatment as their chronic medication. I also developed a desire to engage in discussions with the health care providers providing services on the comprehensive management of HIV and AIDS, so as to help identify gaps in service delivery.

1.3 SIGNIFICANCE FOR THE STUDY

This research study documented the experiences of individuals who were already receiving ARV treatment, as well as the experiences of providers rendering the ARV therapy services. The findings of the study could be shared with the senior management team in the eThekwini health district office. They could also be incorporated into training workshops, and be shared with professional nurses who work in ARV sites.

1.4 PROBLEM STATEMENT

Clients on the ARV programme are faced with many challenges, some of which are:

- The stigma attached to entering the ARV therapy programme
- Poor access to treatment
- Poor- or non-adherence to treatment
- Lack of psychosocial support
- Prevention of re-infection

These challenges may lead to a poor uptake of therapy, development of resistance to treatment for those already in the programme, stress and feelings of inadequacy, and spread of the virus due to irresponsible behaviour perpetuated by unsafe practices. Health care providers are also faced with several challenges in implementing a comprehensive package of prevention, treatment, care and support to PLWHA. These challenges are common to the prevention of mother to child transmission (PMTCT) of HIV and ARV treatment programmes in developing countries. Other non-HIV health services experience similar challenges. These challenges include:

- lack of human resources
- staff stress and burnout
- negative attitudes towards clients
- lack of privacy
- lack of material resources

The provision of ARV therapy has been limited by the poorly developed health care infrastructure of many developing countries. According to Malta, Peterson, Clair, Freitas and Bastos (2005:1424), access to treatment, care and support for PLWHA remains grossly inadequate. Insufficient capacity in the South African health sector, including infrastructure limitations and shortage of trained personnel, are major obstacles to ARV treatment delivery in many countries. These obstructions operate at a variety of levels and these obstacles can be summarized as follows:

- Financial: the cost of providing ARV therapy, particularly the costs of ARV drugs
- Organisational: weak health care infrastructure/systems to deliver ARV therapy
- Physical: this problem includes the lack of transport and transport infrastructure for HIV-positive people (to get to sources of testing, drugs and monitoring)
- Social: such as treatment providers' discriminating against people with HIV by refusing treatment or offering sub-standard treatment, and the fear of stigma attached to the disease (Stewart et al, 2004:8)

These are examples of the multitude of challenges presented by the adequate provision of ARV therapy services in South Africa, including the eThekwini district in KZN, where the study was conducted.

The issue of stigma, and the subsequent fear of disclosure of HIV status, have also been hindering factors to accessing ARV treatment; and, since one of the main problems facing clients on ARV therapy is access to facilities, adherence and stigma related. Bottlenecks in service delivery, including long waiting times and an uncompassionate staff attitude, contribute to the inaccessibility of the service. Lack of knowledge, poor and/or lack of client-provider communication and the aforementioned stigma attached to the ARV therapy service may affect the client's adherence to treatment regimen.

The problem is that adherence of patients to ARV therapy is compromised due to the inaccessibility of the service, as well as the stigma attached to PLWHA, and thus to the entire ARV therapy programme. In the face of these obstacles, the best system in helping PLWHA in South Africa to adhere to ARV therapy is still unknown.

1.5 PURPOSE STATEMENT

The purpose of the study was twofold:

1. It aimed to explore the practice of the ARV therapy rollout, based on the patients' experiences as well as the experiences of the health care workers rendering the services (in the selected ARV initiating clinics in the eThekwini district of KwaZulu-Natal)
2. It aimed to use both the patients and the providers' opinions to compile a support guideline for ARV services for the clinics in the eThekwini district.

1.6 RESEARCH QUESTIONS

1. What are the problems and experiences of patients and health care providers in relation to accessing ARV therapy?
2. What are the best practices for rendering ARV therapy in the eThekwini district of KwaZulu-Natal?

1.7 OBJECTIVES OF THE STUDY

The study objectives were to:

- Conduct a metasynthesis of qualitative research on HIV-positive people on ARV therapy: their feelings, concerns, needs and problems regarding ARV therapy
- Investigate the experiences of HIV-positive people who are on ARV therapy.
- Identify the constraints faced by HIV-positive people receiving ARV treatment
- Explore adherence to ARV treatment
- Explore the experiences of health care providers who have been working on the ARV therapy programme since its inception in 2004
- Compile a support guideline for ARV therapy services in eThekwini district

1.8 THEORETICAL ASSUMPTIONS

According to Polit and Beck (2008:14), an assumption is "a basic principle that is believed to be true without requiring proof or verification". Such assumptions form part of the discipline of nursing. Unlike meta-theoretical assumptions, theoretical assumptions lend themselves to empirical testing. In order to be of use in the research field, theoretical assumptions are expressed as statements, which in turn help to shape the conceptual framework of the study.

1.8.1 **Theoretical Statements**

Departing from modernist thought, no single theoretical approach was delineated for this study, and, consequently, no conceptual framework was developed.

The research field was approached with openness to different views and understandings of reality, and the belief that this reality is a rational construction of experiences and interactions. A multiplicity of viewpoints was anticipated, which required the researcher to engage in a reflexive analysis of the many different truths and layers of understanding she was presented with. Postmodernist thought has shaped these pronouncements and so the approach to this study is characterized by elements of postmodernism.

Postmodern thinking emphasizes the value of deconstruction; that is, taking apart old ideas and structures and reconstruction and putting them back together in new ways (Polit & Beck, 2008:15).

1.8.2 **Definition of Terms**

In the absence of a conceptual framework as a point of departure, terms used in this study were theoretically defined below. These terms will be used throughout the study.

1.8.2.1 **Operational definitions**

- ARVs, ARV therapy (ART), Highly Active ARV Therapy (HAART)

  These are drugs that suppress the replication of HIV. They do not cure the disease but turn HIV and AIDS from being a fatal condition to a chronic one, manageable with medication. These drugs improve the quality of life of PLWHA, as they prevent the onset of opportunistic infections. The terms ARVs, ART and HAART are used interchangeably. The term ARVs will be used for purposes of this study.

- Clients

  These are PWHA, consumers of ARV therapy/people using ARVs as their chronic medication.

- Experience

  According to the Pocket Oxford dictionary (2005), “experience” means “knowledge based on personal observation or contact or incident that affects one”. In this research study, “experience” shall mean “the difficulties and challenges faced by clients throughout their

journey from the time they tested HIV positive throughout their daily encounters while taking lifelong ARV therapy".

- Health care providers

  For the purposes of this research, a health care provider shall be any staff member who provides ARV therapy services to the clients, but at least one professional nurse in charge of the ARV clinic will be interviewed.

- Adherence

  According to The Pocket Oxford Dictionary (2005), to "adhere" means "to stick fast to substance, person, party, and opinion". For this research purposes, "adherence" shall mean "taking ARVs everyday/not missing ARV doses".

- Constraints

  This shall mean "the difficulties faced by HIV positive clients receiving ARV therapy".

- Metasynthesis

  "Metasynthesis" is used here as an umbrella term referring to the synthesis of findings across multiple qualitative reports to create a new interpretation. Types of metasynthesis include:

  - theory building
  - meta-study
  - grounded formal theory
  - theory explication
  - descriptive study

  In this research a meta-study was done.

1.9 DESCRIPTION OF THE STUDY SITE

The study was conducted in the eThekwini district in the KZN province of South Africa. Prior to 1994, the territory now known as KZN was made up of the province of Natal, and all pieces of territory that made up the homeland of KwaZulu.

- History

  From 1839 until 1843 the northern and southern parts of the Zulu Kingdom were briefly a Boer republic called Natalia. In 1843 the latter became the British Colony of Natal, although Zululand (KwaZulu in Zulu) remained independent until 1879.

It is called the garden province and is the home of the Zulu nation. Located in the southeast of the country, it borders three other provinces and the countries of Mozambique, Swaziland, and Lesotho, along with a long shoreline on the Indian Ocean.

- Climate

  KZN has a varied climate. Generally, the coast is subtropical with inland regions becoming progressively colder. Durban on the south coast has an annual rainfall of 1009 mm, with the daytime temperature peaking from January to March at 28 °C (82 °F), with a minimum of 21 °C (70 °F), and then dropping to daytime highs of 23 °C (73 °F) with a minimum of 11 °C (52 °F) from June to August.

- Provincial Districts

  KZN is divided into eleven districts. One of these, eThekwini, is a metropolitan municipality and the others are district municipalities.

- Political Landscape

  KZN, as the name may suggest, is also the home to the Zulu monarch, King Goodwill Zwelithini kaBhekuzulu. Although not holding any direct political power, the Zulu king is provided a stipend by the National Government, and holds considerable sway over more traditionalist Zulu people in the province.

- HIV Prevalence

  One of the most urgent crises facing the KZN province is the unparalleled prevalence of the HIV virus among its citizens. South Africa as a whole has more HIV-positive citizens than any other nation, and, among South Africa's nine provinces, KZN has the highest rate of HIV infection, 39 percent, (UNAIDS 2009).

  Without the proper nutrition, health care or medicine that is available in more developed countries, large numbers of people suffer and die from AIDS-related complications. In some heavily infected areas, the epidemic has left behind many orphans cared for by elderly grandparents. HIV and AIDS also severely retard economic growth by destroying human capital.

- eThekwini District

  District Health services are jointly provided by the Provincial DoH and the Local Government authority, with the former contributing 60% and the latter 40%. The eThekwini District office also manages the Ilembe District. The Provincial Primary Health Care (PHC) service in the Metro has a number of services/programmes which need to be integrated within the context of the overall city plan, as well as the process of devolving PHC Services to Local Government. The eThekwini health District is further subdivided into three sub-districts namely the South, North and West.

  The District has a total number of 140 health facilities, that is, fifteen hospitals, 7 Community Health Centres (CHCs), 113 PHCs, 4 TB hospitals and 1 prison (within which there is a health facility). There are twenty ARV therapy service points in the District: 8 in the South, 7 in the North and 5 in Western sub-districts. The map below highlights the clearly marked health districts of KZN.

Figure 1.1: KwaZulu-Natal Health Districts

1.10 DESCRIPTION OF STUDY PARTICIPANTS

The participants of the study were selected from the three health facilities accredited as initiating-sites for providing ARV therapy. Participants were the clients registered in the ARV programme and the health care providers delivering ARV services in the selected institutions. The clients had a poor socio-economic background, ranging from being unemployed to domestic and/ or factory workers. Their level of education also ranged from primary to secondary level of education. Only one client had a matriculation certificate and had registered at a University for tertiary education. All clients but one were females, since women and girls continue to be affected disproportionately by HIV in sub-Saharan Africa. Women's vulnerability to HIV stems not only from their greater physiological susceptibility to heterosexual transmission, but also to the severe social, legal and economic disadvantages they often confront (UNAIDS, 2009:22). The women' risk to HIV infection had also been exacerbated by poverty; examples of this including girls practicing transactional sex as well as other cases of multiple partners.

1.11 LAYOUT OF THE THESIS

The study comprised of the following chapters:

- Chapter One: Introduction and Rationale For The Study
  This chapter described the background to the study. The significance of this research study was described. The purpose statement and specific objectives were outlined. The terms that were used throughout the study were defined.

- Chapter Two: Literature Review
  This chapter presented a discussion of findings from the literature related to HIV and AIDS; adherence to ARV therapy; and the needs, problems and challenges faced by HIV positive clients.

- Chapter Three: Research Methodology
  The research methodology for the exploration of the experiences of clients on ARV therapy and their health care providers was discussed in this chapter. The target population and the multiple phases of research were explained. Each phase was explained in detail including the design, data collection methods, data analysis and ethical considerations.

- Chapter Four: Results and Description of Findings

  The results were described according to the different phases of the study. The results from the phenomenological enquiries which formed part of all the phases were discussed. This chapter also described the findings from the metasynthesis of qualitative research studies conducted in the field of HIV and AIDS.

- Chapter Five: Conclusions, Limitations and Recommendations for the Study

  In this chapter the findings, conclusions, limitations and recommendations of the study were described.

1.12 CONCLUSION

In chapter one, the background and significance of the study were outlined. This chapter further highlighted the problem statement and purpose statement; the terms used throughout the study were defined; and the thesis layout was presented**.** The next chapter will present a discussion of findings from literature related to HIV and AIDS and ARV therapy.

CHAPTER 2

2. LITERATURE REVIEW

2.1 INTRODUCTION

Access to good quality ARV treatment has transformed the prognosis for PLWHA in the developed world. Although it is also feasible, and desirable, to deliver ARV drugs in resource-poor settings, very few of the 95% of PLWHA, who live in developing countries receive them (Furber, Hodgson, Desclaux & Mukasa, 2004:1281). The rapid scaling-up of ARV therapy in sub-Saharan Africa is generating considerable public health gains. As of December 2008, 44% of adults and children in need of ARV therapy in the region were estimated to be receiving these services, as compared to five years earlier when the estimated regional treatment coverage was only 2% (UNAIDS, 2009:25). Although treatment scale-up is having a profound effect on HIV related morbidity and mortality in the country, important access gaps remain.

By the end of June 2009, South Africa was providing free ARV therapy to an estimated 40% of adults and 10% of children with advanced HIV infection. The number of HIV infected persons enrolled onto the national ART programme has increased over the last few years to over 940 000 at the end of November 2009 (The National HIV Counselling and Testing Campaign Strategy, 2010:5)

Furthermore, Furber et al. (2004:1281) state that, ideally, care for PLWHA should start with voluntary counselling and testing (VCT). However, only 10% of the people who need testing in low- and middle-income countries have access to these services, and therefore most are unaware of their serological status. Care for PLWHA should include psychological, social, and economic support as well as broad based medical care which incorporates nutritional advice, prevention and treatment of opportunistic infections, and palliative care. The issue of confidentiality is a crucially important one in view of widespread AIDS related stigma and discrimination. AIDS related stigma is “the process of devaluation of people living with or associated with HIV and AIDS”. Despite more than twenty years of AIDS education and awareness, the stigmatisation of PLWHA remains strong, although it is now being manifested in more sophisticated ways (Furber et al, 2004:1281).

Even when a person meets the criteria for initiating treatment, non-disclosure of one’s HIV status due to fear of stigmatisation contributes to a lack of access to the necessary ARV treatment.

Holzemer et al, (2008:319-320) explored the reasons for disclosing and non- disclosing of HIV status. Reasons for disclosing included:

- breaking the silence
- economic factors, especially poverty, which led PLWHA to disclose to a health care worker
- support in the form of prayer
- the appearance of physical symptoms, which gave people no choice but to inform their relatives about their HIV status

Reasons for not disclosing included:

- anxiety
- denial, and the subsequent comfort found in keeping the illness a secret
- concerns about confidentiality
- seeing how other PLWHA were treated
- not being able to predict the community's reaction

Failure to disclose one's status delays initiation of care; treatment; and support, all of which PLWHA need as the disease progresses; this contributes to late (or no) initiation of ARV treatment when opportunistic infections have already begun to set in.

Holzemer et al, (2008:320) also state some things that promote disclosure; these include

- counselling
- information
- education
- advice

2.2 ADHERENCE TO ARV THERAPY

Adherence to ARV therapy is essential to maintaining long-term health benefits, and avoiding the development of viral resistance. It is not possible for health care providers to reliably predict which individuals will ultimately be adherent to their treatment plan, since this is because adherence does not correlate with gender, cultural background, socio-economic or educational level; nor does it correlate with language barriers between provider and patient (South African National ARV Treatment Guidelines, 2004:52).

The results of the study conducted by Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex and Marlink (2003:281) in Botswana, state that the lack of strict adherence to HAART is considered one of the key challenges to AIDS care

worldwide. Estimates of average rates of non-adherence with ARV therapy range from 50% to 70% in a wide variety of social and cultural settings, and the risks associated with non-adherence are extensive at both individual and societal levels.

The study by Weiser et al (2003:281) confirms that treatment adherence has been closely correlated with viral suppression, while non-adherence has contributed to progression to AIDS, the development of multidrug resistance, and even death. Non-adherence to treatment is the major threat to the ARV therapy programme in sub-Saharan Africa. A recent study conducted by Peltzer, Friend-du Preez, Ramlagan and Anderson (2010:1) in KwaZulu Natal, South Africa found that a good proportion of patients were adherent to treatment using different adherence instruments. The important socio-economic predictors of ART adherence include residing in the urban area and adequate physical environment including transport and access to health services. Living in an urban area is likely to be associated with lower transport costs and fewer disruptions in access to medications. (Peltzer et al (2010:6). It is true that poor access due to long distances to health services and unaffordable transport costs have negative effects on adherence to ART. This has been seen especially in patients coming from rural areas failing to keep regular appointments for their chronic care and medications.

The ARV treatment programme is a complex programme, as it requires lifetime commitment by the patient. The chronic nature of the virus necessitates that patients take the medication for life, and thus patient adherence to life-long drug therapies is essential for the success of the ARV therapy programme. Patients on ARVs need to have access to sufficient drugs of correct potency, appropriate health care, knowledgeable providers and the relevant education.

El-Khatib and Richter (2009:412) report that the Free State province has the third highest HIV-prevalence (31%) in the country since December 2008. The Free State provincial DoH stopped initiating ARVs because of drugs that were out of stock and lack of funding. This situation contributes to high morbidity and mortality, and the lack of trust in the health system. This also impacts negatively on adherence of existing patients on the ARV programme, and can lead to life threatening effects with emerging drug resistant strains of HIV.

Authors further report that patients already on ARVs share their medication with neighbours, relatives or friends who experience delays in receiving ARVs. This practice raises serious public health concerns about drug failure, subsequent and more expensive drug regimens, and the spread of drug- resistant strains of HIV (El-Khatib et al, 2009:412).

2.3 BARRIERS TO ARV THERAPY

The main barrier to the initiation of and compliance to ARV therapy is the stigma associated with HIV and AIDS. The stigma also discourages people from seeking VCT services. A study on barriers to ARV adherence for PLWHA conducted in Botswana using both qualitative and quantitative methodologies indicates that patients stated their health providers as having significantly impacted upon their lives in the medical, social and psychological realms. This study states that physicians and nurses were often cited by patients as their primary source of support in coping with the challenges of living with their illness (Weiser et al, 2003:284). This is in contrast with another qualitative study done in Brazil by Malta, Peterson, Clair et al (2005:1424), where in-depth interviews were conducted with 40 physicians treating PLWHA. Amongst other questions the interview, topics of the study included experiences in the treatment of PLWHA, relationship and dialogue with patients, barriers and facilitators to adherence and effectiveness of available services. Barriers to ARV adherence were mainly related to the low quality of patient-provider relationship. Other barriers were related to patients' chaotic lifestyles, and inadequate knowledge and the subsequent negative beliefs about HIV, AIDS and ARV effectiveness.

