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THE INTERACTIONAL DYNAMICS OF THE GENETIC COUNSELLING SESSION IN A MULTICULTURAL, ANTENATAL SETTING

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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

Declaration

I, Tina-Marié Wessels, declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy in Medicine in the branch of Human Genetics, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

_____

Date

Dedication

For Esmari and Tanya



Abstract

The present study explored the interactional dynamics of genetic counselling sessions in intercultural clinics in Johannesburg. Genetic counselling is a relatively young profession and although research is available on its outcomes there is a paucity of literature on what actually occurs in the interactions between genetic counsellors and their patients and even less is available on intercultural encounters.

This study's focus was on examining the genetic counselling interactions in a multicultural antenatal setting. The research was concerned with how communication occurred and the methodology selected for the study was based on discourse analysis. The analysis drew on the principles of conversation analysis, theme orientated discourse analysis, and considerations from intercultural communication studies. The data comprised of 17 video-recorded prenatal genetic counselling sessions conducted by six genetic counsellors. The sessions were in English. All the counsellors' first language was English while the women's first language were one of the 11 official languages (with one exception) spoken in South Africa. The women were referred to discuss their increased risk of having a baby with a chromosome abnormality due to advanced maternal age. The sessions were video recorded, transcribed and analysed.

It was apparent during the initial phases of the analysis that there was an order to the interactions and six distinct phases could be identified. These were the opening, information-giving, information-gathering, closing, decision-making and counselling phases. The main components that appeared significant included the opening, decision-making and counselling phases and these were analysed further. Counsellor dominance in

the interactions manifested in the number of strategies used to guide the women through the counselling session. Through their active participation, the counsellors identified the agenda and controlled it throughout the interaction. During the decision-making sequences, the counsellors made an effort to adhere to the ethos of non-directiveness however they used directive strategies to assist the women to make a decision regarding having an amniocentesis performed. Even during the counselling segments where the counsellors and the women discussed issues related to the women's life, the counsellors controlled the development of these segments.

In contrast to the counsellors' dominance of interactional space, the women shared issues relating to their life world during the counselling segments. This apparent contrast seemed to create tension in the counsellors' role as they had to either 'educate' or 'counsel'. Tension was further created by the counsellors' perceived obligations to practice in a particular way. Adhering to the principles of the profession thought to increase autonomy and empower patients seemed to have achieved the opposite in the interactions in this setting.

It is suggested that the emerging tensions in these sessions are linked to the health care setting in which patients, because of social and political reasons, have not been active participants in their healthcare decisions. The interactions were shaped by the health care system of which influences could be seen during the setting of the agenda, the order in the interactions and the counselling techniques used. As a result, context played a critical role in explaining the phenomena described. The interactions were found to be complex. Success could not be ascribed to a single construct and it was rather found that the setting, the genetic counselling agenda and the individuals in the interactions influenced each

other. Unlike what was expected upon starting the research, the emerging phenomena could not be attributed to culture.

The findings mainly have implications for genetic counselling practice in South Africa as existing models of training and practice require adaptation to incorporate the insights gained. A contextual model of genetic counselling was proposed which takes the contextual influences and engagement with the patients' life world into consideration. This model is thought to have benefits and is hoped to advance the profession towards patient-centered genetic counselling practices in South Africa. It is anticipated that the insights gained here will contribute to international literature and that the lessons learnt may be beneficial to practitioners in other settings.

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Abbreviations

AMA	Advanced maternal age
ARV	Antiretroviral treatment
CA	Conversation analysis
DNA	Deoxyribonucleic acid
DNHPD	Department of National Health and Population Development
Exp	Experienced
FPP	First pair part
HCP	Health communication project
HIV	Human Immunodeficiency virus
HPCSA	Health Professions Council of South Africa
ICC	Intercultural communication
Inexp	Inexperienced
MCWH	Maternal, Child and Women's Health
MRC	Medical Research Council
MTCT	Maternal to child transmission
NDEPT	Nonverbal communication in doctor–elderly patient transactions
NHLS	National Health Laboratory Service
NRF	National Research Foundation of South Africa
NT	Nuchal translucency
PDS	Perspective display series
RCS-O	Relational communication scales for observational measurement
RIAS	Roter interactional score
SAIMR	South African Institute for Medical Research
SANPAD	South African/Nederland's Research Programme on Alternatives in Development
SPARC	University of the Witwatersrand Strategic Planning and Resource Allocation Committee
SPP	Second pair part
TODA	Theme-orientated discourse analysis
Wits	University of the Witwatersrand
RMMCH	Rahima Moosa Mother and Child Hospital
CMJAH	Charlotte Maxeke Johannesburg Academic Hospital

Glossary

Acknowledgment token	An acceptance of the previous speaker remark, it includes responses such as 'yes' 'uhm' as well as non-verbal responses such as head nods.
Activity types	Refers to a setting, its participants and the goals of an interaction for example, a medical consultation.
Adjacency pair	Is a minimum of two turns (a pair) for example a question (first turn - *FPP*) is followed by an answer (second turn *SPP*).
Advanced maternal age (AMA)	Refers to a woman who is over 35 years of age and who is at an increased risk of having a child with a chromosome abnormality.
Amniocentesis	A procedure that is performed between 16 and 20 weeks gestation in which a sample of amniotic fluid is obtained.
Bales Scoring system	A quantitative scoring system of small group interactions in which the number of turns, different categories of discussions and who initiated the discussions are counted.
B-event statement	These are declarative statements made by one of the participants of which the other participant has knowledge.
Candidate understanding	A response from the listener that is more than an acknowledgment that s/he has heard. It involves a statement such as 'in other words you mean….'
Chromosome	Compact form of DNA (deoxyribonucleic acid) visualized under a light microscope. Humans have 46 chromosomes.
Client centered therapy	Client-centered therapy (also referred to as person-centered therapy and Rogerian therapy) is an approach to counselling and psychotherapy in which the relationship between the therapist and client plays a key role in allowing the client to understand his/her problems and find his/her own solutions.
Conversation analysis (CA)	A specific analysis method in which an interaction is analysed with regard to turn-taking, turn-design, sequence organization and repair organisation.
Counselling model	Kessler's' model of genetic counselling which is based on taking the emotional aspects of the patients into consideration.

Discourse analysis (DA)	A qualitative methodological approach in social sciences that involves different sociolinguistic approaches to study language at the level of a sentence, behaviours linked to social practices and language as a system of thought.
Discourse types	Refers to style of the interaction for example interview style, which consists of questions and answers.
First pair part (FPP)	This is the initiation section of an adjacency pair i.e. a question.
Formulation	Producing an utterance referring to the most salient aspects of another speaker's talk. It resembles paraphrasing as used in counselling skills terminology.
Frame	A frame refers to setting up the context within which messages or discussions are to be understood.
Information delivery format	Terminology used in HIV counselling in which the counsellor is the speaker/information giver and the patient is the recipient of the information.
Institutional talk	Interactions that take place in institutions such as medical consultations and classroom interactions.
Interactional hybridity	A term that refers to the fact that *activity types* and *discourse types* overlap in interactions.
Interview format	In HIV counselling sessions, this refers to discussions in which the one person asks questions and the other answers.
Life-history narrative model	A model proposed for genetic counselling which recognizes that patients are part of families. In the model the patient is both narrator and respondent and the counsellor is both interviewer and listener.
Nuchal translucency screen (NT screen)	Ultrasound examination performed between 11 and 13 weeks gestation. It measures the thickness of a fluid filled space behind the neck of the fetus.
Perspective display series (PDS)	A specific type of questioning in which the patient is invited to share information and emotions. Also referred to as a '*reflective frame'*.
Polarized questions	Questions which provides options such 'is this your married or maiden surname'.
Reflective frames	*See PDS.*
Roter interactional score (RIAS)	RIAS involves scoring sessions according to the information given and the amount of talk time by the counsellor and patient.

Second pair part (SPP)	The response part of an adjacency pair such as an answer.
Sequence map	A 'map' visualized by using different colours to distinguish patterns or tasks in conversations.
Talk	Sociolinguistic term referring to a conversation.
Teaching model	Kessler's' model of genetic counselling in which the aim is to educate patients.
Tellings	Conversation analysis terminology referring to discussions where patients produce a narrative.
Transcription	The process of producing written documents from voice and/or video recording.
Transition marker	Signals a shift from one topic or phase to another during an interaction.
Translation	Translation into another language.
Trisomy 13	A chromosome abnormality in which a fetus has three number 13 chromosomes. Also referred to as Patau syndrome.
Trisomy 18	A chromosome abnormality in which a fetus has three number 18 chromosomes. Also referred to as Edwards syndrome.
Trisomy 21	A chromosome abnormality in which a fetus has three number 21 chromosomes. Also referred to as Down syndrome.
Troubles talk	In HIV counselling sessions, troubles talk refers to discussions regarding difficult issues.
Turn	Refers to a speaking turn a person takes during an interaction.
Utterance	Spoken words by a person during an interaction.
Voice of medicine	Terminology used by Mishler that refers to medical matters such as diagnosis, treatment, management.
Voice of the life world	Terminology used by Mishler, which refers to issues regarding the everyday life of the patient/client.
Wh-type question	Questions that begin with *what, where, when, why* and allows open answers.
Yes/no questions	Questions which "project" only a confirmation (yes) or refutation (no).

Chapter 1 Introduction

This study is an examination of the genetic counselling interactions in a multicultural prenatal clinic in Johannesburg. Genetic counselling services have been established in the United States and the United Kingdom in the 1940's but it is a relatively young profession in South Africa and many other countries. It is still not clear exactly what the goals of genetic counselling are and what sessions are attempting to achieve (Biesecker, 2001). This lack of clarity is partly due to the complexity of the interactions and the vast array of reasons why patients attend clinics, as well as the fact that a complete model of practice has not yet been developed (Veach, Bartels, & LeRoy, 2007). As a result, the profession has had to borrow theories and philosophies from other disciplines.