PLWHA face not only medical problems but also social problems associated with the disease. One of the barriers to reaching those infected with HIV is stigma, which enhances secrecy and denial. According to Mbonu; Borne and De Vries (2009:5), many Sub Saharan Africans are reluctant to disclose their HIV status even when they've already gone for VCT; moreover, those who disclose it are selective about whom they disclose it to.

Barriers to disclosure include

- fear of stigmatization and the resultant possible victimization
- distrustfulness of assurances of confidentiality
- accusations (like that of infidelity)
- the possibility of abandonment

The consequences of HIV and AIDS stigma may include a low uptake of maternity health services by women, a fear of health care workers getting infected and the subsequent less adequate provision these of health care workers' services (Mbonu et al, 2009:11).

Stigma has serious implications for prevention: people do not want to go for VCT, and even those who do go for testing do not always disclose their HIV positive status to their sexual partners owing to the stigma. Stigma has ongoing effects on adherence to ARV treatment by

PLWHA, affecting their quality of life and increasing complications. People do not take treatment freely in public, they feel they have to hide when taking treatment in public places, and this affects adherence by affecting the times the treatment is taken.

In South Africa, access to ARV therapy is still minimal despite the provision of drugs free of charge. The capacity of the health system to implement the ARV therapy programme is the main barrier to access; however the drugs are becoming increasingly affordable, especially in South Africa where the government provides ARV treatment free of charge to all South Africans. The procurement process and the need to train health care providers is delaying the 2004 goal of at least one ARV service point per health district as outlined by Ijumba and Poole (2005:319). The key challenges in scaling up ARV therapy programme in the public sector as stated by Ijumba and Poole include:

- the continuing lack of human resources (nurses, doctors, pharmacists, nutritionists, dieticians and counsellors)

While not all of these positions need to be filled on a full time basis at the most accessible level of care, it is crucial that the primary health care facility must have knowledgeable personnel with adequate training on ARVs to be able to operate and manage the programme.

- Lack of adequate infrastructure (including water, sanitation, electricity, communication and consulting rooms) and weak support systems (laboratory services, transport and medicine supply)
- The lack of essential services (accessible VCT and effective PMTCT programmes, particularly in resource constrained areas
- The lack of capacity to monitor and evaluate the ARV therapy programme at all levels of delivery, starting at the facility level
- Lack of a strong monitoring and evaluation system. The ability to track and treat patients, regardless of where they present is key to ensuring suitable levels of adherence and monitoring of treatment outcomes

It is worthwhile learning from the PMTCT project and avoiding the same mistake: 3 years after introducing the Nevirapine-based PMTCT programme, it still could not reach many HIV positive pregnant women, particularly in rural areas. (Ijumba et al, 2005:335).
It is of utmost importance to explore the experiences of patients receiving ARV treatment in the public sector, and also learn some lessons from the health care providers in the ARV therapy programme.

A study to explore the knowledge and practices related to HIV and AIDS by rural South Africans by Mabunda (2004:300) was conducted in an HIV outpatient clinic in the Limpopo Province. Qualitative research methods were used to conduct research with a grounded theory approach. Twenty-eight key and general informants participated in individual interviews in the summer of 2001. Key informants were recruited from a support group meeting, and they were chosen for their specific knowledge and experience of living with HIV and AIDS. General informants were chosen for their knowledge and experience related to caring for PLWHA, and for their positions in the community e.g. ministers, nurse administrators and employers. The findings from the study were that all participants were members of a support group, and they had a basic knowledge about HIV and AIDS. However, participants indicated that they lacked basic knowledge of HIV and AIDS until they joined the support group (Mabunda, 2004:300).

Another study by Metcalfe, Langstaff, Evans and Paterson (1998:31-32) was conducted to examine the feelings, concerns and needs of HIV infected women in a mid-sized Canadian city. In order to understand what it was like to live with HIV, the qualitative research method of phenomenology was selected to collect data. Methods of data collection included personal and telephonic interviews and letters (Metcalfe et al, 1998:31-32).

Findings of the study included that at initial diagnosis shock was the first reaction felt, which was then followed by anger. It was further stated that participants gained support from their families; however, the family was not always aware of their relative's status. Coping became more effective as the length of time since diagnosis increased. Participants verbalized the need to belong to a support group once diagnosed HIV positive. However, there was minimal use of community organizations due to lack of knowledge of locally available resources (Metcalfe et al, 1998:32).

The use of qualitative research in the study of personal experiences of PLWHA has been documented as effective in dealing with sensitive material such as sexual behaviour and substance abuse. There is extensive literature about HIV and AIDS, but limited research on the experiences of HIV positive people receiving ARV therapy.

2.3.1 **Factors Contributing to HIV and AIDS Related Stigma**

HIV and AIDS is a life-threatening disease and people react to it strongly; further, HIV infection is still widely associated with behaviours (such as homosexuality, drug addiction, prostitution

and promiscuity) that are considered deviant in many societies, and, as a result, most people who become infected with HIV face harsh judgement from the communities they live in.

There is a lot of inaccurate information about how HIV is transmitted and this promotes misperceptions of personal risk and irrational behaviour; infection is also generally thought to be the result of personal irresponsibility. Religious or moral beliefs lead some people to believe that being infected with HIV is the result of some moral fault (such as promiscuity or deviant sex), that deserves to be punished.

In health care settings, PLWHA experience stigma and discrimination in the form of being denied access to medicines and facilities; receiving non-consensual HIV testing; and disclosure of purportedly confidential test results. These negative responses are often fuelled by ignorance of HIV transmission routes amongst the health care providers. (www.avert.org/aidsstigma.htm:).

Stigma can affect many aspects of the day-to-day lives of PLWHA. Loss of social support, persecution; isolation; job loss; as well as problems in accessing health care services have been reported in a study conducted by Holzemer, Uys, Makoae, Stewart, Phetlhu, Dlamini,Greef, Kohi, Chirwa, Cuca and Naidoo (2007:542). The same authors further describe the contextual factors within which the process of stigma is conceived. These are described as:

- environment
  Environmental factors include cultural, economic, political, legal and policy environment.
- the health care system
  In health care settings informants reported health care workers as a source of stigmatization.
- agents
  Agents of stigma include the individual who may self-stigmatize, family members, work colleagues and community members (Holzemer, et al, 2007:547)

2.4 ARV THERAPY IN ADULTS

The South African National DoH rolled out the National ARV treatment guidelines in 2004.The goals of ARV treatment as specified in the guidelines are twofold:

1. To decrease HIV- related morbidity and mortality
2. To decrease the incidence of HIV

Not everyone infected with HIV qualifies for ARV treatment; the medical criterion for eligibility to commence ARVs is a CD4 count below 200 cells/mm3, or a World Health Organization (WHO) Stage IV disease, irrespective of CD4 count. This means that even if a client has a CD4 count that is above 200 cells/mm3, if he/she presents an AIDS-defining illness which is classified as a Stage IV illness according to the WHO, that client is eligible for ARV treatment (although the patient must express both willingness and readiness to adhere to the prescribed ARV therapy before he/she can receive it).

Although there are important psycho-social considerations which need to be observed, they are not exclusion criteria. These considerations include:

- demonstrated reliability by the client,
- absence of active alcohol or substance abuse,
- absence of active depression,
- disclosure

It is strongly recommended that a patient must have disclosed her HIV status to at least a friend or family member or have joined a support group.

- the client must have insight into his condition, that is, acceptance of his status and the consequences thereof

Anecdotal reports from the public state that communities are not satisfied with the criteria for initiating ARV therapy. Complaints that have been raised by members of the public include:

- the long waiting periods before initiation
- the level of CD4 count at which ARVs are started (200 cells/mm3)
- disclosure

It is also true that the health system has bottlenecks which impact on delivery of the ARV therapy services. Some of the bottlenecks are:

- shortage of skilled personnel
- lack of training of staff on ARV therapy
- protocols and guidelines that are imposed to operational staff without prior training

In South Africa there are two ARV therapy regimens recommended for use in the public sector. These are:

1. Regimen 1
1.1 a: Stavudine (d4T), lamivudine (3TC) and efavirenz (EFV)
1.2 b: Stavudine, lamivudine and nevirapine (NVP)
2. Regimen 2: Zidovudine (AZT), didanosine (ddI), lopinavir/ ritonavir
(National ARV Treatment Guidelines South Africa, 2004:6)

These guidelines have been further supplemented by the South African Clinical Guidelines for the Management of HIV and AIDS in Adults and Adolescents, released by the National DoH in 2010. The latest guidelines have considered people co-infected with both HIV and TB, and HIV-positive pregnant women to be initiated on treatment when their CD4 count is ≤ 350 cells/mm3. The latest guideline recommends replacing d4T with tenofivir (TDF) for all new patients needing ARV treatment.

All HIV-positive clients who meet the criteria for initiation of ARV therapy should be commenced on regimen 1a, unless contra-indicated. Women in the childbearing age unable to guarantee reliable contraception should be put on a nevirapine-containing regimen. If patients experience virological failure despite good adherence, they need to be changed to second line therapy, with close monitoring of adherence.

Patients on ARV therapy need to visit the clinic regularly in order to check the side effects of medication; to do the safety bloods, like liver function tests; and to ensure that the correct drug dosaging is being followed.

The key barriers to care are unaffordable costs; the weak availability of inputs and services; and poor acceptability, collectively referred to as the “access framework”. Although the drugs are provided free to South Africans, other costs incurred by the clients include those incurred by travelling long distances to the health facility; the long waiting times, which can result in absenteeism from work; and the unaffordable prices of the nutritious food that is vital to keeping healthy.

In low- or middle-income countries, patients often either do not seek care or do so only when they have access to funds, thus interrupting the necessary continuity of care. Shortage of health service inputs (staff, drugs and equipment) often mean that appropriate care is not even available. Complex treatment seeking patterns (healer shopping), where a patient consults a variety of providers, can also prevent provision of regular chronic care. If health systems are to

be organized to reduce access barriers, the patient's perspective on the difficulties of accessing care and the tendency to "healer shopping" need to be understood.
As a general rule the fight against any diseases is multi-factorial. HIV and AIDS represent the paradigm of disease requiring a wide spectrum of interventions (medical, social, cultural, economic) to be finally controlled and defeated. Among these interventions, improving access to adequate medical care for those in need is crucial.

On 17 April 2002, the South African cabinet reiterated its commitment to the HIV and AIDS and Sexually Transmitted Infections Strategic Plan for South Africa 2000-2005, at the same time calling for all South Africans to take responsibility for their lives in respect of HIV and AIDS. Cabinet noted progress in the implementation of the Strategic Plan and decided on a number of measures to strengthen and reinforce these efforts, including:

- Noting that ARV treatment can help to improve the conditions and health of PLWHA if administered at certain stages in the progression of HIV and AIDS
- in accordance with international standards, the government's commitment to continue its efforts aimed at dealing with the constraints to systemic access to medicines in the public sector, including ARVs
- The South African government's commitment to providing a comprehensive package of care for HIV and AIDS
- the steps to provide ART to patients in the public sector

The National ART Guidelines released by the National DoH in 2004 served to assist the clinic team in the management of patients on ART as outlined in the Comprehensive Plan for HIV and AIDS Care, Management and Treatment.

The approach adopted was that of continuum of care, with a holistic patient focus in an integrated health system (Figure 2.1).

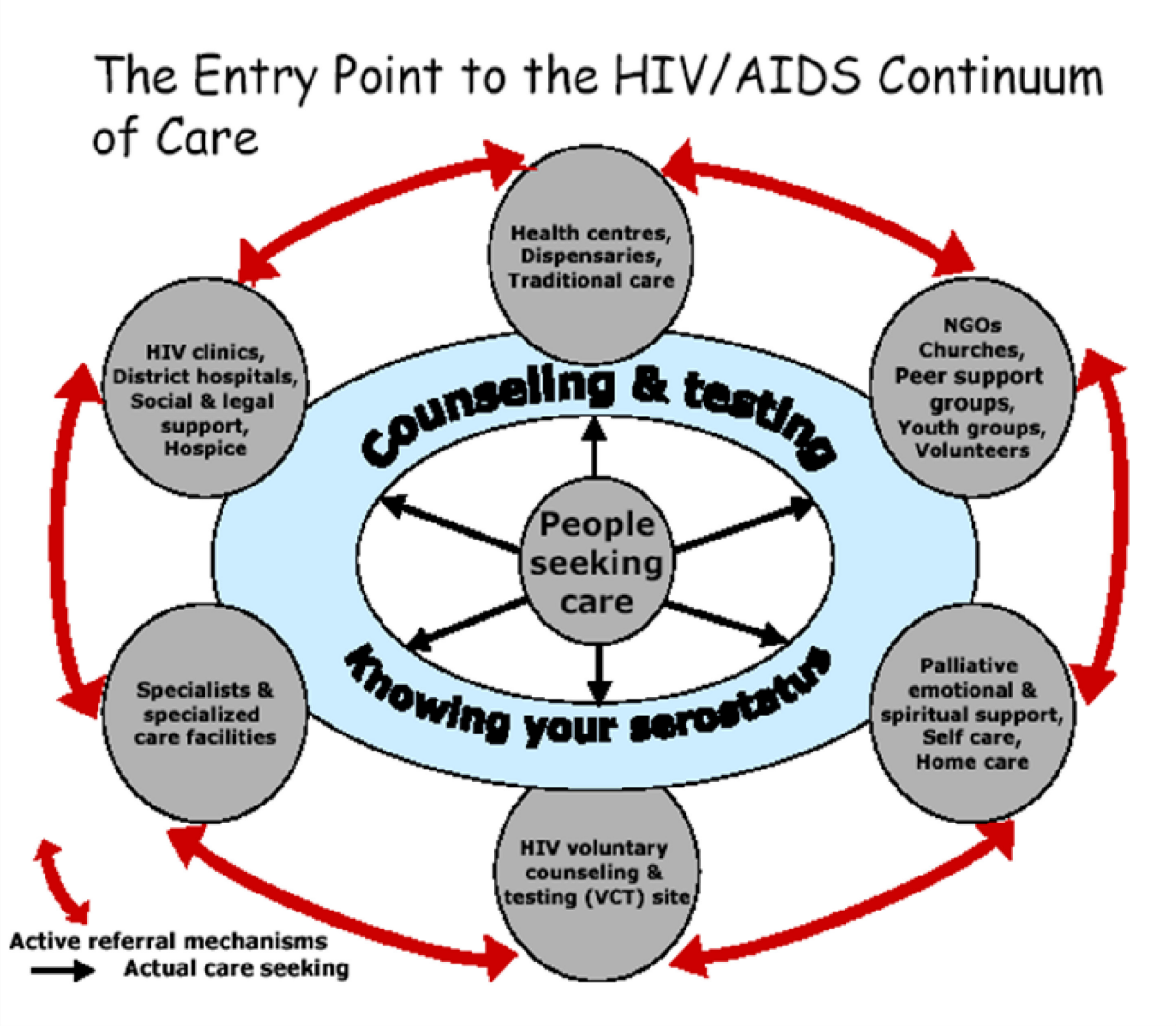


Figure 2.1: Continuum of Care Approach

Source: Adapted from FHI (2007)

A comprehensive service for management of HIV related illnesses needs to build on an integrated approach which focuses on providing a continuum of care. The continuum of care approach refers to integrated, comprehensive services offered to patients throughout every aspect of the Care and Treatment Programme, from diagnosis to treatment.

The continuum should encompass all levels of health care, and include:

- VCT
- management of sexually transmitted infections
- family planning
- reproductive health care
- TB services and outreach

- PMTCT programmes
- links to support groups

Community-based home care is also an important component of the continuum: being cared for in an environment one is familiar with, surrounded by one's significant others, and promotes speedy recovery. Such care includes physical, psychosocial, palliative and spiritual activities.
The continuum of care is a set of comprehensively linked palliative care, treatment, support and prevention services provided at health facilities (hospital/health centres), community and home. Figure 2.1 provides an overview of a continuum of care cycle.

As summarized in Figure 2.1 above, the continuum of care approach acknowledges that VCT, and encouraging people to know their HIV status, is an entry point to all services from the primary health care level to the tertiary level of care which provides specialized services. The continuum also acknowledges the important role played by the clients' significant others, and community based structures (like non-governmental organizations (NGOs), churches, peer support groups, youth groups and volunteers) in comprehensive management of patients. The importance of a multidisciplinary team approach then becomes important in day-to-day management of HIV positive patients, with active referral systems in place.

The continuum of care approach enhances ongoing negotiations between the patient and his//her significant others, the community support structures and the members of the health team. Active referral mechanisms are necessary at all levels, from the home or community to primary level of care (which is the first-line health contact for the client), which may be a primary health care centre or a VCT site.

From this level of care clients may be referred to a district or regional facility and then to a tertiary facility with specialized services and finally back to the community based structures. Other support services like pharmacists, social workers, psychologists and dieticians, also form an integral part of the continuum. Therefore, strong referral systems need to be put in place in order to ensure that there is no break in the continuity of care.

The continuum of care framework serves as a pathway followed by clients registered on the antiretroviral programme in South Africa.

Figure 2.2: The Referral Pathway

Source.www.kznhealth.gov.za/publications.htm/Clinical Guidelines and Protocols (2007)

2.4.1 Problems Facing the ART Programme

Castelli, Pietra, Diallo, Schumacher and Simpore (2010:28-32) shared their work done in Burkina Faso, and they mentioned that the problems that are to be addressed in the fight against HIV and AIDS in resource constrained countries are multifaceted and are briefly analyzed as follows:

- Cost of care

  "Cost of care" includes direct and indirect costs, such as transportation and the loss of working days that may contribute to loss to follow up of PLWHA.

- Qualified human resources

  Most qualified health personnel in resource-limited settings are concentrated in urban areas, leaving rural areas (where the need for health care is as urgent) understaffed.

Training of health care workers in the comprehensive management of HIV and AIDS in resource-limited settings is also often inadequate.

- Infrastructure
  The need for a basic infrastructure to perform at least safety monitoring and CD4 cell count is paramount, especially in underprivileged rural areas.

- Socio-cultural factors
  The most important socio-cultural barriers that limit the effectiveness of any HIV control programme include gender, poor education and stigma.

- Drug-specific constraints
  These include treatment guidelines, toxicity and drug storage.

- Specific complicating issues
  Including pregnancy and lactation, HIV/ Hepatitis B Virus (HBV) co-infection, and HIV/TB co-infection

2.5 CONCLUSION

Stigma is one of the main challenges facing the ART programme, as it discourages people from getting tested for HIV, and, if an HIV positive status is know, starting ART. It also severely compromises adherence to ART.

There is agreement in literature that taking ARVs as life-long medications requires strong relationships with health providers and considerable support from significant others. The main factors contributing to non-adherence to ART were related to poor patient-provider relationships. The literature also highlights key challenges facing the ART programme, including the continuing lack of human resources and the inaccessibility of essential services, like VCT and PMTCT, particularly in rural areas.