The practice of genetic counselling has been evaluated from an outcomes perspective: examining what patients wanted from the sessions; whether patients were satisfied with the service; and whether patients and counsellors have the same agendas. These insights have been very helpful in learning about the profession but have not provided information with regard to what happens during the genetic counselling discussions or whether patients and practitioners actually practise what they say they do in their sessions (Biesecker & Peters, 2001).

Studies examining the genetic counselling process from an interactional perspective provide an opportunity to understand how genetic counselling occurs in practice. Early attempts were made by Kessler and others in the USA, using informal methodologies and a modified Bales scoring system to examine transcripts of antenatal sessions (Kessler & Jacopini, 1982; Kessler, 1981; Rapp, 1988). This work shed some light on moments in a

session where the counsellor has a choice as to whether to engage either with the emotional or with the scientific aspects and different styles of counselling. More formal methodologies were later used to score genetic counselling sessions. Studies using the Roter interactional scoring system (RIAS) (Ellington et al., 2005; Roter, Ellington, Erby, Larson, & Dudley, 2006a) revealed different forms of communication. Psychosocial talk could be distinguished from biomedical talk and history-taking questions. These studies also showed that first and follow-up sessions differed regarding types of communication, with follow-up sessions containing more psychosocial talk. This was a notably significant finding and added to the knowledge gained by the work of Kessler and others, but 'counting and identifying' different aspects had limitations. Simply identifying features could not reveal the nuances of the interactions. Applying qualitative methods from a sociolinguistic perspective provided an opportunity to examine such detail. Research utilising such methodology was able to show both how counsellors maintained non-directiveness in their sessions (Benkendorf, Prince, Rose, DeFina, & Hamilton, 2001; Sarangi et al., 2004) and the strategies that professionals used to achieve this. It showed how antenatal screening was discussed (Pilnick, 2004; Pilnick, 2008), how risks (Sarangi et al., 2003) and information were communicated and how the counsellors discussed and managed discrepant information (Lehtinen & Kääriäinen, 2005; Lehtinen, 2005).

The majority of these interactional studies however, were performed in Western "first world" settings. The biomedical model of disease is not the only view patients hold and it was found that that there were some difficulties in multicultural sessions (Greb, 1998). The discipline called for this problem to be addressed and a number of theories and teaching strategies were developed and advocated to assist counsellors to become multiculturally competent (Weil & Mittman, 1993). Despite these efforts, many questions

remain as to the effectiveness of the services provided to patients in multicultural settings, since what was learned in practice was not always reflected during sessions (Wang, 1998). Studies were focussed on examining how patients from different settings viewed the principles essential in genetic counselling, emphasising the disparity between the biomedical approach of genetic counselling and the patient who values other principles. Despite the emphasis on the need for counsellors to become multiculturally competent, very limited research was done on multicultural interactions. Those that were performed, focussed on miscommunication (Ellington et al., 2007) or provided general descriptions (Ellington et al., 2005), but the understanding of the process in multicultural settings was not clarified. More recent work in Hong Kong revealed that the context in which the sessions took place had an effect on the counselling, specifically on how the socioeconomic circumstances affected the decision-making process (Pilnick & Zayts, 2011) and how providers' adapted to these (Zayts & Schnurr, 2011). This work showed how context could affect sessions, but that the effects are very subtle and may only be revealed by examining sessions from a sociolinguistic perspective.

In South Africa, genetic counselling is generally provided in an intercultural setting (Greenberg, Kromberg, Loggenberg, & Wessels, 2012; Penn & Watermeyer, 2012). Often, providers of the service and patients are from diverse backgrounds with differences in beliefs and languages. Disparity in services provided by the state and private sector exists and the majority of the country's patients who are from lower socio-economic groups and only have access to underfunded and overburdened state health services. Due to the country's socio-political history and the fact that South Africa is a developing country, patients attending state services are historically passive participants and somewhat sceptical of the service they receive (Harris et al., 2011).

As a practicing genetic counsellor and coordinator of the MSc (Med) in genetic counselling post-graduate course, I questioned the effectiveness of the genetic counselling service offered to patients in our intercultural sessions where some of the patients are unable to, or have limited communication skills in English and hold diverse beliefs. As the following case illustrates, there are many complex issues that are not yet fully understood. A young couple was seen for genetic counselling after abnormalities in their fetus were detected on ultrasound examination. The abnormalities were severe and the prognosis for the fetus was poor. Termination of pregnancy was offered. The couple was clear that they wanted to continue with the pregnancy. Further investigations on the fetus were required in order to make a genetic diagnosis. The couple wanted these investigations done which involved a post mortem and a number of genetic tests. They seemed to have a good understanding of the situation and developed a good relationship with the counsellor. The pregnancy did not go to term and the woman delivered the fetus six weeks prematurely. The baby was born and passed away after a few hours. Further investigations were not done. The woman did not want to discuss it with the counsellor and after being referred to her partner it emerged that the family did not agree to further tests being performed. The partner said he tried to explain the importance to their parents but that they did not give their permission. The case brought up several questions but most importantly what could the genetic counsellor do during the session to facilitate the process for patients and their families? The paucity of knowledge about our patient's perceptions and needs, coupled with the highly technical and sophisticated concepts associated with genetic medicine, make the genetic counselling session very complex and challenging. It leaves me, as a genetic counsellor, feeling somewhat unsure and dissatisfied with what I am able to offer to patients. As a result of this lack of detailed knowledge, I wanted to undertake research that would make a contribution to our understanding of the practices of genetic counselling

in our setting. As I started researching the subject I was drawn to studies utilising qualitative methodologies as these seemed to provide very valuable information. In particular, studies examining the actual interactions were very interesting to me as I perceived these to provide fascinating and new perspectives. As a result, I refined my original thoughts and questions (as illustrated by the case vignette) to focus my study on an examination of the genetic counselling interactions from a sociolinguistic perspective.

The thesis consists of 10 chapters. Chapters two to four provide a discussion of the literature, the practice of genetic counselling, the history of the profession, the theories that drove it and how the profession developed in South Africa. Research on interactions is also explored. As relatively few process studies have been performed on genetic counselling, literature regarding medical and counselling interactions is consulted as it addresses a number of overlapping concepts and activities. Finally, it was also necessary to describe the reports on intercultural communication and genetic counselling.

Chapter five describes the methodology selected to examine the interactions. As the study aimed to investigate the genetic counselling interactions in a multicultural antenatal setting qualitative approaches were selected, drawing on a number of methods best suited to reveal the nuances and details of the interactions.

In Chapters six to nine the results, which are structured around an analysis of selected phases revealed during analysis are discussed. The first section presents a description of the overall structure of the session and thereafter, the results from openings, decision-making and counselling segments are reported. These sections were selected for further analysis as they were thought to be the most informative phases of these sessions. The

opening phase was where the agenda of the sessions was set; the decision-making sequence was when the counsellor and the woman engaged in a discussion regarding whether or not the test should be performed, and the counselling segments were selected because the women took up more interactional space.

The final chapter, Chapter 10, contains the conclusions drawn from the findings and the implications of these for genetic counselling in South Africa.

Chapter 2 The Practice of Genetic Counselling

Genetic counselling as a practice has its beginnings in the early 1900s when the first 'genetic advice' clinics were started in the USA and UK (Walker, 1998). At this stage scientists advised people about having children with preferred characteristics. These early advisory clinics were associated with the Eugenics movement. However, when Sheldon Reed coined the phrase 'genetic counselling' in 1955, it signalled a strong move against associating human genetics and counselling with the Eugenics movement (Walker, 1998). Including the word 'counselling' was an attempt to illustrate that giving genetic advice was not about telling people what to do or creating better people, but rather about emphasising the supportive and informative nature of the advice-giving process.

Today genetic counselling is an established practice, though young compared to medical practice. Several theories and philosophies have contributed to the way genetic counselling is practiced, but it is still considered 'a profession in search of itself" (Veach, Bartels, & LeRoy, 2002, p. 187). In this chapter, the practice of genetic counselling is discussed by highlighting some of the theories and philosophies that have guided the profession, the research that has contributed to our understanding and the attempts that have been made to measure the success of the process. The development of the local genetic counselling profession and practice will be discussed in the last part of the chapter.

2.1 Defining genetic counselling

Genetic counselling refers to a process whereby individuals and their families are informed about the genetic and medical aspects of the relevant condition, in a way that supports and

encourages decision-making and adaptation to the condition. The most well known definition was coined by The Ad Hoc Committee on Genetic Counselling of the American Society of Human Genetics (ASHG) in 1974 (ASHG Ad Hoc Committee on Genetic Counselling, 1975). It states that:

"Genetic counselling is a communication process, which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to:

- Comprehend the medical facts, including the diagnosis, the probable course of the disorder, and the available management
- Appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives
- Understand the options for dealing with the risk of recurrence
- Choose the course of action which seems appropriate to them in view of their risk and the family goals and act in accordance with that decision
- Make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that disorder".

This definition has stood the test of time and it was not until 2006, with the advent of genomic medicine and the increasing emphasis on psychosocial aspects, that an update was necessitated. The task force of the National Society of Genetic Counsellors (NSGC) of the United States of America (USA) then produced the following definition that is now widely recognized and used by genetic counsellors (Resta et al., 2006, p. 78):

"Genetic counselling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
- Education about inheritance, testing, management, prevention, resources and research
- Counselling to promote informed choices and adaptation to the risk or condition."

The process thus involves interpreting, assessing, educating, making choices and counselling (Harper, 2010; Plunkett & Simpson, 2002; Walker, 1998). Gathering information, by obtaining a family history and drawing a pedigree, reveals clues to inheritance patterns and diagnosis. This activity is an important first step and aids in establishing or verifying the diagnosis and/or indication for genetic counselling. Once a diagnosis or indication is established, a risk assessment can be done and the patients and their families can be given information about the condition and the associated risks. This information can be used in decision-making. The emotional component of dealing with the disorder is addressed by the counsellor, who makes use of counselling skills. The 'steps' are fairly simple, but the nature of the interactions is highly complex, and, as the rest of the chapter will illustrate, is far from being fully understood.