In the next chapter the methodology of the study is described with regard to the exploration of the experiences of clients on ART, and that of their health care providers. The research methods in the different phases of this study are described, with an emphasis on phenomenology and metasynthesis.

CHAPTER 3

3. METHODOLOGY

3.1 INTRODUCTION

This study explored the practices used in caring for HIV positive clients receiving ART in the public sector, as well as those of the health care providers rendering the ART services.

This study was a multi-phased study using the qualitative research paradigm. It consisted firstly of a metasynthesis, followed by a phenomenological research approach to describe the practices and experiences of participants from their own perspective and as experienced in their everyday lives. Participants were asked to share their real life stories about the path from getting tested for HIV, through to starting and continuing with ART, and were encouraged to share both the positive and negative experiences that they had had.

Health care providers rendering ART services were also asked to share their practices and experiences while treating HIV and AIDS patients on ART. The interviews were tape recorded and field notes were taken to ensure that the lived experiences were captured.

3.2 RESEARCH METHODOLOGY

The research was conducted in multiple phases, using qualitative enquiry methods to collect data. During phase one a metasynthesis of qualitative research articles on HIV positive people was conducted. Phase two of research studied the experiences of clients on ART, the constraints they were faced with while receiving therapy and issues around adherence to ART. Phase three of the study was to document the experiences of health care workers working on the antiretroviral programme

3.2.1 Phase One: Metasynthesis of Qualitative Research Articles on HIV-Positive Patients on ART

A metasynthesis was conducted during this phase; that is, an investigation of the results and processes of previous research studies (primary research). Qualitative research studies conducted in the field of HIV and AIDS were retrieved to conduct a metasynthesis.

The analysis procedures of meta-study involve three components: metasynthesis, meta-method and meta-theory. These components do not necessarily unfold sequentially, and are frequently conducted concurrently. Metasynthesis is derived from the results of the analytic components (Paterson et al, 2001:10).

3.2.1.1 **Method**

Paterson's model (2001) was chosen to conduct the meta-study. Meta-study is composed of four distinct components:

1. The analytic components of meta-data-analysis

   This means "the analysis of processed data, from selected qualitative research studies, to create a systematically developed, integrated body of knowledge about a specific phenomenon" (Paterson, Thorne, Canam & Jillings, 2001:55).

   Analysis of data was done by comparing each individual report with all other reports that have a common focus or that share specific and generic properties; for example, all research relating to the experiences of PLWHA receiving ART (their concerns and fears). Mostly used data analysis methods were identified.

   Meta-data -analysis has been interpreted to mean the comparative analysis of research findings of primary research studies conducted by a variety of researchers (Paterson et al, 2001: 55). Noblit and Hare's (1988) approach to meta-ethnography was used in the meta-data-analysis phase of the study. The following steps were followed:

   - Each primary research report was read in detail, noting how the phenomenon is described. Notes were made about the concepts, key metaphors, categories and phrases that best describe the phenomenon.
   - Data from the primary research report was then compared and contrasted with the data in other studies, as a whole or in subgroups, noting the similarities and differences between the key metaphors for each study. Codes were developed manually.
   - A hypothesis about the nature of the relationships between studies was made, and these relationships were depicted in a schematic representation. The primary research studies were translated into one another by determining how the key metaphors of each study relate to those of other accounts
   - These translations were refined until the phenomenon was described in a way that is faithful to the interpretations of the original data.

2. The analytic components of meta-method

   This is “the study of the epistemological soundness of the existing research as well as the ways the methodological applications may have influenced the findings that are generated, and includes examination of methodological presuppositions necessary for carrying out research; evaluation of research methods in terms of their weaknesses and limitations; and codification of new procedural norms for research in the area” (Paterson et al, 2001:71).

   Meta-method begins with an appraisal of the methodologies of individual primary research reports. This included:

   - a review of the research question
   - the role of the researcher
   - the sampling procedures
   - the data collection procedures for their fit with the stated research method and their influence on the research findings

3. The analytic components of meta-theory

   Paterson et al, (2001:91) defines meta-theory as “a critical exploration of the theoretical frameworks or lenses that have provided direction to research and to researchers, as well as theory that has arisen from research in a particular field of study”. This entailed:

   - reading primary research reports thoroughly
   - noting the theoretical perspective used
   - noting the presence of any emergent theory
   - deciding which additional theories may have had significant influence on primary research

4. The synthetic component of metasynthesis

   According to Peterson et al (2001:13), “metasynthesis brings back together those ideas that have been taken apart or deconstructed in the three analytic meta-study processes. It represents the creation of a new interpretation of a phenomenon that accounts for the data, method and theory by which the phenomenon has been studied by others”.

The additional research processes within which these components are contextualized are

- formulation of a research question
- What are the problems and experiences of patients and health care providers regarding ART?

- What are the best practices for rendering ART in KwaZulu Natal?
- selection and appraisal of data from primary research

The criteria for inclusion of research articles in the meta-study were that:

- the focus of research was on HIV positive people receiving ART (their feelings, concerns, needs and problems)
- the research design was qualitative

The studies included in the meta-study were located through searching literature databases such as:

- Medsearch
- CINAHL
- PsychInfo
- Pubmed
- Google

The search terms used included:

- HIV
- AIDS
- ARVs
- PLWHA experiences, qualitative

The search was restricted to articles written in English, and efforts were made to include a variety of qualitative methods used to conduct the studies. Some articles were excluded, but the nature of the qualitative designs was not an exclusion criterion. The quantitative studies were excluded and only qualitative research studies focusing on PLWHA undergoing ART were included.

- dissemination of the findings of the meta-study (Paterson et al, 2001: 13)

3.2.2 **Phase Two: The Experiences of Clients on ART**

The phenomenological research method was used to conduct phase two of the study. Phenomenology is an approach to exploring and understanding people's everyday life experiences. Topics appropriate to phenomenology are ones that are fundamental to the life experiences of humans. The goal of phenomenological inquiry is to understand fully lived experiences and the perceptions to which it gives rise (Polit & Beck, 2008:227). There are a number of variants and methodological interpretations of phenomenology. The two main

schools of thought are descriptive phenomenology and interpretive phenomenology (hermeneutics).

A descriptive phenomenological research approach was used to describe the experiences as they were lived by the participants. Polit and Beck (2008:228) further state that descriptive phenomenologists insist on the careful description of ordinary conscious experience of everyday life, a description of 'things' as people experience them. In this study the participants were asked to share their real life stories about the journey from getting tested for HIV, living with HIV and accessing treatment, through to starting and continuing with ART. This included:

- Personal experiences , such as adjusting to being HIV positive, living with illness, fears, hopes and secrecy
- Relationships with society, such as the reactions of family, friends, colleagues, neighbours, the wider community, and sexual partners
- Attitudes of health providers, such as doctors, nurses, pharmacists, and CHW
- Experiences with health services, such as clinics, hospitals, laboratories and pharmacies.

The descriptive phenomenological approach was found to be the relevant method to conduct this study because the researcher' interest was on the real life experiences of PLWHA, particularly those taking ART.

3.2.2.1 **Target population and selection of participants**

The study was conducted in the eThekwini district in KZN. The district was chosen because of the number of clinics rolling out ART. Three institutions initiating ART participated in the study; one urban, one semi-urban and one rural clinic, to ensure adequate representation of each group. Participants were recruited from two initiating hospitals and one Community Health Centre providing ART.

The number of participants was determined by the number of persons required to permit an in-depth exploration and obtain a clear understanding of the phenomenon of interest from various perspectives. Twelve participants were interviewed, and interviews were stopped when data saturation was achieved (no new themes or essences emerging from participants and data beginning to repeating itself).

Purposive sampling was used to select study participants. This is the most common type of sampling utilized in phenomenology, since the purpose of this type of research is to accentuate specific information, and not to generalize findings (Streubert, 2003:342). Generally, a

purposive sample is comprised of respondents who are likely to be able to provide information about the phenomenon under investigation (Burns & Grove, 2005: 352).

In phenomenology the guiding principle in selecting a sample is that all participants must have experienced the phenomenon, and must also be able to articulate what it is like to have lived that experience. Polit and Beck (2008:358) state that phenomenologists use a criterion sampling method, the criterion being experience with the phenomenon under study. In this study the sample was targeted to represent HIV positive clients who were taking ART as their chronic medication in selected public health clinics and the predetermined criterion of importance was living with HIV and taking antiretroviral medication.

Clients were selected irrespective of gender, age and socio-economic status. The criteria for including interviewees in the study were that they should be:

- HIV positive and receiving ART
- Attending different clinics receiving HIV and AIDS related care from the public sector
- Clients were to be selected from public sector clinics with rural, urban and semi urban characteristics, irrespective of the clinical stage of the disease or the length of time they were on ART
- Over 18 years of age, but within the reproductive age
- Able to give informed consent to the interview

Zulu speaking as interviews were conducted in IsiZulu.

3.2.2.2 **Data collection**

A semi-structured interview guide was used for data collection and the primary data collection strategy was the use of a tape-recorder, but the practice of note-taking during personal interviews was also utilised, in order to capture any non-verbal cues**.**

Interviews took place in private rooms in the antiretroviral clinics of the initiating hospitals, so that each participant could share his or her experiences freely. Participants were asked to suggest the date and time suitable for the interview. The participants were contacted prior to the formal session to solicit their interest, address the nature of the study, provide an overview of the informed consent and give them time to reflect on the phenomenon of the study.

It was anticipated that the period of reflection would enable richer descriptions during the interview (Streubert, 2003: 344). This meant that participants would be more willing to share

their experiences about their condition and the service they received after being given time to think about the study.

3.2.2.3 **Bracketing**

Bracketing is the cognitive process of putting aside one's own beliefs, not making judgments about what one has observed or heard, and remaining open to data as they are revealed. In descriptive phenomenology, this activity is carried out before the beginning of the study and is repeated throughout data collection and analysis (Streubert, 2003:25).

Before collecting data the researcher explored her own preconceived notions or ideas about HIV positive people and a conscious effort was made to set these preconceptions aside during data collection and analysis. This enabled the researcher to remain neutral with respect to belief or disbelief about the phenomenon. Setting aside previous knowledge or personal beliefs about the phenomenon under investigation prevented these from interfering with the recovery of a pure description of the phenomenon

3.2.2.4 **Data analysis**

Data analysis included four steps as outlined by Streubert (2003:346). These were:

1. Carefully reading the interview transcripts in order to obtain a general sense of the experience
2. Reviewing the transcripts to uncover essences
3. Apprehending essential relationships
4. Developing a formalized, exhaustive description of the phenomenon

The first step involved reading the transcripts while listening to the audiotapes so that the accuracy of the transcripts could be verified. At that stage the researcher began "dwelling in the data". Streubert (2003:346) describes "dwelling in the data" as "the time and reflection committed to reading the interviews over and over and becoming immersed in their content." This process is also called immersion.

The second step was reviewing the transcripts in order to uncover the essences, a process also known as "immersion". The field notes were transcribed by listening carefully to the tape recorder to ensure accuracy of transcription. The qualitative data consisted of transcribed interviews with twelve clients, eight women and four men, sharing their experiences on living with HIV and being on ART. Each transcript ranged from eight to ten pages that had to be read, re-read, and then organized, integrated and interpreted. Transcriptions were done on the

same day as the interview to prevent a backlog; this was also important as each interview informed and led to slight alterations in the line of questioning for the next interview. These were transferred to and stored in a Word document on the computer.

During the third step, apprehending essential relationships, the themes were related to one another. This led to the final step of developing a formalized, exhaustive description of a phenomenon. The exhaustive description was the result of the researcher's analysis of the data and the inter-relationship of themes to one another, resulting in a formalized view of the phenomenon.

3.2.2.5 **Trustworthiness**

"Trustworthiness" is the term used to demonstrate rigor in qualitative research, which, in any research, is required to prevent errors of either a constant or intermittent nature (Morse & Field, 2002:118). Steps were taken while in the field to demonstrate trustworthiness of data, to confirm that the findings accurately reflected the experiences and viewpoints of participants, rather than perceptions of the researcher. As stated by Polit and Beck (2008:71), one confirmatory activity involves going back to participants and sharing preliminary interpretations with them so that they can evaluate whether the researcher's thematic analysis is consistent with their experiences. Accordingly, to confirm credibility of findings, the participants were re-visited to share the interview transcripts with them. During these returns to the antiretroviral sites the transcripts were given to the interviewees to read in order to establish if they agreed with what was recorded as their experiences. Credibility was established as the participants were in agreement with recorded information to be true of their experiences.

Dependability was ensured by careful transcription and analysis of data manually, and also by careful description of the decisions made during analysis of data; reliability was further enhanced by openness to the creation of new themes as these emerged from the data.

3.2.3 **Phase Three: The Experiences of Health Care Providers Rendering Antiretroviral Services**

During this phase in-depth interviews were carried out with health care providers working in the ARV clinics where the study was conducted. Only those health care providers who agreed to participate were interviewed. Health care providers irrespective of category were recruited to participate in the study.

3.2.3.1 **Selection of participants**

Health care providers from three initiating clinics with rural, urban and semi-urban characteristics participated in the study. For the clinics to be included in the study they had to be public health clinics, providing comprehensive management of HIV and AIDS, care, treatment and support. Purposive sampling was used to select health care providers. The health care providers were chosen on the grounds of working with PLWHA on ART and for their knowledge of and experience in management of HIV positive people on ART. Only those health care providers who agreed to participate were interviewed, irrespective of the category. At least one professional nurse in three of the four clinics was interviewed, and a counsellor trained in adherence counselling for ART was also interviewed.

3.2.3.2 **Data collection**

Open-ended questions were asked in order to allow the health care providers to share their experiences in working with HIV positive clients, especially those receiving ART, more freely. The interview was started by asking the question “Tell me about your experiences in working with HIV positive people receiving ART”, and responses were tape- recorded after permission had been granted to do so.

3.2.3.3 **Bracketing**

Before collecting data the researcher explored her own preconceived notions and ideas about working with HIV-positive people, and these preconceptions were rigidly set aside during data collection and analysis. This enabled the researcher to remain neutral with respect to beliefs or disbeliefs about the phenomenon. Setting aside previous knowledge or personal beliefs about the phenomenon under investigation prevented these from interfering with the recovery of a pure description of the phenomenon (Annexure 11).

3.2.3.4 **Data analysis**

The interviews from participants were recorded on an audiotape, and there were notes were also made by the interviewer.

The first step of the data analysis involved writing the transcripts while listening to the audiotapes in order to verify accuracy, and was done on the same day as the interview to prevent a backlog; the same-day transcription was also important as each interview informed and led to slight alterations in the line of questioning for the next interview. These were typed into and stored on a Word document on the computer, and this as well as a hard copy (transcribed and fully translated into isiZulu) for each interview was kept.

The second step entailed reviewing the transcripts to uncover the essences: a sentence by sentence review to identify these. During the third step the themes were related to one another.

This led to the final step of developing a formalized, exhaustive description of a phenomenon. This description was the result of the researcher's analysis of the data and the inter-relationship of themes to one another, resulting in a formalized view of the phenomenon. In-depth analysis commenced after saturation had been achieved.

3.2.3.5 **Trustworthiness**

The preliminary interpretations were shared with participants to confirm the credibility of findings, and transcripts of the interviews were given to health care providers on subsequent visits to review. The participants recognized the researcher's findings to be consistent with their experiences and that meant credibility was established.

3.3 ETHICAL CONSIDERATIONS

3.3.1 Permission to Undertake Research Study

Approval to conduct the study was obtained from the Postgraduate Committee of the University of the Witwatersrand (Annexure One), and ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Annexure Two). Permission was sought from the district manager of eThekwini district to gain access to the clinics, as well as to interview health providers. The facility managers were also informed about the study to gain their cooperation to release the participants during the interviews.

Measures were also taken to ensure confidentiality: the names of health care providers who participated in the study were not disclosed, and nowhere in the research report were clinics identified by their names, being rather identified by codes like "clinic A" for reporting purposes All health care providers who agreed to participate were asked to sign an informed consent.

Permission to use audiotapes during interviews was sought, and acquired. Audiotapes shall be kept for two years post publication, or for six years if not published for audit purposes (SA National Health Act). Data was stored in a locked filing cabinet, and no one had access to it except for the interviewers. Consent was viewed as an ongoing transactional process because there was no way to know exactly what might transpire during each interview.

3.3.2 **Confidentiality**

Participants were assured that information shared with the interviewer would remain confidential: names and addresses would not be disclosed; a code number was used to identify clinics; and data was stored in a locked filing cabinet. A codebook containing both the code numbers and names and addresses of informants were stored in a locked file separate from all other data, and informants were assured that their identities would not be revealed. Any publications resulting from these data will not contain identifying information.

These issues were discussed with all participants before the interviews began. Participants were asked to sign a form indicating that the interviewee had given written consent, and a private venue was arranged within the clinic for the interviews to take place.

3.3.3 **Informed Consent**

An information sheet about the study was drawn up, in which its risks and benefits were explained, and this was read to the recruited participants (Annexures Three and Four). Participation was entirely voluntarily and those recruited were assured that declining would in no way influence their present and future health care.

Written consent was obtained from participants (Annexure Five), and the participants' identity and personal details were protected by assigning a code number for the interview.

Attempts were made to ensure that the setting where interviews were done was quiet and confidential, and that the researcher was aware that sharing experiences about living with HIV was a sensitive subject. Efforts made to phrase the questions tactfully and were sensitive to cultural and linguistic diversity.

Participants were initially addressed in a group setting at the ARV clinic in order to explain the research study, and those clients who were comfortable in proceeding to interviews were invited into a private room to ensure respect for human dignity.

3.3.4 **Rights of Participants**

Participants were given a copy of the information sheet to read after a full explanation was given to them, which included the telephone and fax numbers of the researcher, as well as a statement informing them that they could withdraw from the study at any time.

A consent form (Annexure Five) was designed for the participants to sign after permission has been sought and acquired to tape-record the interviews.

3.4 CONCLUSION

The findings from all of the phases were investigated, and patterns of convergence were identified which helped to confirm findings deduced from other data, literature and the Continuum of Care approach which is the framework underpinning the study. In Annexure 11, the researcher described her own experiences regarding her involvement with clients on ART and the health care providers of ART services.

In chapter four the description of data follows, with reflection on participants and the interviews.

CHAPTER 4

4. RESULTS OF THE STUDY

4.1 INTRODUCTION

The aim of this chapter is to describe the results of the study. This chapter presents an analysis and discussion of data collected through multiple phases, and using qualitative enquiry methods for collection. The results are described according to the different phases of the study.