Genetic counselling is usually conducted by either clinicians with a specialty in Medical Genetics, or Master's level trained genetic counsellors and/or experienced nurses with

specialised training in Medical Genetics (Walker, 2009). However, in some situations, genetic advice is provided by midwives, obstetricians and other medical specialists.

2.2 Goals and models of practice

Consensus still has to be reached with regard to the goal of genetic counselling. Historically two main goals exist, 'the prevention of birth defects and genetic disorders' and 'client psychological well-being' (Biesecker, 2001, p. 323, 324). In prevention, the aim is to provide patients with information (regarding preventing the disorder), and an assumption is made that from understanding the scientific explanation, the patients will make rational logical decisions in keeping with what the professionals consider rational and logical. On the other hand, in the psychological well-being goal, the aim is to help the patients cope with and adapt to their situation. This goal is based on accepting that patients have fears and hopes, that they do not necessarily make rational decisions, that understanding risk is a complex process, and that alleviating guilt is not always possible.

With these different goals in mind, different approaches or models of genetic counselling have been proposed. The most well known are the Counselling and the Teaching models described by Kessler (1997a). If the goal of genetic counselling is thought to be the prevention of birth defects and genetic disorders, Kessler's Teaching model fits best, as this model assumes that if patients are given information and they understand the implications, they will make rational decisions. Such decisions would result in the best possible outcomes – therefore preventing (or accepting) the birth of a child with a birth defect or genetic disorder. If client psychological well-being is seen as the goal of genetic counselling, Kessler's counselling model fits best as this model is based on the perception

that patients come for genetic counselling for complex reasons such as validation, support, and anxiety reduction. The counselling model emphases the importance of addressing the client's fears, hopes, defences, and rationalisations in order to help them view their situation as it is and makes choices that would best suit their situation.

Although the Teaching and Counselling Models have been cited most often in the literature, Kenen and Smith (1995) proposed two other models for genetic counselling practice: The 'Mutual Participation' and the 'Life History Narrative Model'. These two models are well accepted in the social sciences and fit with the goal of psychological well-being. In the Mutual Participation Model participants have equal power, they are interdependent, they engage in activities that are equally satisfying and they work as partners. The client's experiences are important in making their decisions and are integrated in the interaction. The Life History Narrative Model recognizes that clients belong to families and do not exist within a vacuum. In this model the client is both narrator and respondent and the counsellor is both interviewer and listener and the focus is on encouraging the client to tell their story.

Biesecker and Peters (2001, p. 194) stated that "no current consensus exists on the definition of genetic counseling or its goals". Proponents of genetic counselling still have to develop an empirical comprehensive model of practice (Fox, Weil, & Resta, 2007; Veach et al., 2007). In such an attempt, Veach et al. (2007) conducted a workshop with programme directors and genetic counsellors from North America with the aim of defining the current model of practice. The outcome of the workshop resulted in defining the 'reciprocal engagement model' as shown in figure 2.1: "The model is represented visually with a triangle that embodies the five tenets articulated by conference participants:

Education primarily represents the tenet of genetic information. *Individual attributes* reflects the tenets of patient autonomy, resiliency, and emotions. *Relationship* embodies the tenet of counselor–patient relationship" (Veach et al., 2007, p. 724).

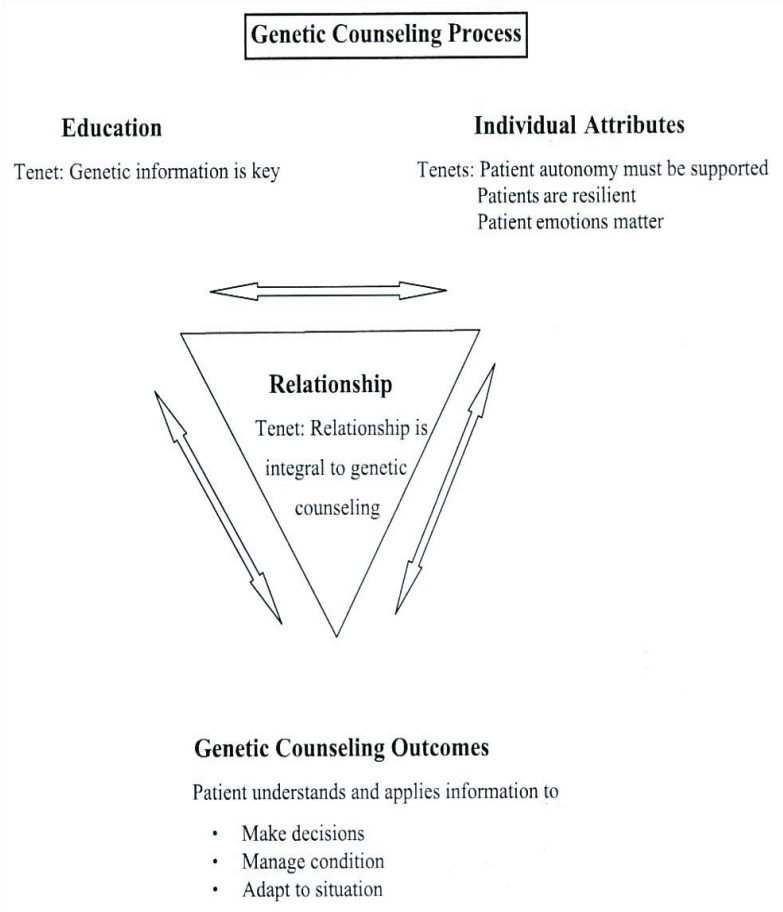


Figure 2.1. *Reciprocal-Engagement Model of Genetic Counseling* (Veach et al., 2007, p. 724)

While this model identified different components and showed that each has an effect on the other, it does not provide guidance with regard to how its tenets and goals are to be realised. This is not an easy process as Biesecker pointed out (2001, p. 192): "Because genetic counseling is a complex, dynamic and multi-faceted endeavor, it is a challenge to demonstrate both whether and how it works".

Practice has been based on the ideas put forward by Kessler's (1997a) models and to a much lesser degree by those proposed by Kenen and Smith (1995). The emotional aspects of genetic counselling have been regarded as important from the inception of the profession; first, in the attempts to distance it from the Eugenics movement and later, in the 1970's, when Joan Marks developed the training programme at the Sarah Lawrence College and included several modules on interviewing skills. However, a teaching model has been promoted (Biesecker, 2003), and evaluations of practice show that counsellors still adopt a teaching approach (Bernhardt, Biesecker, & Mastromarino, 2000; Ellington et al., 2006; Hodgson, Gillam, Sahhar, & Metcalfe, 2009). The discrepancy between what is done, and what is said is being done, demonstrates some disparity in theory and practice. The difficulty in evaluating genetic counselling practices and whether the 'correct' phenomena are being appraised is partially due to the lack of a clearly defined practice model (Veach et al., 2007).

2.2.1 Genetic counselling sub-specialties

Whether it is advisable or possible to have a universal goal and practice model of genetic counselling also needs to be considered as there are sub-specialties that differ with regard to outcomes in a session (Biesecker, 2001; Kenen & Smith, 1995) and many different factors have to be taken into account in each individual session.

Reproductive genetic counselling, or prenatal diagnosis counselling, involves pre-procedure counselling, counselling following medically positive results and termination of pregnancy counselling (Weil, 2000). Patients are faced with risks and choices about testing options relating to having a child with a birth defect or genetic disorder (Biesecker 2001).

Increased risks could be due to recurrent pregnancy losses, infertility, maternal age, or positive carrier screening as a result of ethnic origin (Walker, 1998). The process entails discussions about the risks and the choices available to cope with those risks, with the goal, therefore being to assist the patient in exercising choices (Biesecker, 2001). The focus is on decision-making and addressing the consequences of their choices. The type of decision taken depends on individual personalities, cultural, ethical and religious beliefs and values related to reproduction, parental responsibility, disability and termination of pregnancy (Weil, 2000)

Where a child, adolescent or adult is affected with a genetic condition, the focus is on providing them with information and helping them to adjust to the condition. Some conditions only become evident after birth, childhood or in late adulthood (Walker, 1998). These families are faced with the challenges of adapting to the condition and the issues involved with genetic testing. Concerns around predictive testing and knowing their genetic status before the onset of symptoms, are discussed with patients and their families. Although reproductive choices come into play at some point, this is not the main goal of the counselling. Rather, the goal is to facilitate patient understanding and acceptance in an attempt to assist the patient to adapt to the diagnosis (Biesecker, 2001).

A relatively new area in genetic counselling is the area of 'common diseases', some of which, such as cancer and Alzheimer's disease, have been shown to have a genetic component. In some of these conditions, genetic testing, which would indicate that the individual's risk of developing the condition is increased is available. Here the aim in the genetic counselling session centres on information-giving, risk perception and health promoting behaviour. The goal in these sessions resembles that of other health education

programs and includes facilitating the parents' understanding of personalised disease risk and health-promoting behaviours (Biesecker, 2001).

The question remains as to whether all genetic counselling sessions, irrespective of the nature of the indication (whether it is on decision-making, on acceptance or on understanding of personalized disease risk), can have the same goal and whether it is possible to have a universal model. This question is further complicated by the fact that different service delivery models (Battista, Blancquaert, Laberge, Van Schendel, & Leduc, 2012; Cohen et al., 2012) and practice models (Veach et al., 2007) have been recognized. In view of the fact that sessions have different goals depending on the reasons for the patient seeking genetic counselling (Biesecker, 2001), and that there are different service delivery models (Cohen et al., 2012) and varying practices in different settings (Cohen et al., 2012) it seems unlikely that a universal model of practice can be developed.