Phase one entails a description of how the metasynthesis of qualitative research articles on HIV-positive patients on ART was done.
Phase two of the study includes the results of the experiences of clients on ART.
Phase three describes the findings of the experiences of health providers rendering ART services

4.2 PHASE ONE: METASYNTHESIS OF QUALITATIVE RESEARCH ARTICLES ON HIV AND AIDS PATIENTS ON ARV THERAPY

The aim of conducting a metasynthesis was to study the feelings, concerns, needs and problems of HIV-positive people using evidence-based qualitative research methods. Ten qualitative studies were synthesized using Paterson's (2001:13) method:

- Formulating a research question
- Selection and appraisal of primary research
- Meta-data-analysis
- Meta-method
- Meta-theory
- Metasynthesis

This method is presented diagrammatically in figure 4.1 below. Thereafter each step is described and explained with tables.

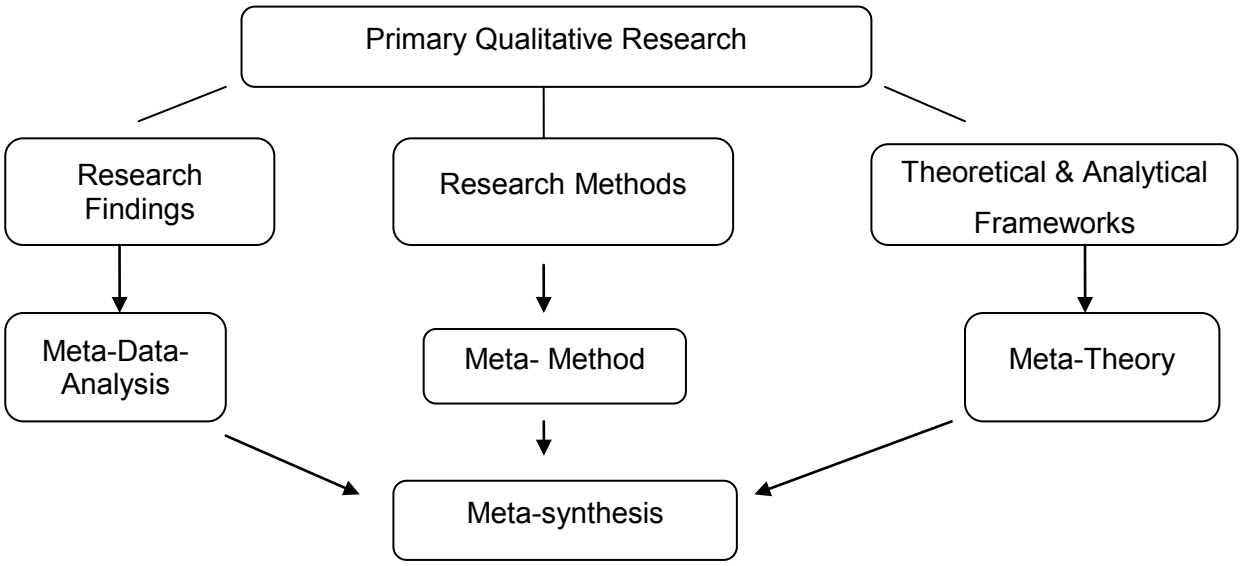


Figure 4.1: Metastudy Process

Source: Paterson, Thorne, Canam & Jillings (2001)

4.2.1 Selection and Appraisal of Primary Research

Qualitative studies published from 1998 to 2007 were selected for this review if they focused on clients' experiences with HIV and AIDS, ART and adherence to ART. Characteristics of studies included in the metasynthesis were considered. These included

- the country of research
- sampling methods used
- sample size
- recruitment strategy
- research design
- data collection methods
- data analysis procedures and results

These characteristics are presented in Table 4.1.

Table 4.1: Characteristics of Studies included in Metasynthesis

Author/ Year	Country	Sampling Method	Sample Size	Recruitment of Respondents	Research Design	Data Collection	Data Analysis	Results
Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Netherlands	Electronic database indexes: CINAHL, PUBMED and Web of Sciences	Qualitative studies published from 1996 to April 2005	Through HIV and AIDS clinics, treatment centres and community organisations. Flyers & Posters, direct invitation	Descriptive Qualitative	In-depth interviews, diaries, focus interviews	Reading publications several times Findings coded inductively Articles organized into themes	Themes: Therapy related factors Condition related factors Patient related factors Health care team and system related factors Socio-economic factors
Sidat, Fairley and Grierson (2007)	Australia	Purposive sample of seven men and three women	Ten participants	Direct invitation by clinicians on routine clinical appointment	Phenomeno-logy Qualitative	In-depth interviews	Guided by Giorgi's phenomeno-logical method Listening of tapes Units of meaning were identified	Themes HAART as life-saving option Rapid improvement of clinical condition Difficulties coping with being HIV infected Psychological and emotional implications of treatment Clinician-patient relationship issue Managing side effects
Rajabiun, Mallinson, McCoy, Coleman, Drainoni, Rebholz and Holbert (2007)	USA	Purposive sampling	Seventy six HIV positive participants	Recruited from seven community & clinic sites	Qualitative	In-depth interviews	Transcribed verbatim Codes QSR Nvivo Software version 2.0	Themes: Level of acceptance of HIV Coping with stigma Health care provider relationships Presence of external support External barriers to care

Table 4.1: continued

Author/ Year	Country	Sampling Method	Sample Size	Recruitment of Respondents	Research Design	Data Collection	Data Analysis	Results
Edwards (2006)	USA	Purposive sample	Thirty three participants, African American female receiving HIV care at the clinic	Recruited from outpatient clinic through physician networks and posted flyers	Qualitative Exploratory	Interviews Journaling	Transcribed verbatim and coded Main themes organized	Themes 1.Barriers to adherence: HIV/AIDS related stigma, Feeling unloved and uncared for Relationship turbulence, Being married to an HIV-positive partner 2. Facilitators of adherence Supportive family Presence of young children
Kumarasamy, Safren, Raminani, Pickard, James, Krishnan, Solomon and Mayer (2005)	India	Purposive sampling	Sixty participants receiving HIV care	Recruited by clinician during routine appointment	Formative Qualitative	In-depth interviews	-Verbatim transcripts of audiotapes read several times, developed coding system -NVIVO software	Themes related to barriers of adherence: Cost, social support system, stigma concerns, perceived benefits of non-adherence
Mabunda (2004)	USA	Convenient sample	Thirteen key informants (HIV positive) and fifteen general informants (carers for HIV positive people and key figures in community)	Recruited from a support group meeting and through 'snowball' method	Qualitative Grounded theory	Observations In-depth interviews	Verbatim transcripts of tapes Patterns and themes identified and compared daily	Themes Support group meetings Acceptance of HIV and ability to cope Positive attitude toward life Ties with extended families, reluctant to disclose for fear of losing relationships

Table 4.1: continued

Author/ Year	Country	Sampling Method	Sample Size	Recruitment of Respondents	Research Design	Data Collection	Data Analysis	Results
Black and Miles (2002)	North Carolina USA	Randomization - was part of a large clinical trial	Forty eight African American women HIV positive	Recruited in two infectious disease clinics and community agencies	Qualitative Descriptive	Telephonic interviews, observations during home visits	Content analysis and constant comparison used to analyse field notes	Themes Feelings of shame about having HIV Need for support and tangible assistance Stigmatization by community following disclosure Stigmatizing experiences with health care professionals
Golin, Isasi, Bontempi and Eng (2002)	North Carolina USA	Convenient sample	Twenty four HIV positive patients	Recruitment by providers in clinics	Qualitative	Focus group discussions	Audiotapes transcribed Content analysis of each transcript	Themes Patient beliefs about ART Struggles integrating complex regimens into daily routine Role of relationship with health care professionals
Marcenko and Samost (1999)	USA	-	Six focus groups	Agency staff, social worker, flyers	Exploratory Qualitative	Focus Group	Audiotapes transcribed Categories/ themes related to research question identified	Themes: Disclosure (who, when & what to share) Spirituality, Positive thinking, Inner strength (coping mechanisms) Future planning Diagnosis- providers not trained to disclose results Lack of confidence in medical knowledge & treatment regimes- adherence was low

Table 4.1: continued

Author/ Year	Country	Sampling Method	Sample Size	Recruitment of Respondents	Research Design	Data Collection	Data Analysis	Results
Metcalfe, Langstaff, Evans, Paterson and Reid (1998)	Canada	Convenient sample	Eight HIV positive women	Recruited by distributing information letters to women who visited the facility	Qualitative Phenomenology	Interviews, personal and telephonic		Themes Initial diagnosis of shock after knowing HIV status Social support from families and support group Support from health care professionals

4.2.2 **Meta Data Analysis**

The data-analysis methods used in all the selected studies were reviewed, and are presented in Table 4.2 below. The most commonly used data analysis method across authors was developing data organisation, coding and organization of themes.

Table 4.2: Data Analysis Methods used in Studies included in Metasynthesis

Author/ Year	**Data Analysis Method**
Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Reading publications several times Findings coded inductively Articles organized into themes
Sidat, Fairley and Grierson (2007)	Guided by Giorgi's phenomenological method Listening of tapes Units of meaning were identified
Rajabiun, Mallinson, McCoy, Coleman, Drainoni, Rebholz and Holbert (2007)	Codes QSR Nvivo Software version 2.0
Edwards (2006)	Transcribed verbatim and coded Main themes organized
Kumarasamy, Safren, Raminani, Pickard, James, Krishnan, Solomon and Mayer (2005)	Verbatim transcripts of audiotapes read several times, developed coding system NVIVO software
Mabunda (2004)	Verbatim transcripts of tapes Patterns and themes identified and compared daily
Black and Miles (2002)	Content analysis and constant comparison used to analyse field notes
Golin, Isasi, Bontempi and Eng 2002)	Content analysis of each transcript
Marcenko andSamost(1999)	Audiotapes transcribed Categories/ themes related to research question identified
Metcalfe, Langstaff, Evans, Paterson and Reid (1998)	Not described

4.2.3 **Meta Theory**

An appraisal of commonly used theories in the selected studies was done. Most authors were using the grounded theory approach, except for one who used the systems theory. In the five studies reviewed, there was no explicit mentioning of theories used (Table 4.3).

Table 4.3: Theories used in Studies included in Metasynthesis

Author/Year	Theories Used
Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Grounded theory
Sidat, Fairley & Grierson (2007)	-
Rajabiun, Mallinson, McCoy, Coleman, Drainoni, Rebholz and Holbert (2007)	Grounded theory
Edwards (2006)	Grounded theory
Kumarasamy, Safren, Raminani, Pickard, James, Krishnan, Solomon and Mayer (2005)	-
Mabunda (2004)	Grounded theory
Black and Miles (2002)	-
Golin, Isasi, Bontempi and Eng (2002)	-
Marcenko and Samost(1999)	Systems theory
Metcalfe, Langstaff, Evans, Paterson and Reid (1998)	-

4.2.4 Metasynthesis

A list of key metaphors/themes was made for each of the studies, and the list juxtaposed. The juxtaposition of themes is reflected in Table 4.4. After reviewing each study in-depth, the decision was made that all studies were directly comparable as reciprocal translations, that is, there was mutual agreement amongst studies. The metasynthesis revealed a shared set of four themes that increase understanding of experiences of PLWHA. The following themes were identified:

Table 4.4: Metaphors Used to Construct Reciprocal Translations

Theme	Metcalfe, Langstaff et al (1998)	Marcenko and Samost (1999)	Golin, Isasi, Bontempi and Eng (2002)	Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Sidat, Fairley and Grierson (2007)	Black and Miles (2002)	Mabunda (2004)	Kumarasamy, Safren et al. (2005)	Edwards (2006)	Rajabiun, Mallinson et al. (2007)
Acceptance and Coping mechanisms	Shock and anger initially Coping became more effective as the length of time since diagnosis	Spirituality, prayer & faith Own inner strength Positive thinking	–	–	Difficulties coping with being "HIV-infected "Psychological & emotional Stress	Faced with feelings of shame about having HIV	Admitting HIV status so as to move forward with life, "Denying HIV status is denying life" Positive attitude towards life	–	Desire to feel loved and cared for Emotional support, affirmations and reassurances reduce stress levels and fear	Coping with HIV status influenced by level of acceptance of HIV status Spirituality helps develop feelings of self worth and gain acceptance of disease
Social support and Disclosure	Gained support from family, however family not always aware of relative' HIV status	Friends, family Formal support group Amount of support correlated with comfort to share diagnosis	Hiding HIV status from family, friends & partners due to fear of discrimination and isolation	Non-disclosure due to fear of stigmatization, discrimination and isolation	–	Need for support and tangible assistance Disclosure-the goal was to disclose diagnosis in the situations where risk was minimized and benefits maximized	Importance of relationship with extended family Valued their ties with extended family Reluctant to disclose for fear of losing relationship	Lack of social support Fears of rejection, alienation and stigma from family, friends and community Disclosure resulting in negative consequences	Social support essential component for daily survival Supportive family members, Stigma noted as a social barrier Young children as primary source of social support	External support from friends, partners and family as ongoing motivators for care.

Table 4.4: Continued

Theme	Metcalfe, Langstaff et al (1998)	Marcenko and Samost (1999)	Golin, Isasi, Bontempi and Eng (2002)	Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Sidat, Fairley and Grierson (2007)	Black and Miles (2002)	Mabunda (2004)	Kumarasamy, Safren et al. (2005)	Edwards (2006)	Rajabiun, Mallinson et al. (2007)
Experiences/ Beliefs about HIV medication	_	Numerous side effects from prescribed medications Conviction for healing properties of own remedies	Treatment life saving yet stigmatizing Struggles integrating complex regimens into daily activities Basic activities (sleeping, eating and working) seen as barriers to taking medicine	Allows people to live longer, Experience side effects, Belief that skipping doses give body time to rid itself of medication and recover from side effects, Demands of medication based on strict rules and complexities of regimen	Life saving HAART Current treatment regimens well suited for their lifestyles Diverse side effects related to HAART	_	_	_	Despite challenges participants followed their HIV medication regimens	Optimistic about treatment, reported desire to be updated and informed about new treatment
Health Care provider relationship/ health system factors	Significant amount of support from health care professionals	Lack of trust Disrespectful ,insensitive and unhelpful Abrupt, judgemental and confrontational	Open, non-judgemental conversations Supportive relationships	Supportive health care providers Caring attitude Effective , frank communication	-Optimal relationships with health providers	Stigmatized interactions with health care professional	Participants lacked adequate knowledge about HIV and AIDS until they joined a support group	Non-caring attitude and no respect “They degrade us and shame us , they make us feel bad”	_	Strong, healthy positive relationships with provider facilitate continuity with medical care and vice versa

Table 4.5: Derived Themes from Concepts in Original Studies

Derived Theme	Authors	Original Concepts
Acceptance & Coping mechanisms	Rajabiun, Mallinson et al. (2007)	Coping with HIV status is influenced by level of acceptance of HIV status Spirituality helps develop feelings of self worth and gain acceptance of disease
	Sidat, Fairley and Grierson (2007)	Difficulties coping with being "HIV- infected" Psychological & emotional Stress
	Edwards (2006)	Desire to feel loved and cared for Emotional support, affirmations and reassurances reduce stress levels and fear
	Mabunda (2004)	Admitting HIV status so as to move forward with life, "Denying HIV status is denying life" Positive attitude towards life
	Black and Miles (2002)	Faced with feelings of shame about having HIV
	Marcenko and Samost (1999)	Spirituality , prayer & faith Own inner strength Positive thinking
	Metcalfe, Langstaff et al (1998)	Shock and anger initially Coping became more effective as the length of time since diagnosis
Social support & Disclosure	Rajabiun, Mallinson et al. (2007)	External support from friends, partners and family as ongoing motivators for care.
	Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Non-disclosure due to fear of stigmatization, discrimination and isolation
	Edwards (2006)	Social support essential component for daily survival Supportive family members, Stigma noted as a social barrier Young children as primary source of social support
	Kumarasamy, Safren et al. (2005)	Lack of social support Fears of rejection, alienation and stigma from family, friends and community Disclosure resulting in negative consequences

Table 4.5: Continued

Derived Theme	Authors	Original Concepts
Social support & Disclosure	Mabunda (2004)	Importance of relationship with extended family Valued their ties with extended family Reluctant to disclose for fear of losing relationships
	Black and Miles (2002)	Need for support and tangible assistance Disclosure- the goal was to disclose diagnosis in the situations where risk was minimized and benefits maximized
	Golin, Isasi, Bontempi and Eng (2002)	Hiding HIV status from family, friends & partners due to fear of discrimination and isolation
	Marcenko and Samost (1999)	Friends, family Formal support group Amount of support correlated with comfort to share diagnosis
	Metcalfe, Langstaff et al. (1998)	Gained support from family, however family not always aware of relative' HIV status
Experiences/ Beliefs about HIV Medication	Rajabiun, Mallinson et al. (2007)	Optimistic about treatment, reported desire to be updated and informed about new treatment
	Sidat, Fairley and Grierson (2007)	Life saving HAART Current treatment regimens well suited for their lifestyles Diverse side effects related to HAART
	Vervoort, Borleffs, Hoepelman and Grypdonck (2007)	Allows people to live longer, Experience side effects, Belief that skipping doses give body time to rid itself of medication and recover from side effects, Demands of medication based on strict rules and complexities of regimen
	Edwards (2006)	Despite challenges participants followed their HIV medication regimens
	Golin, Isasi, Bontempi and Eng (2002)	Treatment life saving yet stigmatizing Struggles integrating complex regimens into daily activities Basic activities (sleeping, eating and working) seen as barriers to taking medicine
	Marcenko & Samost (1999)	Side effects from prescribed medications, Conviction for healing properties

4.2.4.1 **Acceptance of and coping with HIV positive status**

There was consistency amongst authors that HIV infected people have difficulty coping with the disease (Rajabiun & Mallinson et al. 2007; Sidat, Fairley & Grierson 2007; Edwards 2006; Mabunda 2004; Black & Miles 2002; Marcenko & Samost 1999; Metcalfe; Langstaff; Evans; Paterson & Reid 1998). Sidat, Fairley and Grierson (2007) further explain that HIV infection poses serious psychological and emotional stress; there is a need for emotional support and reassurance in order to reduce these high stress levels. Marcenko and Samost (1999) reported that spirituality, faith and prayers contribute to acceptance of living with HIV, whilst Mabunda (2004) claimed that a ppositive attitude towards life increases coping mechanisms.

4.2.4.2 **Social support and disclosure**

There was strong agreement across studies that while PLWHA need support from significant others (family, partners and friends), disclosure remains a challenge (Rajabiun & Mallinson et al 2007; Vervoort, Borleffs, Hoepelman & Grypdonck 2007; Edwards 2006; Kumarasamy, Safren, Raminani, Pickard, James, Sri Krishnan, Solomon & Mayer 2005; Mabunda 2004; Black & Miles 2002; Golin, Isasi, Bontempi & Eng 2002; Marcenko & Samost 1999; Metcalfe, Langstaff et al 1998). There was concern regarding whom to disclose the diagnosis to, as well as the question of when and how. Reasons for non-disclosure were categorized as follows:

- Disclosure to family members: fear of rejection and negative reactions, (Kumarasamy et al. 2005).
- Disclosure to friends: fear of alienation and stigmatization (Kumarasamy et al 2005).
- Disclosure to the community: fear of discrimination and isolation. (Vervoort et al. 2007; Kumarasamy et al. 2005 and Golin et al. 2002).

PLWHA highlighted stigma as a social barrier, and Vervoort et al. (2007) confirms this by stating that “most HIV-infected patients do not disclose their HIV diagnosis fearing stigmatization, discrimination and isolation”.

4.2.4.3 **Experiences of and beliefs about HIV medication**

Sidat et al. (2007), Vervoort et al. (2007) and Golin et al. (2002) were in agreement that although PLWHA perceive HIV medication as life-saving there were concerns about side effects and the demands of medication (based on the complexities of the regimens).

4.2.4.4 Health care provider relationships/health system factors

Significant amount of support from health care providers was shared by studies. Highlights of non-judgemental and caring attitudes were made (Sidat et al. 2007, Vervoort et al. 2007, Rajabiun et al. 2007 and Golin et al. 2002 & Metcalfe et al. 1998), and ppositive relationships with providers were mentioned as motivators for continuity of care. However, Marcenko and Samost (1999) highlighted the negative aspects of less-than-satisfactory relationships, including disrespectful; insensitive; confrontational and non-caring attitudes, as well as the lack of trust from practitioners. Doctors and providers displaying these positions were described as being abrupt, not answering questions comprehensively, and making clients wait for long periods of time before attending to them.

4.3 PHASE TWO: THE EXPERIENCES OF CLIENTS ON ART

A semi-structured interview guide was used as a source of data collection to explore the experiences of clients receiving ART in public sector initiating clinics. Data was collected over a period of four months, and a total of twelve clients receiving ART in the initiating clinics of eThekwini district were interviewed for the study. After interviewing the tenth participant, data saturation was reached. Data saturation was confirmed by interviewing two more clients.

4.3.1 Size of the Sample Interviewed

Eight women and four men agreed to be interviewed, all of whom were unmarried, with an age range from 26 to 42 years. Although most clients had children who were alive and well, many had also experienced the death of their babies.

Table 4.6 below presents the number of clients who participated in interviews in the three participating institutions. 50% of the interviewees were from clinic A, which was the first clinic to participate in interviewing.

Table 4.6: Sample of Clients interviewed During Phase Two in the Three Participating Clinics

Clinic	Frequency	Percent
A	6	50
B	3	25
C	3	25
Total	**12**	**100**

4.3.2 Main Themes of the Interviews

Table 4.7 depicts the main themes that emerged from the interviews and these themes outline the information provided during the interviews. Each participant is identified by the code and the line number of his or her words in the transcript, e.g. 3:298, that is, participant 3 line number 298. The important concerns expressed by the participants are highlighted in the analysis. In practice the themes are strongly linked to each other and as such, some repetition of key points was unavoidable.

Table 4.7: Main Themes in the Participants Words

Theme	Examples from participants
Life before and after knowing HIV positive status	"I was not well generally, but I was not bedridden" (1:4) "I was sick, having running stomach [sic]", getting sick now and again (3:298)
Initiating and continuation of ART	"They made us to attend classes, took bloods and given appointment for follow up, until I was put on treatment by that time one is singing the information about medication even before you take them [sic]". (10:1324-1336)
ART: Adherence to and side effects of treatment	"My CD4 was low so they recommended to start antiretrovirals [sic]"(1:26) "You are taught about different ARVS with your supporter" (3:376) "I used alarm in my phone [sic], to remind me to take them at 8am and 8pm, at 7.30 I make porridge and take them [sic] at 8am, and my supporter reminds me in the morning and evening" (3:378-380) "I used to feel dizzy, I think Stocrin caused it even if I was sleeping but it was for a short time and then it was over" (3:383-384) "So I developed rash [sic], and sometimes I was weak, there is one tablet I take in the evening which made me feel dizzy, once I had taken it, I was forced to go to sleep" (5:541-543)
Social support for people on treatment	"The only person who knows is my daughter who will disclose to my parents when my last days come, because she's my blood she's with me through all hardships" (9:1222-1225) "I think home is an important support system [sic], people who are close to you, someone or all need to know at home so that they remind you" (3:388-389)
Positive outcomes of being on ARV treatment	"So I got used to treatment and things got better and I was right [healthy], my weight improved because I lost weight until I weighed 69kg, it improved to 80,4kg. So this year I've started my studies with UNISA [the University of South Africa]…"(5:545-547)
Improving access to ARV treatment services	"I spend R24-00 return trip coming to the clinic" (11:1515) "My home is far, I stay in my workplace, I'm a domestic worker my employer brought me here, my home is at Ndwedwe…"(5:685-689)

4.3.2.1 **Life before and after knowing HIV positive status**

This theme describes the experiences as shared by interview-participants before finding out their HIV positive status; what motivated them to get tested for HIV/AIDS; and what it was like living with an HIV positive status. Most participants highlighted that before knowing their HIV positive status they were suffering from multiple illnesses. They had repeated bouts of sickness, although they were not bedridden:

- "I was not well generally but I was not bedridden…" (1:4)
- "I was sick having running stomach getting sick now and again..." (3:298)

TB was reported as a common opportunistic infection by the majority of participants: one participant mentioned that she was coughing a lot in the evenings and was tested to exclude TB at the clinic. Most interviewees had already been on a TB regimen by the time they were started on ART:

- "It was discovered that I have TB of glands [sic]… I was put on TB treatment; I took it until I finished treatment..." (1:6&10).
- "They discovered also that I have TB..." (7:828).
- "I started treatment in December 2007, I was told to start with TB treatment first for a month then take ARVs [sic], I think I started ARVs in January 2008 even now I'm taking them [TB drugs] because I was told to take them for nine months..." (7:890-893).
- "I developed TB as well, I treated TB this side and 'this condition' this side, they gave me TB treatment for two weeks then I started ARVs [sic]..." (8:1060-1062).
- "They told me to start TB treatment , I think I was not yet seriously ill except for chest problem , I took TB treatment for six months and finished them, by then I was not at the stage of starting ARVs I was found to have TB [sic]..." (9:1165-1166).
- "I was coughing a lot in the evenings and afternoons, I decided to check TB and I discovered I had TB..." (11:1397-1398).
- "I was right [healthy] the only problem I had was difficulty in breathing, loss of weight, as from 2003 I was ok [healthy] weighing 48-50kg, it's TB that gave me problems..." (12:1534-1535).

For many interviewees the process of HIV testing and accessing ART occurred in a context of multiple stresses, such as illnesses or the death of a family member. One participant sought HIV testing because she was pregnant and was enrolled in the PMTCT programme:

- "I was right [healthy] I didn't have any problems, then in 2003 I fell pregnant and I was tested for HIV and found to be positive"(12:1524.)

Most participants indicated that relatives and frequent illnesses were the motivating factors to test for HIV. Discovering the positive status raised a variety of emotional reactions to participants including crying, being ignorant, difficult feelings, spending sleepless nights and thinking endlessly. However, for some, discovering the status brought relief:

- "I accepted and I got relieved [sic] and I wished I could start treatment… maybe it's because when I was sick I was suspecting [sic] that I may be infected" (3:360)

Most participants shared that when living with HIV they were using Zulu medicines from traditional healers. Some mentioned that they were scared of ARVs, although the counselling that they received in the clinics after testing positive included literacy sessions on ARVs, most still preferred traditional remedies in the form of 'Imbiza' (herbal medicine) to ART:

- "I was using Zulu herbs, scared to take pills for life" (7:842).
- "I was just using Zulu medicines, enema [sic], steaming everything..." (10:1304).

Most participants started by shopping around for other locally available remedies in an effort to manage the condition themselves; the cost involved was also shared by some participants since affordability was a problem for some:

- "I used to go and search for imbiza [herbal medicine] with red ribbon sign [sic] and when checking the price …R150-00 / R100-00 hmm no, for life [sic]! I thought I was not going to afford [sic]" (11:1456-1457).

It was interesting to note that when people were diagnosed as HIV-positive, their first point of contact to seek assistance was the traditional healer or herbalist. These therapists provide treatment in the form of inducing vomiting (ukuphalaza), an enema (ukuchatha) or steaming (ukugquma). It was only after these efforts had failed that participants sought medical assistance by approaching the nearby clinics.

4.3.2.2 **Initiation and continuation of ART**

This theme highlights experiences shared by participants by relating to procedures they went through, from testing for HIV up to starting ART. The route followed by clients, from deciding to be tested for HIV through to being enrolled to a lifetime ART programme, is a long one, and requires commitment and strong will power to be able to face the challenges.

- "She told me about HIV, that when results are positive or negative, it does not mean that you are going to die…but when I need assistance and when I'm in a stage for getting ARVs, they offer assistance [sic]. She told me that after doing a test I'll need to do CD4 test as well [sic]" (1:16-18).

- "I came to meet the dietician, I was told to go for classes …We were taught about ARVs, we were taught about all types of ARVs" (4:491)
- "Doctor started me on treatment, CD4 was 74 [sic], my mom was my supporter" (8:1058)

One participant was not satisfied with the waiting list clients are put on before being initiated on ART, especially when the individuals have low CD4 counts. This participant felt that certain clients need to be prioritized and be initiated on treatment sooner.

- "The way I was sick [sic]… some people were given earlier appointment [sic]... The way I was sick I ended up going to a private hospital... thereafter I had no complaints but they didn't prioritize me in spite of reporting that I'm sick [sic]"(8:1119-1121).

4.3.2.3 **ART: adherence to and side effects of treatment**

In this theme, the participants' experiences of taking ART, strategies for adhering to the treatment and the side effects of the medication are highlighted.

Participants reported that they had received basic information about the reasons for taking ARVs, how they should take the pills, the importance of not missing the doses and the fact that ARVs have some side effects. They all reported that before they were put on ART, they were made to attend literacy classes. At the start of ART, interviewees reported that the main criterion for enrolment into the ARV programme was to come with a treatment supporter (an individual to whom PLWHA had disclosed their status to). Their role was to attend the literacy classes with the client they were supporting, as well as offering ongoing support and enforce adherence to ART.

Generally, adherence levels to ART were reported to be high for all interviewees; although the majority of them had only been on ART for a short period of time, most of them had initiated their treatment when they had AIDS-defining illnesses. All participants had a clear understanding that ART was life-long therapy, and some even equated this with other types of chronic medication. Some participants were concerned about the side effects of medication.

Most participants discovered their HIV status when they were already experiencing symptoms of AIDS-defining illnesses. They were often initiated on ART as soon as the CD4 test and safety bloods results were known. Some participants had been advised to postpone initiation of treatment until the criterion for starting ARVs was met.

- “Doctor started me on treatment; CD4 was 74 [sic]” (8:1056).
- “It was in 2005 when tested but scared to take lifelong medication [sic], then in 2008 I started the medication, my CD4 was found to be low, I said I’m starting medication. I told myself I’ll take these pills for the rest of my life…I was told to go for classes, for three sessions” (7:848-849).
- “They checked my CD4 again in July and it was 9… I was then referred here at VCT [sic] and I started ARVs” (12:1532.)

Most participants had developed their own methods and reminders for taking medication. These included:

- using a cell phone alarm
- linking doses with meals
- always carrying a supply when leaving the house
- linking doses with their favourite television programmes
- Filling up prescriptions before running out of ARVs.

Significant others also played an important role in reminding them to take their medication, whether or not the relatives knew what they were for. The importance of the correct timing of doses was well understood, and the majority of participants were receiving their medications twice-daily:

- “I used alarm in my phone [sic], to remind me to take them at eight in the morning and eight in the evening, at seven-thirty I make porridge and take them at eight in the morning, and my supporter reminds me in the morning and evening”(3:378-379)
- “I use my phone alarm, even at home they know that I take them at 9 in the morning and 9 in the evening, my phone also reminds me [sic]”(4:495-496).
- “I decided to discuss this with my daughter…I disclosed to her…So I said ‘Please be my time keeper, remind me’” (5:628-645).
- “I take them regularly, I made this to be part of my life [sic], I know my times, eight-thirty in the morning and eight-thirty in the evening, I don’t forget, I haven’t missed them even a single day [sic]…If I’m out till late I take the dose with me to make sure I take it at the right time” (10:1370-1373).
- “I chose to take them at nine in the morning and nine in the evening... nine pm is right because at eight pm I watch the Generations soapy [sic] and watch the next drama until nine pm, then take my pills; after that I go to bed straight and not do anything [sic]” (11:1475-1480)

Some individuals were also taking other medications, for the treatment of opportunistic infections such as TB, in addition to undergoing ART. They reported that combined medications caused additional challenges for adherence because of the ensuant "pill burden" (number of pills taken by the client).

In the scenario where a client is taking both ARVs and TB treatment, a client may take more than ten pills just for a morning dose: the public sector standard treatment regime for these combined conditions is five tablets of Rifafour for TB, vitamin B6 (Pyridoxine) as part of the vitamin complex needed to prevent occurrence of peripheral neuropathy (South African National ART Guidelines, 2004:87), ARVs and other prophylactic therapy to prevent Pneumocystis pneumonia (PCP).

- "I started ARVs, I developed TB as well, I treated TB this side and this condition [being HIV positive] this side, they gave me TB treatment for 2 weeks then I started ARVs" (8:1060-1062)
- "It was discovered that I have TB of glands [sic]…I was put on TB treatment and I took it until I finished" (1:6-7)

Most participants reported that it had been explained to them that ART might cause side effects, and most reported experiencing side effects including skin rashes, headaches, and fatigue and sleeping disturbances during the weeks of initiating ARVs. Very few individuals reported not having experienced side effects of the medication, although for some, side effects had disappeared completely by the time of the interview. In spite of this, participants reported that the benefits of taking ARV medication outweighed the risks and discomfort.

- "So when I started treatment in 2006, I got sick, treatment made me to be sick [sic]…I developed rash [sic] and it made me uncomfortable. Well, I told myself that I'll get used to the pills…so I developed rash [sic], and sometimes I was weak,… there is one tablet I take in the evening which made me feel dizzy; once I had taken it, I was forced to go to sleep...so I got used to treatment and things got better [sic]"(5:537-543).
- "Problems started; painful feet, I couldn't walk at all; my mom did warm compresses and they helped me as I was not given any treatment for painful feet…and I developed rash in my face [sic] but it subsided again…only the feet that were problematic [sic] my head was…. especially the tablet I take at night my head was like dizzy [sic]" (8:1064-1066).

Participants used a variety of strategies for dealing with side effects, some of which included taking pain killers; using topical ointments (for skin rashes); warm compresses; and rest and perseverance.

Most participants also reported dramatic improvements in health, including weight gain as a result of the return of their appetites, and so participants were motivated to sustain ART and ensure that they minimized defaulting treatment. Motivation to adhere to treatment was high, and centred on personal, social, family and health aims. Many indicated a strong desire to survive long enough to ensure care for children and not leave them as orphans.

4.3.2.4 **Social support for people on ARV treatment**

This theme describes the support structures available for people on ART and the importance of having these when coping with the demands of the ART programme. Participants mentioned a variety of support needs, including:

- emotional support
- counselling
- food
- family support s
- support from health professionals

Families were placed at the forefront of social, emotional, physical and economic support for HIV- and AIDS- related treatment and care. Relatives are often sources of information and encouragement on advising other members to go for HIV testing, including where to go and where to access support for HIV- and AIDS- related care and ARVs.

- "I think the home is an important support system, people who are close to you…(pause) you need to disclose to make it easy, even if you forget the pills someone at home will remind you by asking if you've taken your pills"(1:73-74)
- "My mother is so supportive…So, that afternoon I showed her results and she was supportive…I haven't been in a difficult situation" (4:454-456)
- "I knew my status in 2005 and my health status was not good, my sister kept on saying I must take ARVs…I asked my sister to come and sleep with me…she kept on reminding me not to forget and I told her I'll never forget"(7:851-856)
- "My mom was my supporter since I started ARVs" (8:1058)
- "I have no problems; my daughter supports me and my parents are a warm [sic], my children make sure I take pills at the correct time, they ask me if I've taken pills, they even pack for me the ones I take when I'm at work [sic]…my daughter is with me through all hardships"(9:1238-1240)
- "I get a huge amount of support from my partner, as she is the one who motivated me to get to this programme, she kept on nagging me" (10:1375-1376)

CHWs were also reported as significant people in providing support for PLWHAs. Their roles included home visiting for further support regarding adherence to treatment (including

treatment for opportunistic infections); assisting with the various difficulties of disclosure; and making arrangements for food parcels if necessary.

- "There are CHWs who do home visits so I called her and told her that I'm positive and told her that no one was working at home only granny is at home, so she tried to bring me food parcels at home [sic]… I also asked her to tell my granny because she was going to be surprised why I was receiving food parcels [sic]" (3:362-367).
- "My CHW, I have a CHW who helps me since I started TB treatment" (12:1562).
- "She [the counsellor] used to come and visit me in the ward and invite me to visit, so I became free [sic] and got attached to her… she motivated me because I wanted to desert even my work [sic], but she encouraged me to continue with my studies" (11:1429-1431)

Most interviewees highlighted the support they got from the nurses who were rendering treatment, care and support in the ART programme.

- "Nurses are my friends I don't have a problem [sic]" (10:1382)
- "I have no problems, even with my doctor I ask her everything, I believe in voicing concerns, I feel warmth from clinic sister [sic], I told myself I won't have problems when the sisters are available to help me"(9:1257-1259)

However, some did report negative attitudes and bad treatment by the nurses.