2.2.2 Psychological theories

In the profession's attempts to distance itself from its Eugenics history, emphasising the psychological aspects in the genetic counselling became important. The patients seen are individuals who have unique personalities, coping styles, values, beliefs and defences (Weil, 2000). They experience a range of emotions when faced with a genetic risk or genetic condition, which has psychological significance for them. Because of the emotional aspects, the profession has borrowed several theories and concepts from psychology and social science (Djurdjinovic, 1998; Weil, 2000).

The genetic counselling session is a short term intervention, typically one or two sessions and occasionally a third and a fourth (Harper, 2010). As a result, some of the existing psychological techniques have limited application for genetic counselling but they provide a framework for understanding the depth of the patients' emotional responses (Djurdjinovic, 1998). Freud's psychodynamic theory is such an example. In psychodynamic theory, human behaviour is said to be determined by irrational forces, unconscious motivations and drives, but by bringing the unconscious into the conscious, one is able to free oneself to make choices about behaviour. It can be appreciated that to apply Freud's principles effectively, long term interaction is required. A genetic counsellor is unable to work effectively with the unconscious motivations and drives of a patient in a single genetic counselling session. However, as Tassiker (2005) showed, psychodynamic theory in predictive counselling and testing for Huntington Disease can help counsellors in their work of preparing and assisting patients with adjustment.

A theory that is more amenable to genetic counselling practice is Carl Rogers' person-centered approach (Djurdjinovic, 1998). Joan Marks, in developing the first genetic counselling training programme at the Sarah Lawrence College in the 1970's, based the programme on Carl Rogers' approach (Marks & Richter, 1976). As this approach is based on the principles of genuineness, empathic understanding and unconditional positive regard, it is attainable in the usually brief genetic counselling interaction.

Not only individual but also family dynamics need to be considered as a genetic condition affects the whole family (Weil, 2000) as the family is a dynamic social system of interacting individual personalities where each member has an effect on the others. Further, a genetic condition in the family places extra stress as the family move from one

stage to another. Family systems theories offer an understanding of how families function and how they respond to critical life events (Djurdjinovic, 1998). Several theories have relevance for genetic counselling such as the Family Systems Genetic illness model (Rolland & Williams, 2005), which addresses how families cope with illness over time and the unique challenges posed by being at risk and Deborah Eunpu's (1997) Systemically Based Psychotherapeutic Technique which, in families with a genetic condition, links individual, interactional and intergenerational issues. Another model, the stages of change model of Prochaska and DiClemente was evaluated in Huntington Disease predictive testing (Houlihan, 1999). The authors showed that their model was useful in building effective communication and assist patients during the genetic testing process as it can explain how patients change problem behaviour to positive health related behaviour.

As shown, there are a number of theories that have been proposed or adapted for genetic counselling. Some have been evaluated while others have been put forward as models. Individual theories have been evaluated in select sessions and settings suggesting the complexity and multidimensionality of the genetic counselling process. This suggests the difficulty of developing an all-inclusive model of practice and that there is no one ideal method or model that can address all its facets.

2.3 Main elements as a basis for practice

2.3.1 Non-directiveness

A historically fundamental ethos of genetic counselling is non-directiveness. When and how exactly non-directiveness was introduced into the field is uncertain (Weil, 2000;

Wolff & Jung, 1995). It was initially an attempt to distance genetic counselling from the Eugenics movement (Kessler, 1992). Also in the beginning, scientists who were providing genetic counselling emphasized the neutral transmission of information rather than following the traditional rules of advice-giving as practiced in doctor-patient relationships (Wolff & Jung, 1995). As social workers and psychologists started working in the field, they practised and encouraged non-directiveness. Another contributing factor was the development of the first Masters programme for 'Genetics Associates' at the Sarah Lawrence College, New York (Marks & Richter, 1976).

The counselling skills component of the Sarah Lawrence course was founded on Carl Rogers' person centered approach with its philosophy of non-directiveness (Rogers, 1942). Rogers' theory states that people have the capacity to become self-aware, that they can self-direct and actualize into whole, fully functioning individuals, and the counsellor's attitude and the counsellor-client relationship determine the outcome (Weil, 2000). The theory is based on three key counsellor attributes; unconditional positive regard, empathy and genuineness. Rogers' definition of non-directiveness is that the client defines issues and selects solutions and the counsellor assists the client in achieving these goals, while in directiveness, the counsellor defines the problem and its cause for the client and proposes clarification and solutions (Wolff & Jung, 1995).

The difficulty with the use of non-directiveness in genetic counselling is that the concept is not well defined in this context and it is inconsistently presented in the literature (Kessler, 1992, 1997b; Weil, 2000; Wolff & Jung, 1995). It has been defined as a non-prescriptive process where the genetic counsellor avoids giving advice or making recommendations (Weil, 2000). The most obvious example being the counsellor's response to the question

'what would you do?' (Kessler, 1992, 1997b). A counsellor cannot completely avoid answering this question as the counsellor's beliefs and/or attitudes are often conveyed by non-verbal behaviour, by what information s/he gives and how it is presented. Attitude, suggestions, value judgments and preferences focusing on particular aspects, and the order of providing information can suggest preferred courses of action. As Weil argues, this narrowly defined non-directiveness is not achievable in genetic counselling (Weil, 2003). He provided four reasons: there is *inadvertent* directiveness that refers to the impossibility that the genetic counsellor is value and attitude free; there is *inevitable* directiveness that refers to the fact that genetic counsellors make decisions with regard to the information they provide and the counselling approach they take; there is *institutional* directiveness that refers to the fact that the offer of testing available gives the message that this is the preferred option; and there is *meta* directiveness, which refers to the fact that there is directiveness due to the choice of a particular approach. Kessler has also argued that narrow definitions of non-directiveness are limiting and inhibit the genetic counsellor's practice (Kessler, 1997c).

Non-directiveness, however, can be viewed as protecting patient autonomy (Hodgson & Spriggs, 2005; Kirklin, 2007; Weil, 2000). From this perspective patients are required to play an active self-confident role in the decision-making process, and counsellors should make use of active counselling approaches and techniques, in order to support and promote patient autonomy. Kessler (1997c) advocates this application of non-directiveness, as it is more attainable in the practice of genetic counselling: "Since the beginning, there has been a second aspect of non-directive methods that practitioners recognized, namely their ability to promote the autonomous functioning of the client. This aspect of ND is clearly applicable to genetic counseling and I offer it as a definition: *ND describes procedures*

aimed at promoting the autonomy and self-directedness of the client" (Kessler, 1997c, p. 166). Weil proposed that the ethos of non-directiveness be replaced by an ethos of including the psychosocial component in the practice, "The central ethos of genetic counseling should be to bring the psychosocial component into every aspect of the work" (Weil, 2003, p. 207). The benefit of this is that such an approach would allow the genetic counsellor to meet the fundamental role to assist patients to use the medical and scientific information available to them to adjust to their situation.

Kessler (1992) further states that both directiveness and non-directiveness are strategies by which the counsellor attempts to influence the patient. In directiveness, the counsellor attempts to influence the patient's behaviour, and in non-directiveness the counsellor attempts to influence how the patient thinks about the problem which will ultimately affect behaviour and increase self-determining ability. He suggested that process studies be performed in an attempt to understand how non-directiveness and directiveness manifest in practice: "We need to know the extent to which counseling philosophy and practice intersect. Do what genetic counselors say they do relate to what they actually do in the course of counseling? Study of the process of genetic counseling may be the only way to answer this question and to clarify the operational differences and similarities between directiveness and non-directiveness" (Kessler, 1992, p. 15). Clarke (1991) adds that social structures influence the provision of non-directive genetic counselling in relation to prenatal diagnosis and termination of pregnancy and suggests that the mere fact that prenatal diagnosis is offered, implies a recommendation to accept that offer. Therefore, irrespective of the counsellors' thoughts, wishes or intentions the encounter may be partially directive.

No consensus could be found among studies examining non-directiveness. Some found counsellors to be directive (Michie, Bron, Bobrow, & Marteau, 1997), others that a non-directiveness stance could not be maintained (Hallowell, 1999), while others identified counsellor strategies used to maintain a non-directive stance (Benkendorf et al., 2001; Sarangi et al., 2004; Zayts & Schnurr, 2011). Non-directiveness, as with the goals and models of genetic counselling, has been based on theories developed in other disciplines. As the profession developed over the years it has evolved and, as Weil (2003) suggested, it may be time to remove the term 'non-directiveness' from genetic counselling practice and aim to bring more attention to the emotional aspects of the session, or, alternatively, decide on a definition of non-directiveness in the context of genetic counselling.

2.3.2 Risk communication

Providing risk information is central to genetic counselling (Baty, 2009; Weil, 2000). Patients may be at risk of having a child with a genetic condition, may have a risk of spontaneous abortion associated with invasive testing, or there may be a risk to other family members of having a genetic condition, or a risk of inheriting a genetic condition and/or a risk of developing the familial genetic condition once the mutated gene is inherited. Risk communication, however, is not as simple as providing a risk figure. How risks are communicated, how patients perceive the risks provided and how they apply this information in the decision-making process, is complex (Weil, 2000).

Research has found that the way in which professionals communicate risk information varies (Fransen, Meertens, & Schrander-Stumpel, 2006; Henneman, Marteau, & Timmermans, 2008; Lippman-Hand & Fraser, 1979; Michie, Lester, Pinto, & Marteau,

2005). Some professionals use percentages or odds or rate risks as high or low, or use both numerical and descriptive phrases, while others give both positive and negative risks and some use the words 'risk' while others use the word 'chance'. Counsellors' views on how they present risks showed that preference varied depending on their training, experience and abilities and the presentation is rarely based on literature on the subject (Henneman et al., 2008). Counsellors reported that they tailor their risk presentation based on their assessments of their patients' verbal and non-verbal responses and needs. Similarly from a patient perspective, there is no consensus as to what is preferred (Baty, 2009; Lobb et al., 2004). Some patients have a preference for being given numerical probabilities, whilst others wanted qualitative probabilities or had no preference (Baty, 2009). A numerical risk given as a one in X odds was most preferred and resulted in most accurate recall by women at risk for breast cancer (Hopwood, Howell, Lalloo, & Evans, 2003). Hallowell et al. (1997) found that in 40% of cases, risks were not provided in the patient's preferred format. Hallowell (1999) also found that risk management options in breast cancer were presented 'non-neutrally'.