- "Sometimes they treat you badly, as if your mind is not functioning! So [sic] if she treats me badly it will be difficult for me to come back and share my problems with her next time…so [sic] if they [the nurses] can be open that will make easy for us [the clients] to be open as well…some will treat you as if you are an idiot!... let's say they tell you something you don't understand and you ask them to re-explain, some react badly if you ask!"(4:500-511)

4.3.2.5 **Positive Outcomes of Being on ART**

This theme highlights the participants' experiences about the outcomes of being on ART. Most interviewees shared positive outcomes and experiences while taking ART, including an improvement in physical, social and emotional well being, as well as a greater sense of optimism about the present and the future. Although some participants raised concerns about the possible long-term side effects of medication that could counteract the positive outcomes, many participants mentioned that being able to continue to care for their families and children was an enormously beneficial outcome of being on ARVs, and interviewees praised ART for the positive results they noticed in their health (including weight gain and the return of physical strength):

- "My weight improved...I lost weight until I weighed 69kg, it improved to 80,4kg [sic]" (5:546)
- "I noticed the difference, started to gain weight and recovered from weakness and became normal again. Even people who knew me when I was sick noticed the difference" (9:1168-1169)
- "I feel very well, I'm light [sic], able to work, before my whole body was sore [sic]…I'm well, I highly recommend these pills" (7:897-899)

One participant mentioned that ARVs also improved his libido:

- "The feelings… your body becomes strong again… you seek to have a sexual relationship now! I'm right, I feel right truly" (10:1357)

Another participant reported to have been registered with a university to further her studies because she has regained normal life:

- "So, this year I've started my studies with UNISA…" (5:547)

4.3.2.6 **Improving access to ARV treatment services**

Interviewees often have to travel considerable distances to access HIV- and AIDS-related treatment. This is costly, both in terms of finances and the sometimes considerable waiting times for treatment (resulting in abseentism from work). Centralization of ART-initiating hospitals contributes to these problems, as ART is not initiated in the primary health care clinics (which are more within reach to clients). The average time travelled to the initiating hospitals was 30 minutes to one hour with a maximum cost of R24-00 per return trip:

- "My home is far [sic], I stay in my workplace [sic], I'm a domestic worker, my employer brought me here [to the clinic]..." (5:685-689)
- "I spend R24-00 coming to the clinic and going back home" (11:1515)

4.4 PHASE THREE: THE EXPERIENCES OF HEALTH CARE PROVIDERS WORKING IN THE ART PROGRAMME

A total of four health care providers were interviewed on their experiences with rendering care to HIV positive clients receiving ART. These interviewees were comprised of both professional nurses and counsellors.

The concerns raised by health care providers were related to health service provision and the quality of nursing care. Health care providers spoke about the human resources constraints that prevail in the public sector. They raised concerns that the health care provider/patient ratio was inadequate to deal with ever-increasing patient numbers needing ART, and that this had a negative impact on the overall quality of nursing care. Data

saturation was reached after interviewing the third health care provider. To confirm this, one more health care provider was interviewed. The following themes emerged from the interviews:

Table 4.8: Main Themes in the Health Care providers' Words

Theme	Examples
Establishing and maintaining good client-provider relationship	"The difficult time is the first day; you need to establish good relationship and make the client close to you, don't scold them, be at their level even if they do wrong things don't shout at them [sic]"(2:75-79)
Facilitators of adherence to treatment	"Trying by all means to make clients feel at home, to make them feel like they are coming to their support group if they come to clinic [sic]"(1:45-47)
Barriers to access to treatment	"Sometimes clients when they come here they recognize members of staff who are their neighbours [sic]"(1:28-30)

4.4.1 Establishing and Maintaining Good Client/Provider Relationships

Health care providers mentioned that the first day of meeting the client is the crucial one in establishing sustainable long-term relationships. They reported that warmly welcoming clients during the first encounter puts the clients at ease and goes a long way to allaying fears and anxiety. The establishment of a trusting relationship was reported to be enhanced by the type of questions that the provider asked the clients, these needing to be as simple and non-threatening as possible. Providers also mentioned the importance of non-verbal cues, as the clients observe facial expression during communication.

Friendliness that is displayed by facial expression in the form of a smile, and acceptance of the clients irrespective of their condition were reported to be the main factors contributing to trust and a positive long-term relationship. Providers also highlighted the importance of listening to the clients, as they tend to need a lot of attention, especially during the first encounter:

- "I give him a warm welcome and make him feel more welcomed the way you talk with him, even when looking at your facial expression, the client must feel at ease to talk to you [sic]" (1:3-5)
- "If they are welcomed well and listened to during first encounter they develop to trust you and develop that long term relationship with you, listening to your clients establishes relationship [sic]" (1:15-17)

- "You need to be friendly, your facial expression when greeting the client for the first time, show the smile, give love , even if she has sores touch her, hug her if there is a need because they feel its end of the world and they look at your facial expression as you talk to them to watch your reaction , there are those with cancer of cervix, vaginal discharge with a smell, but make sure you don't show them with your expressions and by opening windows [sic]"(2:58-65)
- "The difficult time is the first day you need to establish good relationship and make the client close to you, don't scold them, be at their level even if they do wrong things don't shout at them [sic]"(2:75-79)

Health care providers reported that the environment where interaction takes place needs to be conducive to welcoming the client, and free from interruptions to encourage the client to talk openly. Achieving these was reported to be construed by the clients as respectful, and in return the clients were more willing to trust the provider:

- "Even the environment helps; it must be free from interruptions so that the client feels easy to talk even private issues, there are things clients would not like to talk about in the presence of other people [sic]"(1:10-13)

4.4.2 **Facilitators of Adherence to ARV Treatment**

Interviewees reported that creating an enabling environment for clients facilitates adherence to ART:

- "Trying by all means to make clients feel at home, to make them feel like they are coming to their support group if they come to clinic [is important]..."(1:45-47)

Interviewees also mentioned that improvements of the patient's condition manifested in the form of general health improvement, including weight gain due to increased appetite and reduction/improvement of opportunistic infections, due to the adherence to ART. On-going counselling on the importance of adherence to treatment and the ill-effects of defaulting treatment were also reported as motivating factors to stick to ART.

4.4.3 **Barriers to Access to ARV Treatment**

Nurses and counsellors reported that when clients visit the clinic and discover that there are staff members they know they do not feel comfortable, especially since, at this point, most of them will not have disclosed their status and that this occurring does lead to non-adherence.

Denial, in the form of non-acceptance of an HIV-positive status and the sometimes harsh treatment by staff members were also reported as barriers to treatment. Health care

providers were viewed as being “harsh” by clients if they were scolded for not complying with clinic appointments and defaulting on treatment. Interviewees also reported that some clients register in the ARV programme for the sake of getting a disability grant and once that is approved they disappear and only return when they develop complications.

- “Sometimes clients when they come here they recognize members of staff who are their neighbours who may spread the news in the neighbourhood that he attends ARV clinic and they don’t feel at ease to come and they end up defaulting. We’ve seen this when we were implementing the down referral programme and when we transferred clients to their nearby clinics, clients resist to go there and they prefer to attend the service where they are not known even if they can spend a lot of money [sic]” (1:28-37)
- “Sometimes clients default treatment and when being scolded by sisters, clients label that sister as "harsh" and they avoid her, but our staff are very friendly to patients, it’s very rare to get such instances [sic]”(1:50-53)
- “Clients come to the clinic for the sake of getting pension [disability grant], some people come to start treatment, comes regularly for three months keeping appointments well, then assisted to apply for a grant then disappear, so they come for the sake of pension especially those who are unemployed [sic]“(2:99-103).

4.5 CONCLUSION

There was agreement between the first two phases of the study regarding ART being seen as life-saving medication by the clients.

Phase one revealed evidence from literature of the beliefs PLWHA had about ART, and this evidence was substantiated by the voices of participants during phase two of the study, when clients shared their experiences of undergoing ART.

While health providers confirmed the effectiveness of these drugs marked by general improvement of the clients’ condition, they also mentioned that the human resource constraints in public health institutions undermine the ART programme.

In chapter five the recommendations, conclusions and limitations of the study are discussed.

CHAPTER 5

5. DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The purpose of the study was to explore the practice of the ART programme regarding patient issues and experiences, as well as the experiences of the health care providers rendering ART services in three selected ARV clinics, and to develop a guideline for ARV services in the eThekwini district. Qualitative research methods were used to conduct the study.

During phase one, a metasynthesis of qualitative research studies on HIV-positive patients was done. During phases two and three, a phenomenological research approach was used to describe the experiences of HIV and AIDS patients as they were lived by the study participants in the ART programme. This chapter discusses the findings, conclusions and recommendations for each phase of the study, as well as the limitations of the study.

5.2 DISCUSSION ON METASYNTHESIS OF QUALITATIVE RESEARCH STUDIES ON HIV-POSITIVE PATIENTS ON ART

The metasynthesis revealed a shared set of four themes that increased the understanding of the experiences of PLWHA:

1. acceptance of, and coping with, HIV positive status
2. social support and disclosure
3. experiences/beliefs about HIV medication
4. health care provider relationship/health system factors

Studies reported that accepting and coping with a positive HIV status was difficult. This is in agreement with the view of Metcalfe et al. (1998:32) that at initial diagnosis shock was the first reaction felt by HIV-infected clients. The importance of people who are HIV positive admitting that they have the disease so that they can move forward with their lives is highlighted. One informant, as reported by Mabunda (2004:302), said “Denying HIV testing is denying life”, as she believed that people must expose themselves to testing, know and accept their status and can then begin to protect self and others. Rajabiun et al. (2007:23-24) confirm that the ability to cope with a positive HIV status is influenced by the level of acceptance of a positive HIV status.

The role of social support and disclosure for PLWHA has been emphasized in most studies. Friends, partners and family have been highlighted as the most important support systems, and Marcenko et al. (1999:40), in their study on “Living with HIV: the Voices of HIV Positive Mothers”, agree that the amount of support available for women to cope with their status was directly correlated to their level of comfort in sharing the diagnosis. However, there is evidence in the literature that clients still hide their HIV positive status from family, friends and partners, due to the fear of discrimination and isolation (Golin et al.2002). This poses an approach-avoidance conflict for PLWHAs, as they need support from significant others, and yet fear rejection and stigmatization due to disclosure.

Studies by Golin et al. (2002:324) and Sidat et al. (2007: 512) reported patients’ perceptions about ART that the treatment is life saving yet stigmatizing. There is also agreement across studies that PLWHAs taking ART report side effects of the medication; however, it is mentioned that they do believe the benefits outweigh the risks, and that this is a motivating factor to adherence.

The study by Rajabiun et al. (2007: S-24) mentions that strong, healthy positive relationships with health care providers facilitates continuity with medical care, and vice versa. However, a non-caring attitude and a lack of respect amongst health providers is equally powerful: “They degrade us and shame us, they make us feel bad” (Kumarasamy, et al. 2005:531)

5.2.1 **Conclusions of Phase One**

This metasynthesis provides health care providers working with HIV infected patients with a broader understanding of the feelings, needs, concerns and problems of PLWHAs. For example, in all studies the patients’ need for social support and the concurrent reluctance to share diagnoses with relatives, friends and/or partners for fears of stigmatization, discrimination and isolation were reported. It is therefore recommended that ongoing community education continues in order to raise awareness of the disease in the form of Information, Education and Communication (IEC) messages (like leaflets and posters written in local languages); mass media campaigns; and individual education to eradicate the stigma attached to HIV infection.

Because of this enormous need for strong support systems for PLWHA, it is recommended that systems be established within the facilities that render comprehensive care management and treatment of PLWHAs, including ART. Counsellors trained on the ART programme could facilitate the establishment of support groups for people taking ART as their chronic medication. Liaison with community-based structures also needs to be

enforced; there are already CHWs who are based in the community and conduct daily home visits, do community outreach programmes and play an important role in improving people' knowledge about HIV care and treatment, helping them to build skills to incorporate HIV into their daily routine, as well as providing a support network. CHOs can provide ongoing support, and serve as a link between the health facilities and the clients in the community to ensure continuity of care. Health care workers can also help clients to establish a network of support services in the community.

Clients perceive ART as life-saving and health care providers need to strengthen and sustain this positive view. This can be achieved by having sessions with clients registered on the ARV programme which highlight the benefits of the medication by emphasizing the fact that the benefits outweigh the risks.

Health care providers need to maintain a stable relationship with their clients, one which is non-judgemental and free from prejudice. The importance of displaying warm and caring attitudes at all times when interacting with clients cannot be over-emphasized; HIV and AIDS is a sensitive subject that needs to be handled with sensitivity and care.

This metasynthesis does have several limitations however, one being that qualitative studies that were located and included in the analysis do not represent all possible responses to experiences of living with HIV infection.

5.3 DISCUSSION ON THE EXPERIENCES OF CLIENTS ON ART

In this phase, the experiences of clients on ART; the constraints they are faced with while receiving treatment; and the issues around adherence to ARV therapy were explored. This phase provides a rich description of the phenomenon of clients' experiences while receiving ART in public health clinics. Six themes emerged from this phase of the study:

1. Life before and after knowing HIV status
2. Initiating and continuing ART
3. Adherence to and side effects of ARVs
4. Social support for people on treatment
5. Positive outcomes of being on ART
6. Improving access to ART services.

In this study there was consensus that people approached health services for voluntary counselling and testing only after they started becoming sick. TB had been reported to be the commonest infection amongst the immune-compromised individuals who participated in the study, and this is consistent with the South African National Guidelines for rolling out

ART (2004), which state that TB is the most common cause of death amongst HIV-positive people in South Africa.

Another notable finding in the study was the importance of the role that significant others play in motivating relatives to go for VCT. This confirms the findings in phase one of the study, the metasynthesis, that the friends, partners and family form a major support system for PLWHAs.

This study has revealed that PLWHAs accept antiretrovirals as a last intervention, having first exhausted the curative properties of herbal remedies in an effort to cure the disease. The perception that the side-effects of ARVs can cause long-lasting damage also contributed to the postponement of initiating ART.

The long waiting-lists for ART also remain a barrier to access. One participant verbalized his dissatisfaction with the waiting period from the time he got his CD4 test results to the time of starting ART; he further expressed that clients need to be prioritized according to their CD4 test results, to ensure timely access to therapy -this attitude is explained by the fact that clients regard antiretrovirals as life-saving medication (Sidat et al, 2007:512).

Another notable finding in this study was that PLWHAs who meet the criteria for starting ART were taken through literacy classes with their “treatment buddies”, where positive-living and adherence to treatment was emphasized. This finding is in line with the South African National ART Guidelines (2004). The National Guidelines for Initiation of ART in South Africa recommend that a person must disclose to at least one person who is either a friend or a relative before initiating therapy, for support and adherence purposes.

ART has brought hope to PLWHAs, and plays a huge role in improving their quality of life. However, the effectiveness of this therapy is directly related to the level of adherence and commitment to them. Researchers have demonstrated that there are many factors that play an important role in adopting and maintaining adherence behaviour.

The parent-child role is reversed as it relates to HIV and AIDS medication adherence for the participants in this study, and the fact that children are an important source of social support cannot be overlooked. Findings from the current study indicate that children play an active role in reminding and encouraging their mothers to take their medications on a daily basis, as well as being an important source of comfort. Similarly, clients mentioned the role played by other individuals, like sisters, or partners, in providing support to adhere to the programme.

In keeping with the findings of other studies, the study participants reported a 100% adherence to HAART. This resulted from a combination of the following issues:

- trust in the effectiveness of HAART
- readiness to go on HAART
- optimal integration of HAART regimens into individual lifestyles
- incorporating the taking of HAART medication into a routine
- planning ahead for events that disrupt daily routines, in order to avoid missing or forgetting pills
- the use of personalized tools and reminders for HAART pill-taking times

HAART is viewed as a lifeline, and so it becomes an integral part of the lives of PLWHA; the continuous development and increasing availability of new HAART regimens also engenders optimism and a positive future outlook. These findings are consistent with the findings of other studies on HAART adherence. (Sidat et al, 2007:512-514).

Although families have been placed at the forefront of the primary social, emotional, physical and economic support for PLWHA, all participants but one reported having excellent relationships with, and feeling well supported by, their health care providers, including counsellors. Community-based resources like CHW were also reported in this study as playing a significant role in providing support to PLWHA.

The study participants felt very optimistic about their future outlook with HAART; they referred to HAART as responsible for the improvements they observed in their health and well-being, as well as in their biological parameters (weight and CD4 counts).

The study findings revealed problems related to accessibility of ARV services, since the majority of clients incurred the travelling costs to the initiating sites. This situation is then worsened by long waiting periods for the service to be rendered, which has effects on absenteeism at work.

5.3.1 **Conclusions of Phase Two**

Conclusions from the first theme, “Life before and after knowing HIV status”, indicates that people usually manifest symptoms of opportunistic infections before they become aware of their HIV status. TB was reported by most clients as the primary infection, since the majority of them were diagnosed with TB and were taking treatment for it before they become aware of their HIV positive status. TB is a huge public health problem, and is the leading cause of death amongst HIV-positive South Africans. Efforts towards strengthening

existing TB control programmes and combating the high default rate need to be applauded, but contact tracing and prophylactic treatment still need to be strengthened.

Conclusions can also be made that clients seek assistance from traditional healers before visiting health centres.

The conclusion drawn from the second theme, “Initiating and continuing antiretroviral therapy”, was that the turnaround time from testing for HIV to initiation of ART was very long, and the lack of prioritization of critically ill people was specifically mentioned by one participant.

In making conclusions based on the third and fourth themes, “ART, adherence and side effects” and “Social support for people on treatment”, it was clear that people do not voluntarily approach health services to seek HIV testing services unless there are strong compelling factors. The discussion with HIV-positive participants clearly revealed that frequent illnesses were the most compelling factors to test for HIV, but that relatives were also important motivators for HIV testing when these illnesses occurred. The role of significant others in providing support for PLWHAs cannot be over-emphasized, while other community-based structures, including CHW, also play a significant role. General improvement of well-being was repeatedly mentioned as the motivating factor in HAART adherence.

All the participants confirmed that people who had experienced advanced AIDS disease-symptoms tend to adhere more to treatment than those who had never experienced such symptoms. This finding confirms the researcher’s practical experience whilst giving technical support in the ARV initiation sites when the ARV programme was still in its infancy stage. Clients never missed their appointment dates for examination by the doctor, and always arrived to collect their medication. Clients also displayed commitment to attending the literacy sessions accompanied by their treatment supporters, who played a further role in therapy by reminding the clients to take their medicine at the proper times.

Clients testified to the positive results of being on treatment (theme five, “Positive outcomes of being on ART”); as these effects enabled them resume their roles as providers for their families. General health improvement and the regaining of physical strength were amongst the benefits highlighted.

Issues of access still need to be addressed. This phase of the study indicates that the ARV services remain inaccessible to some clients, as long-distances travel is required to access them and this has an element of cost involved. The long waiting-times for treatment are also included under issues of access.

5.4 DISCUSSION ON THE EXPERIENCES OF HEALTH CARE PROVIDERS WORKING IN THE ART PROGRAMME

This phase of the study discusses the experiences of health care providers rendering ART services to PLWHA enrolled in the ARV programme in the public health sector clinics.

There was an agreement amongst health care providers that clients' relationships with their health care providers were critical in clinical management of HIV infected individuals. A good provider/patient relationship was mentioned as a motivating factor in maintaining clients' commitment to ART, including treatment for opportunistic infections. The establishment of a good rapport from the first meeting was emphasized in the establishment of positive long-term relationships.