A patient's risk perception varies according to context, their previous perception of the risk, the desirability of the outcome, emotions associated with risk, personality, cognitive ability, beliefs, values, culture and experience (Baty, 2009; Lippman-Hand & Fraser, 1979a; McAllister, 2003; Pilnick, 2004; Sivell et al., 2007; Weil, 2000). Patients have prior beliefs about their risk; a concept Weil (2000) calls 'anchoring'. These beliefs affect how they interpret the numerical risk given in genetic counselling. A patient would perceive a risk of 25% as high if their prior belief was that they have a high risk and the same risk would be perceived as low if their prior belief was that they have a low risk.

Patients also perceive a given numerical as high if they have experienced the event and the emotional impact has been difficult.

The theory of engagement explains how patients perceive their risks based on family inheritance patterns and their engagement status (McAllister, 2003). Interestingly, if the patient has an experience of a normal child they may perceive the numerical risk as low. Weil (2000) describes this as 'availability'. In Weil's (2000) concept of 'representativeness', couples perceive their numerical risk depending on whether they have only a first child or more than one child together, their knowledge of population risks, desire for certainty, perspective of themselves (optimistic or pessimistic), whether they have pre-selected the individual as affected or unaffected, and their difficulty in interpreting numerical values. Being at risk results in emotional responses. Patients find it difficult to understand and quantify risk and they have a tendency to overestimate their risks, which might adversely affect their health and lead to inappropriate uptake of medical services (Sivell et al., 2007). In women at risk of breast/ovarian cancer, Bennett et al. (2008) showed that anxiety and depression are often associated with cancer risk assessment.

Based on the findings from research studies, professionals are advised as to how to present risk information and how to assist patients to make their decisions. An extensive list of recommendations based on a number of models or conceptual frameworks is available (Baty, 2009; Smerecnik, Mesters, Verweij, Vries, & Vries, 2009; Veach, LeRoy, & Bartels, 2003; Weil, 2000). Smerecnik et al. (2009), after undertaking a systematic review of the topic, suggest that when counsellors offer patients risk information they should provide them with the context in which to interpret their risk, with both verbal and

numerical risk presentations and make use of visuals aids. Fransen et al. (2006) suggest working according to a developed checklist.

Even though a long list of recommendations exists as to how counsellors should communicate risk, we do not have a clear understanding of all the nuances. Austin (2010) argues that research on risk communication has been ineffective as risk and probability have been merged into one concept and that only numerical risk recall is generally assessed. The author suggests "… a more thorough and nuanced conceptualization of risk perception, as a multifaceted entity comprising numerical probability, context, and severity…." (Austin, 2010 p 233).

Research that can add to the understanding of risk communication includes studies, based on qualitative measures, which examine how risk is communicated in interactions, as shown by O'Doherty (2006) in a study on cancer genetic counselling sessions. The author found that there were distinctions between different types of risks and that the meanings these have were dependent on the discursive context. Only very clear explanations, which require a deep understanding of risks and probabilities on the part of the professional, would result in patients understanding the given risk or probability. Similarly, in a study on Huntington disease and cancer predictive sessions Sarangi et al. (2003) showed that the different types of risks, the risk of inheriting (genetic risk) and the risk of knowing you are at risk could become merged. Both patients and professionals use several strategies (abstraction, reformulation, externalisation, localisation, temporalisation and agentivisation) to escalate or de-escalate the risks. Sarangi (2002) also showed that professionals' risk communication is affected by their attempts to maintain a non-directive stance. As these studies have shown, examining how risks are communicated in practice

has been every helpful in understanding risk communication and it has illustrated some of the nuances Austin (2010) articulated.

2.3.3 Decision-making

As already alluded to, the premise is that individuals should be provided with information regarding their risks, diagnosis and options, and, then, make their decisions (Fraser, 1974; Shiloh, 1996). Informed choice has been defined by Marteau et al. (2001, p. 100) as "An informed choice is one that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented". Closely linked to this premise, is the idea of non-directiveness which places the responsibility for making a decision on the patient. In a non-directive ethos, genetic counsellors take the role of facilitator and thereby help "clients reach a decision wisely, rather than reach a wise decision" (Shiloh, 1996, p. 87). The professional is encouraged to refrain from persuading the patient to take a particular course of action, but allow them to come to a decision which is best for them in their circumstances (Elwyn, Gray, & Clarke, 2000). Elwyn et al. recognised that there may be some instances for example when a clinical recommendation or an ethical recommendation is required, when a model of shared decision-making might be more helpful. Shared decision-making centres on the principle that the patient and the professional share information and their views on a particular issue and then come to a decision which is acceptable for both and for which both take responsibility. Ahmed et al. (2012a, 2012b) showed that many women want healthcare professionals to engage in a discussion and did not see advice as a barrier to them making an informed decision.

In genetic counselling sessions, patients are faced with a number of choices: whether to have children, whether to have prenatal diagnosis, whether to terminate a pregnancy, whether to undergo testing and at what age or stage this should this be done (Shiloh, 1996). Decision-making is a complex process where patients have values and beliefs and different decision-making styles which influence how they make a decision (Veach et al., 2003). There are cultural and religious beliefs, and partners and other family members may participate.

In the area of prenatal diagnosis, research has shown that the patient's intentions prior to genetic counselling, as well as their experience of having an affected child, play a major role in the decision made after counselling (Weil, 2000). In some situations the patient chooses not to have a child because of the fear of having another affected child, while in other instances, avoiding having a child with the same condition may devalue the life of the affected child. The patient's attitude towards termination of pregnancy also plays an important role: some patients might undergo prenatal diagnosis only because they would request termination for an affected fetus and, in other instances, they would not terminate an affected pregnancy but still want prenatal testing for the emotional preparation. Lippman-Hand and Fraser's (1979; 1979a, 1979b) seminal work, on how patients resolve problems and formulate their decisions with regard to childbearing, revealed the complexities involved. They found it was crucial for women to limit uncertainties and neutralize the consequences found most problematic (Lippman-Hand & Fraser, 1979). Parents chose a course of action that they perceive as the 'least lost'. In deciding what 'least lost' means, they consider their previous experiences, their perception of the risk and the consequences. Patients might not use numerical numbers but rather binarize or dichotomize risk figures into what will or will not happen and subsequently arrive at a

decision (Lippman-Hand & Fraser, 1979a). Parents were reported to simplify their risk and focus on the implications of being at risk, the meaning of having an affected child, the uncertainty of how to make a choice, how this choice would be viewed and whether they would be able to fulfil their role as parents. Decision-making in parents who have experience of a childhood genetic condition is complex and uncertainties and obligations of responsible parenting are weighed against possible reproductive choices (Kelly, 2009)

Other studies have focused on specific aspects, such as the role of information in the decision-making process (Shiloh, Gerad, & Goldman, 2006), problems encountered after reproductive decisions (Frets, Duivenvoorden, Verhage, Peters-Romeyn, & Niermeijer, 1991), the burden of disease, the effects of screening and decision-making in couples at risk of having a child with retinoblastoma (Dommering et al., 2010), and autonomy in prenatal screening (García, Timmermans, & Van Leeuwen, 2008). In another study, women were found to be ambivalent about undergoing an amniocentesis as they reported experiencing ambivalence between being responsible and their desire to protect their pregnancy from harm (Sapp et al., 2009). In the area of genetic testing, research has found that, for example, in familial breast cancer, the available management plays a role in decisions regarding having or not having testing (Baty, 2009). In cancer genetic counselling, the patient's sense of responsibility, not only to themselves but also to the other family members, plays a major role (Etchegary et al., 2009). From a patient perspective it was found that although couples wanted decision-making to be a shared process they wanted to make the final decision (Carroll, Owen-Smith, Shaw, & Montgomery, 2012).

Research on the factors that influence patient decision-making is thought help genetic counsellors and other professionals understand how patients make difficult choices and that if the factors and complexities are understood, patients can be better assisted with their decision-making (Baty, 2009; Veach et al., 2003; Weil, 2000). With this in mind, researchers have developed decision-making aids or models (Baty, 2009; Veach et al., 2003). These aids are standardized and evidence based and they can be in the form of printed, video or internet based information that patients can access themselves, or that the professional can discuss with them. They are aimed at helping patient's personalize the information, emphasize patient participation in the decision-making process and help patients communicate their values. Veach et al. (2003) suggested that regardless of the decision-making model used, several strategies can be used to assist patients, such as exploring their reasons, opinions, values and cultural variables and engaging them in anticipatory activities. Similarly, Weil (2000) advocated assessing the counsellees' situation: their sources of difficulty; available options; emotional state; and the role significant others play in the process.

Despite these techniques, a study on women's decisions to undergo an amniocentesis due to an increased risk of having a child with a chromosome abnormality, found that the professionals and the women had different goals regarding the testing (Hunt, De Voogd, & Castañeda, 2005). Professionals were concerned about identifying and controlling pathophysiology while the women were most concerned about protecting their pregnancies. This emphasises again the difficulty of bringing theories into practices and highlights the needs for studies on the actual interactions.

2.4 The success of genetic counselling

What makes genetic counselling effective is still not entirely understood. Several outcome measures have been considered in attempts to identify the success of the process. It is assumed that a successful genetic counselling session will result in patient satisfaction, but the relationship between these two concepts is not well understood.

Bernhardt et al. (2000) found that the counsellors and patients agreed that the goal of genetic counselling is providing information, increasing knowledge, making opportunities for decision-making and providing support.

Providing information, educating patients and information recall was thought to be an important measure of the success of genetic counselling. Improvement in knowledge has been shown by several authors (Braithwaite, Emery, Walter, Prevost, & Sutton, 2004; Hunfeld et al., 1999; Michie, French, Allanson, Bobrow, & Marteau, 1997; Michie, McDonald, & Marteau, 1997; Pieterse, Ausems, Van Dulmen, Beemer, & Bensing, 2005). Michie et al. (1997) found an overall accurate recall of information of 78% in their study in the UK, with information about family issues recalled more accurately than genetic or medical information (Michie, French, et al., 1997; Michie, McDonald, et al., 1997). They also showed that not all the information which the researchers thought important was recalled four weeks after the consultation. Different types of information were recalled differently, with clinical aspects generally accurately recalled (Hunfeld et al., 1999). There were significant differences between perceived recollection and interpretations of test results in cancer and between cancer risks and hereditary likelihood which were not affected by actual communicated test information, experience of cancer and treatment,

elapsed time, measuring risk in percentages and sociodemographic status (Vos et al., 2011). It was shown that patients had a better understanding of the information and increased satisfaction with the information given at the cancer genetic counselling clinic when they viewed an information video before the consultation (Cull et al., 1998). Improvement of knowledge was also demonstrated when culturally appropriate visual aids were used together with phone based counselling (Pal et al., 2010).

While the amount of information given and communication styles have an effect on psychological outcomes (Braithwaite et al., 2004; Lobb et al., 2004), there are no clear correlations. In some instances women's anxiety was shown to decrease (Davey, Rostant, Harrop, Goldblatt, & O'Leary, 2005; Lobb et al., 2004), while other researchers found no effect (Braithwaite et al., 2004; Michie, McDonald, et al., 1997). In one study on breast cancer consultations, where there was more supportive communication, the women's anxiety after the consultation was heightened (Lobb et al., 2004). However, facilitating the women's understanding resulted in a decrease in depression (Lobb et al., 2004). Whether patients are affected or not affected with cancer influenced their perceived risks and anxiety levels (Metcalfe et al., 2010; Pieterse et al., 2005). However, where perceived needs were met, the women had higher perceived personal control and lower anxiety (Pieterse et al., 2005). Sending a summary letter also decreased anxiety, while simultaneously increasing the accuracy of the perceived risk (Lobb et al., 2004).

The impact of genetic counselling on patient expectations, satisfaction, wellbeing and perceived personal control has been investigated (Berkenstadt, Shiloh, Barkai, Katznelson, & Goldman, 1999; Davey et al., 2005; Macleod, Craufurd, & Booth, 2002; Metcalfe et al., 2010). Perceived personal control was improved when the condition involved a physical

disability, as well as in self-referrals (Berkenstadt et al., 1999). Improved perceived personal control was associated with high levels of satisfaction (Berkenstadt et al., 1999; Davey et al., 2005). However, as might be expected there was no increase in situations where a diagnosis could not be made and limited information and testing were available (Berkenstadt et al., 1999). Patients felt somewhat relieved of their vulnerabilities when they or the professionals were able to do something about the situation (Macleod et al., 2002). If the patient's expectations were met, their anxiety levels were generally lower but this was not necessarily associated with better outcomes and none of the variables measured predicted expectations or satisfaction (Michie, McDonald, & Marteau, 1997; Pieterse et al., 2005). In another study, patients felt their expectations regarding information were met but that their expectations related to assistance with decision-making and coping were not met (Davey et al., 2005). Different communication styles were found to have an impact on patient outcomes of anxiety, depression, knowledge and satisfaction (Lobb, Butow, Barratt, Meiser, & Tucker, 2005), and, although information communication was fairly standard facilitation skills varied significantly. A further study showed that counsellors and patients disagreed on their perceived expectations of genetic counselling (Bernhardt et al., 2000), however, it was shown that identifying patient expectations correctly could increase satisfaction (Davey et al., 2005). Physicians' attributes were also shown to contribute towards satisfaction and women were more satisfied when the physician was seen as trustworthy, as an expert, self-confident and decisive (Hunfeld et al., 1999; Macleod et al., 2002), while in cancer genetic sessions, a discussion of prophylactic measures resulted in more women feeling that their expectations were met (Lobb et al., 2004). Patient satisfaction has been linked to empowerment (McAllister et al., 2008; McAllister, Dunn, & Todd, 2010). In McAllister et al. (2008) grounded theory approach, empowerment was described as a belief system linked to

feeling in control and having the autonomy in decision-making, understanding, accessing services and looking to the future.

More recently, instruments have been developed which can be used in clinical practice as well as in research. Various patient satisfaction tools were developed: one focused on respect given and patient questions answered (Zellerino et al., 2009); another captured constructs of empowerment, perceived patient control, decisional conflict and hope (McAllister, Wood, Dunn, Shiloh, & Todd, 2011); while a third measured patient backgrounds, needs and expectations (Peters & Petrill, 2011).

It is clear from the many studies and findings reported that a single validated all encompassing tool for evaluating the effectiveness of genetic counselling does not exist (Payne et al., 2008). Whether such a tool could be developed is debatable. What seems important however, is how the communication occurs. Lobb (2005) showed that significant differences existed between counsellors' communication skills, but what accounted for these differences and how they affected outcomes could not be identified. Both counsellors and patients agreed that 'connecting' and a positive interpersonal interaction was a measure of success (Bernhardt et al., 2000) and that the manner in which the counsellor related to the patient was important in rating their satisfaction (Davey et al., 2005). Examining the interactions between patients and counsellors can provide additional information based on what occurs during the consultations. Kessler's (1981) analysis alluded to a pivotal moment in the session in which the counsellor addressed an underlying fear of the patient and that this seemed to have affected the success of the session. As there is an emphasis on using findings which help counsellors tailor their sessions (Peters & Petrill, 2011), drawing on both outcome and process studies might yield more relevant

and informative results. Interactional research on the genetic counselling process is discussed in chapter three.

An important point that needs to be considered is the application of the research findings in the sections above in multicultural settings. Most of the work reviewed, was performed in Western settings and the researchers drew on Western principles to formulate and assess their findings. The composition of their subject groups was not always specified, and how patients from different cultures perceived their risks or applied risk information in their decision-making processes did not appear to be explored. Whether the use of decision aids and the recommendations made by researchers are applicable to patients from different cultures remains unclear. As Veach (2003) and Weil (2000) state that patients have different cultural and religious beliefs and values and that these affect their decision-making (Potter et al., 2008), it could be assumed that the applicability of Western principles might be somewhat limited in patients from different cultures (Ahmed et al., 2012a). There is some evidence with regard to cultural limitation from research in Hong Kong that showed that decision-making in a prenatal context is affected by the health context (Pilnick & Zayts, 2011; Zayts & Schnurr, 2011). Intercultural communication is explored further in chapter 4.

2.5 Genetic counselling in South Africa

2.5.1 Health in South Africa

In 2011 the total population of South Africa was estimated at 51.8 million people of diverse cultures and language groups (Statistics South Africa, http://www.statssa.gov.za). The majority (79.5%) of the population was Black African, 9% was White, 9% was

Coloured and 2.5% was Indian/Asian. Of the total population, 22% or 11 328 203 South Africans live in the Gauteng province. There are 11 official languages, of which isiZulu (24%) and isiXhosa (18%) are most common. Many different religions are practiced; these include Christianity, Islam, Hinduism, and Judaism, to name a few. A large number of people in the country are unemployed (25.5% as at third quarter 2012).

There are many disparities in health and access to health care in South Africa (Benatar 2004). South Africa has both public (State) and private funded healthcare services (Kromberg & Jenkins, 2012; Penn & Watermeyer, 2012). The majority of the population is dependent on State services, while only those with financial means can afford to belong to a medical aid and to access private health care services (Kromberg et al., 2012). The South African Government has, since 1994, attempted to address inequalities by establishing a district-based system of Primary Health Care, nationalization of the health laboratory services, regulation of health care professionals and reforming health legislation. Several laws, some specifically attempting to improve women's heath, have been passed: the Choice on Termination of Pregnancy Act; the National Committee for Confidential Enquiry into Maternal Deaths; the National Contraceptive Policy; and the National Maternity Care Guidelines (Adar and Stevens 2002). Despite these efforts, change remains slow. There is still disparity between services offered in the private and state sector and shortage of staff and allocation of resources remain a challenge. In 2008, 35% of medical practitioners and 40% of nursing posts in the public sector were vacant (Kromberg et al., 2012). Health outcomes relating to maternal, infant and child health have worsened (Chopra, Daviaud, Pattinson, Fonn, & Lawn, 2009) and maternal mortality has doubled since 1990 (Blaauw & Penn-Kekana, 2010). Further social inequalities such as poverty, negative attitudes towards women and girls, racial and other discrimination,

disempowerment and the HIV/AIDS pandemic, remain some of the issues that South Africa still faces.

Inequality is most evident in poor, rural and African patients who only have access to State funded health care (Harris et al., 2011). Patients reported several barriers to accessing health care, which included cost of service, cost of transport and travel distances, disrespectful healthcare providers and a belief that care will be ineffective (Harris et al., 2011). Patients have been shown in general to be passive participants in their healthcare decisions and seemed to have high regard for doctors (Penn & Watermeyer, 2012). This is partly brought on by the country's apartheid history. Further, policy change and implementation programmes tend to dismiss the individuals involved in the implementation and service delivery (Walker & Gilson, 2004). Barriers to service delivery lie deeper than financial and staff shortages, with power relations and personal experience of change playing a bigger role than expected (McIntyre & Klugman, 2003). These oversights may have further contributed to the lack of improved health care.