Providers also highlighted the importance of being aware of their non-verbal cues, as these may send negative messages to clients. The importance of displaying a caring and non-threatening attitude with respect for clients was repeatedly emphasised by providers. Vervoort et al. (2007:278) states that "having faith in the health care provider, and the experience of a good relationship with the health care provider that is based on trust and professional support, seem to influence adherence positively. Characteristics of a supportive health care provider include a caring attitude, effective and frank communication and clear instructions, being responsive and accessible and showing respect". Therefore the attitude displayed by health care providers in the daily management of patients is crucial in promoting service-utilisation by clients. Customer service is not a department, it is an attitude.

One notable finding reported by the clients was that the general improvement of client's condition, combined with ongoing counselling and educating clients about the negative effects of failing to stick to treatment were important in keeping appointments to come to the clinic.

Fears of being identified by neighbours or staff members known to them through community ties, is a problem faced by PLWHA, as that would mean behavioural disclosure. Clients preferred visiting clinics far from their neighbourhoods to avoid this, and this

response had a cost element involved. Disclosure and stigma were therefore main factors contributing to the poor access of treatment by clients.

These findings are in line with the findings from other studies. Golin et al. (2002:322) indicates that “participants were afraid that taking antiretroviral medication would reveal their HIV serostatus to others and many perceived a severe social stigma associated with being known to be HIV positive. The fear of being identified as HIV positive lead many to miss antiretroviral doses”. This concurred with the responses from health care providers, as they stated that when clients visited the clinic where they were known by a staff member, they seemed uncomfortable and would then default on any future appointments.

Health care providers also mentioned that occasionally clients seek ARV clinic services for the sake of accessing the disability grant. They explained that clients become compliant for the first three months while their application for the grant is being processed and thereafter disappear. This behaviour has a negative effect on adherence to therapy as clients need to take treatment for the rest of their lives to prevent development of drug resistance. Non adherence to antiretroviral therapy is a public health problem because individuals who default treatment will be spreading resistant HIV strains to members of the public should they practice unprotected sex.

Health care providers reported that they also need ongoing training on HIV- and AIDS-related care to prepare them to face daily challenges in the management of HIV infected individuals.

5.4.1 **Conclusions of Phase Three**

The health care provider has a fundamental role as either facilitator or barrier in the process of clinical HIV and AIDS management for PLWHAs. Health care providers in this study emphasized the importance of caring, respect, good communication and proper skills to render the service. Similarly, participants had closely observed their providers’ actions, words and body language and they valued the providers’ time and attention.

Health care providers serve as the initial points of contact in a health facility and therefore they need to be welcoming to clients at all times in order to establish and maintain good relationships. They also need to have good skills in customer-care, as, ultimately, clients approaching health centres are customers, and consumers of a service. A long-lasting, trusting relationship is built upon the first contact with the client, and health care providers working in the ARV clinics need to be sensitive and show respect to clients at all times due to the sensitive nature of the subject.

Health care providers need to observe the ethical principles of justice, beneficence and privacy in order to maintain sustainable provider/client relationships. Health care providers need to be conscious of the fact that creating a therapeutic environment for clients that is non-threatening and non–intimidating can facilitate adherence to ART. Displaying knowledge about the disease, providing information and the ability to answer questions correctly about the subject at all times can assist clients to adhere to their medication. Good communication skills and a gentle manner when addressing clients contribute to treatment access. Health care providers need to realize that a breakdown in communication serves as a barrier to accessing services.

5.5 RECOMMENDATIONS

The following are the recommendations made based on the lessons learnt from different phases of the study:

The path from HIV testing to initiating treatment and ongoing care and support needs to be a seamless path with no barriers to access of the service.

PLWHAs have problems in accepting and coping with the disease. Efforts must be directed at combating the stigma attached to HIV infection by empowering communities with knowledge. Communities need to change their mindset about HIV infection and realize that HIV and AIDS is a chronic disease and can be prevented and managed like other chronic conditions. The South African government is making efforts towards destigmatizing HIV and AIDS by implementing the upward and downward referral programme. The ARV initiating clinics within the hospitals and CHCs commence treatment, and thereafter refer clients to their local clinics for continuity of care. The clinics can refer them back to the initiating sites should they experience severe side effects or if complications arise.

PLWHA must be reassured that being infected with HIV is not a sin, and therefore feelings of guilt are misguided reactions. The multidisciplinary team approach towards comprehensive management of HIV and AIDS must be strengthened. Psychologists, as members of the team where available, must provide ongoing counselling to assist PLWHAs in gain accepting and coping with the disease and therefore reducing stress levels and fear. In the sites where there is lack of psychologists, professional nurses registered as psychiatric nurses and even trained counsellors must render these services to ensure comprehensive management of PLWHAs. It is also recommended that chaplains be members of the multidisciplinary team to address the spiritual needs of HIV infected individuals as it documented that spirituality, prayer, faith, “inner strength” and even positive thinking help to develop feelings of self worth and gain acceptance of the disease.

The need for support groups for PLWHAs cannot be over-emphasized, and the role of support groups becomes evident when HIV infected individuals become comfortable to disclose their HIV status. Significant others, including family members, friends and partners, are vital in providing social support and thereby facilitating disclosure.

Health care providers must strengthen education on the mode of action of drug regimens, the possible side-effects of the medicine, and the importance of adherence to medication, and so dispel the myths and misconceptions surrounding antiretrovirals. Health care providers must also assist PLWHAs on treatment to fit the treatment regimens into their lifestyles in order to achieve maximum benefits of treatment.

Health care providers must display professionalism at all times when caring for patients. They must be supportive, respectful, non-judgemental, and always show sensitivity when working with HIV infected individuals. Health care providers must always strive for a long-lasting relationship rooted on a foundation of trust with their clients. Health care providers can be either facilitators or barriers in terms of ART access.

Study participants mentioned that they were suffering from multiple illnesses before they became aware of their HIV status, with most of them already taking treatment for TB. It is recommended that members of the public be encouraged to test for HIV and know their status regardless of their seeming wellbeing, as this will assist with both early identification and the management of opportunistic infections caused by a deteriorating immune system they'll be registered on the comprehensive HIV and AIDS management programme and being monitored on an on-going basis.

Education needs to focus on motivating members of the public to seek assistance early from health centres. Most participants shared that they started by shopping around for locally available remedies in an attempt to manage the condition on their own. Foregoing this route and approaching health services early on will ensure maximum benefits for their health, as infections will be managed before complications arise. The South African government launched the HIV Counselling and Testing (HCT) campaign on the 1st of April 2010 in an attempt to mobilise all South Africans to get tested for HIV and know their status. HCT is offered by health providers on the occasion of any patient's visit to any health facility for any ailment. HCT is considered to be the entry point to HIV prevention: knowing one's status and knowing what to do next, and so facilitating access to ART.

In this study, although high adherence levels were reported by the study participants, it is still recommended that the public health sector trains more counsellors on adherence counselling. The success of the ART programme is totally dependent on adherence. People taking antiretrovirals need to achieve <95% adherence to treatment, and failure to do so may lead to emergence of drug resistant HIV strains -hence the need to strengthen adherence counselling. There is also a need to improve the turnaround time for initiating treatment and waiting times in the clinic, in order to improve the accessibility of ART service. The human resource constraint remains a challenge in the public health sector, and this also needs to be addressed for effective service delivery.

5.6 SUPPORT GUIDELINE FOR ART SERVICES IN ETHEKWINI DISTRICT

This is a description of the daily processes followed in the ARV clinic whenever a client walks in for HAART initiation:

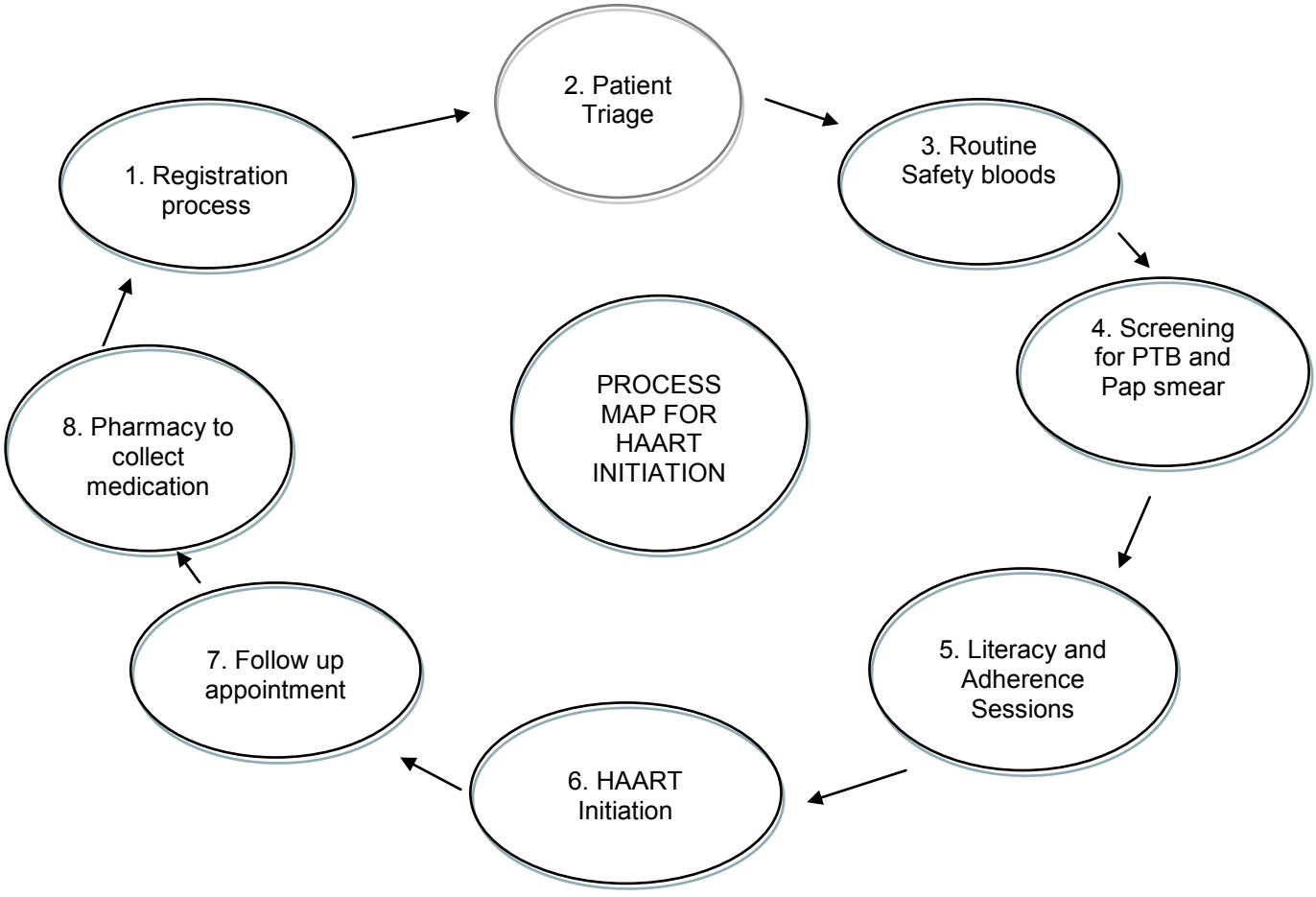


Figure 5.1: Process Map of a Patient Referred for Initiation of HAART

5.6.1 Explanatory Notes for the Process Map

5.6.1.1 Registration

A patient is entered into a register for statistics purposes. Vital signs are also done at this point (temperature, blood pressure and weight measurements).

5.6.1.2 Patient Triage

The patient is triaged by staff either to the blood room (if he/she has never had a CD4 done), or if he/she was referred with his CD4 test results from a local clinic, he/she will then be sent for literacy sessions with the lay counsellor. He/she will also see the dietician, and, if there is a need, he may be referred to a social worker.

5.6.1.3 Routine safety bloods

Routine bloods for preparation of HAART initiation are done:

- Liver Function tests (LFT)
- Urea and Electrolytes (U&E)
- Full Blood Count (FBC)
- Wasserman' Reaction (WR)
- HBV.

A Viral Load (VL) test is no longer a requirement before initiation of HAART.

5.6.1.4 Screening for Pulmonary Tuberculosis (PTB) and Pap smear

If the patient was not screened for PTB and or given a Pap smear at the local clinic, this is done at the ARV clinic.

5.6.1.5 Literacy and adherence sessions

These are initiated at the local clinic. Further sessions are done by both the counsellor and the pharmacist to discuss treatment options and a treatment plan.

5.6.1.6 HAART initiation

The patient is seen by the doctor for initiation of antiretroviral therapy.

5.6.1.7 Follow-up appointment and medicine collection

The patient is given a date for a follow-up appointment and sent to pharmacy to collect medication.

It is important to note that the above process can range from one week to one month before the patient is initiated on HAART.

5.7 GUIDELINES TO IMPROVING ACCESSIBILITY TO ARV SERVICES

Urgent training of health care providers on comprehensive HIV and AIDS management is needed, and this needs to be done both at the initiation sites (which are usually within the hospitals), and at a clinic level. All PHC nurses should be able to provide Provider Initiated Counselling and Testing (PICT) at every opportunity. This would increase VCT uptake.

Once the patient has tested positive on a CD4 test, literacy sessions should be started immediately and the patient should be screened for opportunistic infections like TB, as well as a pap smear for female patients. This would then decrease the screening being done at the ARV clinic, and so shorten the time for initiation of HAART.

Early identification and referral of patients for HAART initiation should be done as soon as possible. If training is provided at a PHC level and PHC nurses gain confidence in the process of initiation of HAART, ideally patients could start treatment at a clinic level, meaning treating HIV and AIDS as a chronic condition.

Good systems and adequately trained and knowledgeable health providers should be in place in order for the process to run smoothly. Less preparation could be done at the ARV clinic if the patients were properly prepared or screened at the PHC level. CD4 staging at a PHC level is also crucial to enhance HAART initiation.

5.8 LIMITATIONS

The limitations of this study were conditions inherent in qualitative research studies:

- Open-ended questions give much discretion to researchers and respondents
- The conversational tone has the potential to prompt particular responses or inadvertently direct answers
- The unconscious process is difficult to avoid even with experienced researchers. Participants might be reluctant or afraid to tell researcher their views or they may wish to promote a particular view of their experience, or may tell only what is in their interest
- The active presence of the researcher can potentially influence the behaviour and responses of participants, thereby compromising research findings

5.9 CONCLUSION

This study investigated the experiences of clients receiving ART services, and the health care providers rendering these services in the eThekwini district, KZN. The study aimed to explore the practice of ART specifically regarding patient issues and experiences, as well as those of health care providers.

In this study the literature on previous qualitative research done on HIV and AIDS including ART was reviewed. This formed the metasynthesis phase, which came up with new body of knowledge from previous studies. The metasynthesis revealed four themes:

1. acceptance of and coping with HIV positive status
2. social support and disclosure
3. experiences of and beliefs about HIV medication
4. client/provider relationships/health systems factors

In this study in-depth interviews were done with participants receiving ART in the selected clinics in the eThekwini district. This phase of the study generated six themes namely:

1. initiating and continuing antiretroviral therapy
2. life before and after knowing HIV status
3. adherence to and side effects of ART
4. social support for people on treatment
5. positive outcomes of being on antiretroviral treatment
6. improving access to antiretroviral treatment services

The last phase of the study consisted of conducting interviews with the health care providers providing comprehensive HIV and AIDS treatment, care and support services. Health care providers shared their experiences of working with HIV infected individuals including those taking ART. The following issues unfolded during the interviews and repeated themselves

- establishing and maintaining good client/provider relationships
- facilitators of adherence to treatment
- barriers to access to treatment

This study attempted to answer two research questions:

1. What are the problems and experiences of patients and health care providers regarding ART?
2. What are the best practices for rendering ART in KwaZulu Natal?

Both questions were answered at different phases of the study. Question one was answered during the discussion of phases two and three of the study. The discussion of the findings of the study during phase two gives a detailed description of the problems and lived experiences of PLWHA and taking ART medication. During phase two clients shared their journey from before they discovered their HIV status, as well as living with HIV before initiating treatment and the experiences and problems they had when they were eventually put on ART.

The experiences of health care providers are shared in the discussion of phase three of the study.

After repeated interviews with clients and the health care providers who were participants in this study, the researcher took a closer look at the current practice in the ARV clinics in which the study took place. The process map was drawn, highlighting all the important steps that need to be taken into consideration before the client is initiated on HAART. The processes were unique to each clinic, as not all clinics provided screening for opportunistic infections and pap smears for female clients, and the lack of these services prolonged the turnaround time for HAART initiation.

The support guideline was developed to improve accessibility of the service and to address some bottleneck issues to ensure that the ARV services are user-friendly. This will also enhance standardisation of the service across all clinics, providing comprehensive management of HIV in eThekwini district.

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ANNEXURE 1

- **Postgraduate Approval Letter**

ANNEXURE 2

- **Ethics Clearance Certificate**

ANNEXURE 3

- **Information Sheet for Clients**

INFORMATION SHEET FOR CLIENTS

Dear Participant

I would like to invite you to participate in my research study. The study is on the Experiences of Clients on Antiretroviral therapy and their Health care providers in KwaZulu Natal. The purpose of this information sheet is to give you the information you will need to help you decide whether or not to be in the study. Please read it carefully. You may ask questions about what we will ask you to do, the risks, the benefits, your rights as a participant, or anything else about the research or this sheet that is not clear. When all of your questions have been answered, you can decide if you want to be in this study or not. This process is called “informed consent”. I will give you a copy of this form.

This study is done to understand the experiences of people living with HIV who are receiving antiretroviral treatment, their experiences while taking antiretrovirals and how they adhere to treatment.

Your contribution in this study will benefit others in future by improving antiretroviral services and support for people receiving antiretroviral treatment. You will not receive any direct benefit. The interview will take from 45minutes to 1 hour. The interviewer will ask questions and write notes about experiences, there are no right or wrong answers to any questions asked during the interview. You can refuse to answer questions that you think are private and sensitive.

Your personal information will be kept strictly confidential, only the interviewer will be present with you at the interview. Your name will not be disclosed in any report. The code number for the interview will be used for identification purposes so that your real identity and personal details are protected and cannot be disclosed to others. Information learned from this study will be used in reports, presentations, and publications but you will not be personally identified.

Participation in this research is voluntary, you may refuse to participate or withdraw from this study at any time without coercion. You will not be deprived of any treatment at the clinic should you withdraw from the study.

If you have any concerns or problems after the interview contact the researcher at the following telephone number: 0833613341 (Mbali), Fax number: 031 7057047

Have you understood information that has been discussed with you? Yes/No

Have all your questions been answered? Yes/No

Do you give your consent to taking part in the interview? Yes / No

ANNEXURE 4

- **Information Sheet for Health Providers**

INFORMATION SHEET FOR HEALTH PROVIDERS

Dear Participant

I would like to invite you to participate in my research study. The study is on the Experiences of Clients on Antiretroviral therapy and their Health care providers in KwaZulu Natal. I'm requesting you to share your experiences in working with HIV positive clients receiving antiretroviral therapy. This study is done to understand the experiences of people living with HIV who are receiving antiretroviral treatment, their experiences while taking antiretrovirals and how they adhere to treatment.