HIV/AIDS remains a significant burden despite efforts to reduce the incidence. South Africa is reported to have the highest incidence and prevalence rates of HIV/AIDS in the world (Doherty and Cohen 2006). It is estimated (midyear 2011) that there are 5.4 million people living with HIV in South Africa (Karim, Churchyard, Karim, & Lawn, 2009). The prevalence estimate for HIV positive women attending antenatal clinics is 29%. HIV/AIDS affects not only the already strained health system, but also the South African economy as the illness affects people in the most productive age group. The condition accounted for 38% of total life-years lost from premature death (47% females and 33% males) (Benatar, 2004). An additional 25% of life-years lost are due to other

communicable disease, maternal and perinatal conditions, nutrition deficiencies, associated with poverty, and underdevelopment. The HIV/TB co-infection rate is estimated at 70%, which results in a significant burden (Karim et al., 2009). It has increased the toll on the already over-burdened health services, increasing workloads for health care workers, clinic visits and hospital admissions.

The South African government's stance on HIV has resulted in delays in implementing and promoting prevention campaigns (Benatar, 2004). South Africa has a National Strategic Plan for HIV/AIDS that includes education, programs for the modification of sexual behaviour and treatment of opportunistic infections (Benatar, 2004). However, many obstacles inhibit introduction and maintenance: high prevalence of high-risk sexual behaviour; extensive sexual violence against children and unemployed women; constraints on financial and human resources; inadequate health care infrastructure; resistance to adopting bottle feeding rather than breast-feeding; concern about the potential adverse effects of antiretroviral-drug therapy in poor and nutritionally vulnerable populations; concern about promoting drug resistance and fear of not meeting constitutional requirements for equity.

Further, HIV/AIDS also has a direct impact on genetic counselling. The roll-out of antiretroviral treatment to pregnant women, in an attempt to reduce maternal to child transmission, may pose a risk of injury to the developing fetus (Chersich et al., 2006). It is known that certain medication such as (Epilim and Warfarin) may cause abnormalities in a fetus if the mother is exposed to these during pregnancy (Harper, 2010). These women receive genetic counselling so that the risks and options can be discussed. The safety of ARV's and extent to which they may cause fetal abnormalities, however, has not been

established and HIV positive women need to be informed of their potential risks and options. In addition, the risk of transmitting the HIV virus to the fetus is increased if the woman undergoes a prenatal invasive test such as amniocentesis. Bee (2005), in a study on HIV status in women of advanced maternal age (AMA) seen for genetic counselling, found that more HIV positive women chose not to have an amniocentesis, compared to HIV negative women, as they were concerned about the increased risk of transmitting the virus to their fetus. Hospital policies now state that when an amniocentesis is performed, an HIV positive woman is required to be on antiretroviral treatment to reduce the risk of maternal to child transmission. As Bee (2005) found, unknown status or delays in starting antiretroviral treatment may deter or delay the woman from having testing. This was seen in one of the sessions in this research as the woman delayed having an amniocentesis because she was anxious to find out what her HIV status was. With the pressures of HIV and high infant mortality rates, the contribution of birth defects and genetic disorders to poor health outcomes is seen as a low priority (Kromberg et al., 2012).

2.5.2 The development of Medical Genetics

Medical Genetics in South Africa started in the 1950's with the development of cytogenetic laboratories and the South African Genetics Society (Greenberg et al., 2012; Jenkins, 1990). In the late 1950's Professor L. Hurst, Professor of Psychiatry and Professor P. Tobias, a Professor of Anatomy, at the University of the Witwatersrand, offered the first genetic counselling services (Jenkins, 1990). In 1972 a Department of Human Genetics was founded at the University of Cape Town and in 1975 a chair of Human Genetics was created at the University of the Witwatersrand. Departments of Human Genetics were later set up at the University of Stellenbosch and, in 1989, at the University of Pretoria.

By 1985, there were 14 clinics offering genetic counselling in South Africa (Jenkins, 1990). In 1990, staff of the University of the Witwatersrand ran general genetics and pregnancy counselling clinics, the University of Cape Town offered general genetics, pregnancy counselling, Huntington Disease and an orthopaedic clinic and the University of Stellenbosch staff ran general genetics, prenatal and paediatric clinics. In Durban, a paediatrician with a special interest in medical genetics offered a service (general paediatric genetics, and specialist clinics for Cystic Fibrosis and Spina Bifida) to patients. A limited genetic counselling Service was also offered at the Medical University of Southern Africa, the University of Pretoria and the University of the Free State. These services were unevenly distributed and were concentrated around University based medical schools with outreach within their provinces and occasionally to other provinces. In addition to services being offered by academic departments, the Genetic Services Division of the Department of National Health and Population Development (DNHPD) employed genetics nurses who were distributed throughout the country. These nurses provided a genetic service to patients living outside of the major academic hospitals in smaller towns in various parts of the country (Jenkins, 1990).

Presently (2013), genetic counselling services are offered in four of the nine provinces of South Africa: Gauteng, Western Cape, Free State and Kwazulu Natal, The departments of Human Genetics staff at the Universities of Cape Town, Stellenbosch, Witwatersrand, Free State, and paediatric staff at the Inkosi Albert Luthuli (Kwazulu Natal) and Steve Biko Hospitals (Pretoria) (Greenberg et al., 2012). The universities offer a fully integrated service with laboratory and clinical support, although the number of available staff and genetic tests offered at the different centres varies greatly (Kromberg, Sizer, &

Christianson, 2012). The genetic services division of the DNHPD was restructured in 1994 after which the genetic nurses were deployed in primary health care services. There are currently only four genetic nurses actively involved in genetic counselling and they are attached to two of the major academic centres and one hospital.

Genetic services were initially offered by scientists, medical doctors and nurses (Jenkins, 1990). Today services are provided by specialists in medical genetics, genetic counsellors and the few genetic nurses. In 1990 there was a gross shortage of staff, with 20-40 consultants needed (as well as a shortage of posts for laboratory and clinical staff) and unevenly distributed services. In 2012, the situation has hardly changed (Greenberg et al., 2012; Kromberg et al., 2012). There continues to be a serious shortage of posts and staff and the service is still unevenly distributed. The United Kingdom's report on Clinical Genetic Services into the 21st Century recommended that two full-time clinicians and eight genetic counsellors are required per 1 000 000 people of a population (Royal College of Physicians 1996). By this standard, 100 clinicians and 400 genetic counsellors are required in South Africa. With only 10 clinicians and five in training, and 18 genetic counsellors with three more in training of which not all were practicing in 2012, the country still has a serious shortage of adequately trained staff.

The demographics of the medical genetics staff are not representative of the South African population. The majority of the staff is female (although there are three males) and from the minority White population group (but there are two Black and three Indian Medical Geneticists). These professionals are mostly conversant only in English, while very few can converse in other languages (there are 11 official languages in South Africa). This means that interpreters have to be utilised to assist with communication during the genetic

counselling sessions. These interpreters are often nursing sisters in the ward, or family members, other patients or non-medical hospital staff. There are no trained interpreters dedicated to the clinics.

2.5.3 Development of a Master's degree in genetic counselling training course

The first Master's programme was developed by Professor Jennifer GR Kromberg at the University of the Witwatersrand in the late 1980's (Greenberg et al., 2012). In developing the curriculum, Kromberg visited programmes in the USA, discussed their training and observed their models. The curriculum initially consisted of five modules: Cytogenetics, Biochemical Genetics, Medical Genetics, Genetic Counselling and a research project. The course was a two year Master's degree in Medicine in Genetic Counselling (MSc (Med) Genetic Counselling). The training included psychosocial theory, as well as counselling skills training. In 2000, the curriculum was revised to cover three modules: Medical Genetics, Principles and Practices of Genetic Counselling and a research report. In 2004 a Master's programme in genetic counselling was started by Ms Patricia Craig and Professor Jacquie Greenberg at the University of Cape Town (Greenberg et al., 2012). The programme also runs over two years with three modules: Medical Genetics, Principles and Practices of Genetic Counselling and a research report. The training and practice of genetic counselling in both centres are based on the 'Counselling Model' (Kessler, 1997a) and the goal of 'Client psychological well-being' (Biesecker, 2001) as described in previous sections and counsellors receive extensive experiential training in counselling skills.

In the 1990's regulation of the profession was introduced and genetic counsellors were required to register with the Health Professions Council of South Africa (HPCSA) (Greenberg et al., 2012). Genetic counsellors were placed in the category Medical

Scientists under the South African Medical and Dental Board. A number of scientists with PhD or MSc degrees, who had been working in Human Genetics Departments providing genetic counselling for some years, were registered under a 'grandfather clause'. Genetic nurses were excluded. The first Master's trained genetic counsellor registered in 1998. New regulations regarding the Scope of Profession, training and registration requirements were promulgated in 2009 (http://www.hpcsa.co.za/). A professional group, Genetic Counsellors-South Africa (GC-SA) founded in 2008, has developed professional documents, which address the scope of practice, guidelines, intern training, exit assessments and continuing professional development.

2.5.4 Genetic counselling in the Division of Human Genetics, Johannesburg

The first genetic counselling clinic of the Division of Human Genetics of the National Health Laboratory Service (NHLS) (previously the South Africa Institute for Medical Research - SAIMR) and the University of the Witwatersrand, was established at the Transvaal Memorial Hospital (TMI) in 1972 (Jenkins, Wilton, Bernstein, & Nurse, 1973). This clinic mainly provided a service to the white population in the Johannesburg area. Later in 1987, a genetic counselling clinic was set up at Chris Hani Baragwanath Hospital (CHB) (Kromberg & Berkowitz, 1986; Kromberg & Jenkins, 1988) and provided a service mainly to patients from the Soweto area.

The genetic counselling service grew and clinics were set up in other state hospitals (Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospitals) and a private hospital in the Johannesburg area, as well as at smaller rural hospitals through regular national outreach clinics. There were several clinics at these hospitals covering antenatal, paediatric and adult cases as well as condition specific clinics,

such as those for cystic fibrosis, haemophilia and breast cancer. However since 2009, the service has had to be reduced as a result of a lack of staff. The Division currently runs five weekly clinics.

The genetic counselling Service is provided to patients from all the population groups in South Africa. On average, about 80% of the patients seen are from the State sector. In 2012, just over 2000 patients were counselled by staff of the Division.