Your contribution in this study will benefit others in future by improving antiretroviral services and support for people receiving antiretroviral treatment. You will not receive any direct benefit. The interview will take from 45minutes to 1 hour. The interviewer will ask questions and write notes about experiences, there are no right or wrong answers to any questions asked during the interview. You can refuse to answer questions that you think are private and sensitive.

Your personal information will be kept strictly confidential, only the interviewer will be present with you at the interview. Your name will not be disclosed in any report. The code number for the interview will be used for identification purposes so that your real identity and personal details are protected and cannot be disclosed to others. Information learned from this study will be used in reports, presentations, and publications but you will not be personally identified.

Participation in this research is voluntary, you may refuse to participate or withdraw from this study at any time without coercion.

For further information please contact Mbali at 0833613341 (Cell number), 031 7057047 (Fax)

ANNEXURE 5

- **Participant's Statement of Consent**

PARTICIPANT'S STATEMENT OF CONSENT

The study has been explained to me. I agree to take part in this research. I have had a chance to ask questions. I know that if I have questions about the research or about my rights as a participant I can ask one of the researchers at any time. I agree not to disclose to any person outside this study any confidential information disclosed to me during the course of this study. I will receive a copy of this consent form for my records.

Interviewee code EDP : _____

Interviewee's signature : _____

Interviewer's signature : _____ Date: _____

(This signature certifies that informed consent has been given by the interviewee).

ANNEXURE 6

- **In-depth Interview Guide - Clients**

IN-DEPTH INTERVIEW GUIDE - CLIENTS

Instructions: The in-depth discussion can only be started after having read the informed consent and the respondent has understood and consented to be interviewed. Remember to seek permission to use the tape recorder and explain in detail to the respondent before the interview begins that the recording is simply made to remind the researcher what was said and its use is completely anonymous and confidential.

Date of interview : _____

Tape record number : _____

Start time for interview : _____ Time interview ended_____

Purpose and process:

The purpose of this interview is to enable the participant to tell his or her “story” about living with HIV from the time they were tested through to starting and continuing with antiretrovirals. Participants will be asked to tell the story about their experiences, the interview will begin with a question:

“Tell me about your life before finding out about your HIV positive status”

If the discussion ceases, probes such as these will follow:

What led you to do an HIV test? Explain.

Tell me about your experiences when you started ARVs from the time you heard about ARVs until you participated in the ARV programme.

ANNEXURE 7

- **Interview Guide - Health Providers**

INTERVIEW GUIDE - HEALTH PROVIDERS

The interview will begin with a question:

“What are your experiences in working with HIV positive people receiving antiretroviral therapy”

If the discussion ceases probes such as these will follow:
Tell me about how you establish relationship and dialogue with your patients
What do you think are the barriers to ARV adherence and effectiveness of available services?
What do you think are the facilitators to ARV adherence and effectiveness of available services

ANNEXURE 8

- **Transcript of a Client Interview**

TRANSCRIPT OF A CLIENT INTERVIEW

Interviewer: Good morning, thank you for allowing me to talk to you. Can you tell me about your life before finding out that you are HIV positive?

Participant: About my life

Interviewer: Yes

Participant: Ok, so my life was ok I was right until I got a boyfriend, so I got a boyfriend and we got our first baby in 1991 and I didn't have any problem

Interviewer: In 1991

Participant: Ya, then the second one in 2003, so that's when I discovered I'm HIV positive with my second pregnancy

Interviewer: Ok

Participant: So I was given Nevirapine and the baby was born negative. My CD4 was right at that time. So after 2003, 2004, 2005 I started to get sick…2005, that's when I started taking actions though I was not seriously ill.

Interviewer: Hmm

Participant: So I came back to hospital, to test my CD4, by then it was 30 but I was right and active…

Interviewer: Hmm

Participant: …I didn't have problems; I was started on treatment in 2006. So when I started treatment in 2006, I got sick, treatment made me to be sick, I developed rash and it made me uncomfortable. Well, I told myself that I'll get used to the pills
Interviewer: So, can you tell me what problems did treatment give you?

Participant: So I developed rash, and sometimes I was weak, there is one tablet I take in the evening which made me feel dizzy, once I had taken it, I was forced to go to sleep.

Interviewer: Hmm

Participant: So I got used to treatment and things got better and I was right, my weight improved because I lost weight until I weighed 69kg, it improved to 80,4kg. So this year I've started my studies with UNISA… So I think I'm a bit stressed because I'm losing weight, but I make sure I condomise! That's no joke I'm very strict with that! (LAUGH)

Interviewer: Hmm

Interviewer: Ok you said you discovered your status when you were pregnant?

Participant: Yes I discovered when I was pregnant

Interviewer: What motivated you to check your status?

Participant: What motivated me to check?

Interviewer: Hmm

Participant: I was motivated to check my HIV status because of my partner's behaviour.

Interviewer: How was he behaving?

Participant: She was fond of women

Interviewer: Ok

Participant: So I thought I need to protect my baby. At the clinic they educated us on the importance of checking one's status... so I just made a decision to check my status whether I'm positive or negative, so that's when I discovered my status

Interviewer: Hmm

Participant: So I was a bit disturbed initially when I learnt about my status but the way they counselled me, I told myself that life will go on.

Interviewer: Ok, tell me more about the counselling you received when testing for HIV.

Participant: So I got counselled at Redhill clinic the counsellor told me that being HIV positive does not mean that it's the end of life….

Interviewer: Hmm

Participant: …So life will go on and I'll be given Nevirapine as I'm pregnant to protect the baby. She also told me that if I take care of myself I'll be right! So they counselled me about diet, what type of food to eat, the importance of using condoms, and to motivate my partner to test as well. You know males don't easily accept, he said he knows that obviously he is infected.

Interviewer: Hmm

Participant: He told himself that it's obvious that he is as well infected and didn't want to test. He became sick last year and then started making actions and I helped him to follow the correct channels.

Interviewer: Hmm

Participant: So it's me who was counselling him better, so he also started taking ARVs and he became better

Interviewer: Hmm, ok, when you learnt about your HIV status how did you react?
Participant: I don't want to lie, I was shocked! I was nearly knocked down by a car on the road (LAUGH), it was heavy! It was very very heavy when they told me. So when I got out of the clinic, knowing my positive result, I crossed the road and sat down quietly (MUMMBLE)

Interviewer: Hmm

Participant: I didn't want to take transport home immediately; I wanted to regain my sense of thinking well. When recovering from shock I told myself that it's not the end of life... all you need to do is to take care of yourself and the unborn baby, it's you who's going to make the baby survive and therefore to make yourself survive as well.

Interviewer: Hmm

Participant: So at the clinic they gave me tablets to take for the duration of pregnancy, after delivery the baby was given Nevirapine

Interviewer: Hmm, so tell me how was it living with HIV, before starting treatment?

Participant: It was difficult, very difficult! It was difficult but I couldn't wait to start ARVs!

Interviewer: Hmm

Participant: It was difficult, thinking endlessly and I could see I was stressed. Sometimes I used to spend sleepless nights thinking but each time I came to the clinic, I was praying that they start me on treatment, I mean ARV's

Interviewer: Why?

Participant: Because I had met other people in the clinic who were on ARVs... because if we meet at the clinic we discuss, sometimes a person reads stress in your face and start counselling you that you'll be fine. Sometimes start sharing her story that 'I was like this and that but I started ARVs and became better as you can see me'

Interviewer: Hmm, how do you make sure that you stick to treatment?

Participant: Ok, what helps is that I decided to discuss this with my daughter, so I disclosed to her

Interviewer: How old is she?

Participant: She's 16years

Interviewer: Ok

Participant: I discussed with her, there was a talk about AIDS on TV… then I just said 'nana, what can you say if I can tell you that your mom is HIV positive'… She just said 'ma there is no difference between 6&9, (LAUGH) what you'll need to do is to take treatment.

Interviewer: Hmm

Participant: She said 'ma we are taught about HIV at school so… do you think you have it ma'? I said 'listen my child your mom is positive' (pause).... she said 'ma there is no problem' So I said 'Please be my time keeper, remind me, I'll also try to remember but if you see that I've missed the time remind me'

Interviewer: Hmm, tell me how did you deal with side effects?

Participant: I used to make appointment with my doctor and she gave me treatment … she gave me some treatment to apply on the skin...then itchiness became better…

Interviewer: Hmm

Participant: …for dizziness, doctor didn't give me anything, I make sure that after taking it I go to sleep… it helped me, so as time went on I got used to it now it does not affect me, now I take it and do not have problems even if I don't sleep

Interviewer: Hmm, ok, what support do you think people on ARVs need in order to continue taking their treatment well?

Participant: To take their treatment well?

Interviewer: Yes

Participant: I think even if people take ARVs, some of them are not well counselled because sometimes as we chat to each other you find that some people have stopped taking them because of side effects. I thing people need more and more counselling.

Interviewer: Hmm

Participant: Yes we are taught about ARVs not that they don't teach us…but you find that some people, if taking ARVs and encounter some problems with medication, they desert them… and say these pills are problematic, I'm stopping to take them…I won't continue taking them. I don't know what can be done with this

Interviewer: Hmm

Interviewer: Ok, how old are you?

Participant: I'm 42 years

Interviewer: 42 years, are you married?

Participant: No, it's on the way

Interviewer: What's your religion?

Participant: I worship at Ekuphakameni, at Shembe?

Interviewer: How long does it take you to get to the clinic from home?
Participant: My home is far, I stay in my workplace, I'm a domestic worker…I'm using my work address, my employer brought me here, my home is at Ndwedwe… but I work in Durban North

Interviewer: Ok, Durban North

Participant: It is not far

Interviewer: Do you have any questions to ask?

Participant: No, because I think I'm losing weight because of stress related to studies

Interviewer: Hmm how was the interview?

Participant: It was right, I enjoyed it.

Interviewer: Thank you

Participant: I liked your questions

Interviewer: Thank you sisi for your participation

ANNEXURE 9

- **Transcript of a Health Care Provider Interview**

TRANSCRIPT OF A HEALTH CARE PROVIDER INTERVIEW

Interviewer: Tell me how do you establish relationships with your clients who are in the ARV programme

Participant: What makes good relationships with our patients is that firstly, you need to be friendly, your facial expression when greeting the client for the first time, show the smile, give love , even if she has sores touch her, hug her if there is a need because they feel its end of the world and they look at your facial expression as you talk to them to watch your reaction , there are those with Ca cervix, offensive PV discharge with a smell, but make sure you don't show them with your expressions and open windows,

I: Hmm

P: that's why we have a good relationship with them because they usually have their problems solved after 3 months and how would you feel when you want to come close to her when they are better and the client distances herself because you distanced yourself initially

I: Hmm

P: So that's why they become so close to us

I: Ok

P: The difficult time is the 1st day when coming to start treatment that's when you need to establish good relationship and make the client close to you, don't scold them , be at their level even if they do wrong things don't shout at them

I: Ok ..What do you think encourage the clients on the programme to stick to their treatment?
P: Improvement of condition , as they gain weight, have good appetite even those who had warts, as they continue with Rx warts also disappear, so general improvement of condition makes them realize the importance of sticking to treatment

I: Besides improvement are there any other measures from your side as staff that help clients to stick to Rx

P: Yes, Counselling to tell them what will happen to them if they default treatment and to stress importance of adherence

I: Ok... What do you thing are the barriers of adherence to treatment

P: Some clients come to the programme because they want pension, once they apply for the grant they disappear

I: Hmm

P: Those are the people who give us problems, pension is the main problem

I: Ok

P: Clients come to the clinic for the sake of getting pension , some people come to start treatment, comes regularly for 3 months keeping appointments well, then assisted to apply for a grant then disappear, so they come for the sake of pension especially those who are unemployed

I: Ok, so until when

P: We phone them using contact details in files and trace them

I: Ok

P: Sometimes we find that some are late or some tell us that they don't want to be on the programme anymore, then [sic] we take those out of the programme
I: Have you ever had instances where they come back after defaulting

P: They come back we are expecting one defaulter tomorrow, so we'll make her start literacy classes again Dr said so because she was put on the programme then disappeared after grant approval, now grant has been discontinued and she has requested to be put back to the programme

I: Hmm

P: Some come back when they are sick again

I: So you think the grant also causes people not to stick to treatment

P: Yes some after approval of grant

I: Ok... any other barriers to adherence you can think of

P: Others default treatment because they haven't disclosed at home to families, to husbands, boyfriends especially when staying together

I: Ok

P: Then it becomes difficult to come for treatment, some clients meet at the clinic yet they are neighbours, and you find client asking you to see her outside and explain that she's not at ease because her neighbour will see her and will know that she is also positive

I: Hmm... Ok thanks. Are there any questions you like to ask me?

P: The only problem that we have is PMTCT training

I: Ok...that's the department of health responsibility but as my research site I can assist you with training on PMTCT and ARVS

P: Ok thank you, may I request your phone number
I: Ok fine. Thank you for your participation

ANNEXURE 10

- **Permission to Conduct Research Requested**

PERMISSION TO CONDUCT RESEARCH REQUESTED

1 Datchet Place
New Germany
3610
01 February 2007

The District Manager
eThekwini District
Cc: Clinical Programmes Manager

Dear Sir / Madam

PERMISSION TO CONDUCT RESEARCH

May I request permission to conduct a research study in the Antiretroviral therapy (ARV) clinics in eThekwini district? I'm currently working for the Reproductive Health and HIV Research Unit (RHRU) and I'm studying towards a PhD degree with Wits University. My study is entitled "An exploration of the Experiences of Clients on Antiretroviral Therapy and their Health Care Providers in KwaZulu Natal (KZN)" and will involve interviewing clients on ARVs and staff working in ARV clinics

I'm enclosing the copy of the research proposal and the interview guide. I'll appreciate your timeous response as your permission is one of the requirements for ethical approval of my proposal.

Thanking you in advance.

Yours faithfully

Euphemia Mbali Mhlongo (Mrs)

ANNEXURE 11

- **Permission to Conduct Research**

PERMISSION TO CONDUCT RESEARCH

1 Datchet Place
New Germany
3610
27 August 2007

The District Manager
eThekwini District Office
P/Bag X54318
Durban
4000

Permission to Conduct Research

With reference to your letter dated February 14, 2007, I hereby attach in addition to the proposal and interview schedules the Ethics Clearance certificate from University of Witswatersrand, Johannesburg.
May I kindly get your permission to visit ARV clinics in eThekwini district to get consent from patients and staff to conduct research?

Thanking you in advance for considering my request

Yours faithfully

E M Mhlongo (Mrs)

ANNEXURE 12

- **Bracketing Document**

BRACKETING DOCUMENT

The Researchers' Experiences with HIV infected Individuals

1. **Introduction**

Before the researcher started with data collection and analysis, she needed to suspend all beliefs, assumptions and preconceived ideas about experiences with antiretroviral therapy as the phenomenon under investigation. The researcher decided to write down all her encounters with clients taking antiretroviral therapy and those with health providers. Setting aside the researcher's preconceived ideas helped her to be constantly aware of what she believed and tried to keep it separate from what was shared by participants. The researcher decided to share experiences about her involvement with the South African antiretroviral programme since its inception, experiences with the clients in the sites initiating them on antiretroviral therapy and experiences of working with health care providers in the antiretroviral initiating sites.

2. **Experiences with the South African Antiretroviral Rollout**

The researcher's experience of working with HIV infected individuals started in 2004 when the South African Government rolled out the National Antiretroviral treatment guidelines. These guidelines served to assist the clinic team in the management of patients on antiretroviral drugs as outlined in the Comprehensive Plan for HIV and AIDS Care, Management and Treatment.

The researcher was working for the Reproductive Health and HIV Research Unit in Durban as an HIV and AIDS and STIs Project Coordinator. As a Unit we were giving programme support to the KwaZulu Natal Provincial Department of Health. My work since 2004 was to conduct training on comprehensive management of HIV infected individuals including antiretroviral therapy to the Primary health care nurses in clinics and hospitals in KwaZulu Natal Province. The researcher was doing training in the eleven health districts in KwaZulu Natal Province. She was also providing technical support to the antiretroviral initiating sites in eThekwini Health District. Through provision of technical support, the researcher gained experience in working with HIV infected clients on antiretroviral therapy, the management of opportunistic infections and learnt to understand work life of the health care providers rendering antiretroviral treatment services.

3. **Experiences with Clients**

As a trainer, the researcher used to visit the Antiretroviral clinics in the initiating hospitals and look at the flow of clients and the proceedings from the time the client enters the clinic until she leaves. Her interaction with patients on antiretroviral therapy was when they got

into the doctor's consulting room during history taking and examination. Patients would share their experiences before being enrolled in the antiretroviral therapy programme, how sick and helpless they were and they'll compare that with their current wellbeing. Clients used to praise the drugs they were taking for their benefits in improving their lives. Clients would also indicate that drugs had side effects but their benefits outweighed the risks.

4. **Experiences with Providers**

The researcher established a relationship with clinicians rendering antiretroviral services in the initiating sites. For each and every client entering the consulting room, the doctor would take me through his or her records from the time the client was registered on the programme. The researcher had an opportunity of learning all the details pertaining to the number of visits made to the health facility, investigations done, number of flu attacks if any and management thereof, drug side effects experienced and management thereof and drug switches done if any. During this period the researcher also learnt about the practical details of drug regimens, the indications for changing the regimen and when to decide to stop antiretroviral therapy.

5. **Personal, Family and Cultural Beliefs about HIV and AIDS**

As a person the researcher believes that HIV infected individuals are human beings who deserve to be treated with respect and dignity like all the citizens of the country. The researcher as a member of the family and the community which is predominantly Zulu speaking is exposed to myths and misconceptions regarding HIV and AIDS. She tries in her everyday life to assist friends, relatives and the community at large to understand facts about HIV and AIDS in order to overcome the myths. As a Zulu woman, the researcher initially had difficulties of raising awareness messages about the subject to communities because it is culturally sensitive to talk about sex related issues and negotiating safer sex practices in our culture. Values clarification workshops contributed a lot in assisting the researcher to separate personal and professional values. Trainings and courses attended on HIV and AIDS have also assisted the researcher to deal with her own biases, fears and concerns regarding HIV and AIDS.

6. **Conclusion**

Reflecting on these experiences helped the researcher to exclude biases and to adopt a non-judgemental attitude throughout the period of data collection and analysis. It also assisted her to work with PLWHAs without any discrimination and stigmatization. It also assisted the researcher to remain neutral and made efforts not to influence data by asking leading questions to participants.