The staffing of the Division has decreased drastically due to shortages of posts and, at present, there are seven clinicians, while at the time of the data collection for the present study there were nine clinicians and three registrars. Currently, the Division has three genetic counsellors and three interns in training, while at the time of the data collection there were five genetic counsellors, three interns and two genetic counselling students.

2.5.4.1 Advanced maternal age counselling

One of the main indications for genetic counselling at the Division is women of advanced maternal age. It is well recognised that a woman's risk of having a baby with a chromosome abnormality, especially Down syndrome, increases with advancing age (Penrose, 1934). Since the 1960's, advanced maternal age (AMA) has been regarded as the main indication for amniocentesis and prenatal diagnosis for chromosome abnormalities. Different countries and centres have considered various different ages at which women are regarded as being of AMA (Beekhuis, De Wolf, Mantingh, & Heringa, 1994). Locally, women at or over the age of 35 years are considered to be of AMA. The cut-off is based on the risk of having a child with a chromosome abnormality being approximately the same as the risk of losing the fetus due to an invasive prenatal genetic test (Harper, 2010). This is a

purely statistical cut-off level designed to ensure maximum pick-up and a low false negative rate.

The risk to these older women is for having a child with a chromosome abnormality, more specifically a trisomy (Harper, 2010). Trisomy occurs when there is inaccurate segregation during meiosis, a process called non-disjunction, which results in an extra chromosome (47 instead of 46 chromosomes) during gametogenesis. Although this error can result in an extra chromosome in the sperm or egg, the risk is higher in oocytes of women of AMA. Non-disjunction can occur with any of the chromosomes, but trisomy 21 (Down syndrome), Trisomy 13 (Patau syndrome), Trisomy 18 (Edwards's syndrome) and abnormalities of the X and Y chromosomes are the only viable aneuploidies. Other aneuploidies and most structural chromosome abnormalities are non-viable and mostly result in first trimester spontaneous abortions.

A woman's risk of having a baby with one of the common trisomies increases with age with the risk being around 1 in 1000 at 30 years, 1 in 500 at 35, 1 in 100 at 40 and 1 in 10 at 50 (Harper, 2010). Screening based on age alone has a low pickup rate and as medical knowledge advanced, biochemical markers were found to be associated with trisomy pregnancies (Wald et al., 1988). Later, in the 1990's ultrasound markers were found to be even more sensitive in screening for babies with chromosome abnormalities (Nicolaides, Azar, Byrne, Mansur, & Marks, 1992) (Table 2.1).

Table 2.1. *Screening for chromosomal disorders.*

	Markers	Detection rate
Maternal age alone	Maternal age ≥35 years	~40%
Biochemical markers	Second trimester triple screen - ß-HCG - Oestriol - Alpha-fetoprotein	~60%
Ultrasound markers	First trimester nuchal translucency screen (11-13w) - Absent nasal bone	~90%
	Second trimester fetal anomaly scan (18-23w) - Soft markers such as nasal hypoplasia, increased nuchal fold	~80%
Ultrasound and biochemical markers	First trimester nuchal translucency Screen (11-13w) - Absent nasal bone - ß-HCG - PAPPA	>95%

Table 2.1 is a summary from the articles by (Benacerraf, Neuberg, Bromley, & Frigoletto, 1992; Centini et al., 2005; Nicolaides et al., 1992; Spencer, Spencer, Power, Moakes, & Nicolaides, 2000; Wald et al., 1988) on the detection rate using various screening methods.

To identify women at an increased risk of having a baby with a chromosome abnormality, the ideal screening currently is to combine first trimester biochemical markers and ultrasound screening (nuchal translucency) (Spencer et al., 2000). This is however only available to patients accessing the private health sector in South Africa. First trimester nuchal translucency screening became available in Gauteng Province in tertiary hospitals in about 2003 (Naidoo, Erasmus, Jeebodh, Nicolaou, & Van Gelderen, 2008), and women who present to an antenatal clinic in one of these hospitals in their first trimester will be able to have a first trimester nuchal translucency screen. However, few women are referred for genetic counselling early enough in their pregnancy to have this undertaken (Watcham, Schön, & Christianson, 2007) and the state services does not offer biochemical testing.

The options available to a woman of AMA in her second trimester to manage the increased risk are ultrasound (to detect major fetal anomalies) and invasive prenatal testing. Detailed ultrasound can be performed between 18-23 weeks to screen for ultrasound markers. Several ultrasound markers have been found to be associated with a fetus with a chromosome abnormality, however these markers are also sometimes found in normal fetuses. Thus finding these markers is not diagnostic, but indicates that the woman is at an increased risk of having an affected infant. Amniocentesis, obtaining a sample of the amniotic fluid from the uterus, is a diagnostic procedure offered to women to confirm whether or not their fetus is affected. The procedure is ideally performed between 16 and 20 weeks of pregnancy, but in the local setting is performed up to 24 weeks and it carries a spontaneous abortion risk of less than 1%.

Genetic counselling for a woman with AMA involves explaining the concepts of chromosomes, non-disjunction, ultrasound, amniocentesis, the risk of having a baby with a chromosome abnormality, the risk of procedure related spontaneous abortion and the option of termination of pregnancy. Counselling involves education techniques, and using a range of counselling skills to assist women to use the information provided to make a decision regarding amniocentesis and to provide her with support regarding her choices. The uptake of amniocentesis has been shown to be around 30% in Cape Town (Urban, Stewart, Ruppelt, & Geerts, 2011) and in Johannesburg (Wessels, unpublished data from 2003/4). The reasons women have given for not wanting to have an amniocentesis undertaken were: she would not terminate an affected fetus (21%); or that she needed to discuss the matter with a partner/family before making a decision (21%), or she was concerned about the miscarriage risk (20%). The low uptake rate and reasons for not

wanting an invasive procedure are not fully understood and consequently the service provided to these women may not meet their needs entirely.

2.6 Summary

In this chapter genetic counselling as a practice has been described. Genetic counselling was first introduced internationally in the 1940s and it involved educating patients about the medical and scientific aspects of a genetic condition or risk, as well as decision-making and psychosocial support. Several philosophies and psychological theories borrowed from other disciplines, mostly social science and psychology, have guided the profession. The fragmented approach, as well as the lack of consensus with regard to its goals, has contributed to genetic counselling being without a distinct model of practice and still being viewed as a profession in search of itself. Research has found that many of the ideals held by professionals are not evident in practice or that they are inconsistently achieved.

The South African health care context and a brief history of the local development of the genetic counselling profession and its current practices with particular reference to advanced maternal age counselling have also been discussed. Advanced maternal age counselling constitutes about 15% of the total cases seen by genetic counsellors and involves education and counselling related to a woman's increased risk of having a baby with a chromosome abnormality. The development and training of genetic counselling in South Africa was based initially on programmes from the USA and there are a number of difficulties with regard to providing the service.

Chapter 3 Interactional Research

Research on genetic counselling interactions, examining the discourses in process (interactional research), gained momentum towards the late 1990's. Prior to that very little research, except for case discussions with informal methodologies had been conducted. In this chapter the findings of research focussing on examining interactions are considered. The research in the present study aimed to understand structural, interactional and analytic features of the sessions and did not aim to investigate specific phenomena. As a result the literature review in this chapter is structured to present a broad overview of genetic counselling process studies, which allowed the researcher to gain a general idea of the features investigated.

Genetic counselling is considered a hybrid activity as it combines the elements of traditional medical encounters and psychosocial counselling encounters (Sarangi, 2000). As a result comparisons between genetic counselling and other counselling interactions seem worthwhile. In light of this, selective findings from research in general medical and counselling interactions are also discussed in this chapter.

3.1 Overview of interactional research on genetic counselling encounters

To the best of the researcher's knowledge, the first attempts at examining the genetic counselling process were in the 1980's by Kessler (1981), Kessler and Jacopini (1982) and Rapp (1988). These investigations were based on informal methodologies used in antenatal genetic counselling session/s. Kessler (1981) commented on a transcript and with Jacopini (1982) used Bales scoring to analyse a transcript. Rapp (1988) made comments

based on observing sessions. Since these early attempts, more research has been conducted utilising more formalised methodologies in different genetic counselling settings and different study populations.

The predominant specialities investigated, included prenatal genetic counselling (Benkendorf et al., 2001; Browner, Preloran, Casado, Bass, & Walker, 2003; Gordon, Prince, Benkendorf, & Hamilton, 2002; Hodgson et al., 2009; Hunt et al., 2005; Kessler, 1981; Marteau, Slack, Kidd, & Shaw, 1992; Pilnick, Fraser, & James, 2004; Pilnick, 2004; Pilnick & Zayts, 2011; Roter, Ellington, Erby, Larson, & Dudley, 2006b; Zayts & Schnurr, 2011) and cancer genetics (Butow & Lobb, 2004; Duric et al., 2003; Ellington et al., 2005, 2007; Ellington et al., 2006; Hallowell, 1999; Lobb et al., 2002; O'Doherty, 2006; Pieterse, Dulmen, Ausems, Beemer, & Bensing, 2005; Pieterse, Dulmen, Beemer, Bensing, & Ausems, 2007; Roter et al., 2006b). The specialty of prenatal genetic counselling represents a large proportion of the work in genetic counselling, and it is thus not surprising that a large number of studies are conducted in this area. Investigating the genetic counselling process in a prenatal setting is very valuable, as it allows for the examination of risk discussion and decision-making which are central aspects in most genetic counselling sessions, irrespective of the indication.

With the discovery of genes for breast cancer and the subsequent introduction of cancer genetics, a number of studies examining cancer genetic counselling sessions appeared. This research contributed to the understanding of other aspects of the genetic counselling process, such as risk management. A few studies examined paediatric and adult genetic counselling sessions (Armstrong, Michie, & Marteau, 1998; Babul-Hirji, Hewson, & Frescura, 2010; Lehtinen & Kääriäinen, 2005; Lehtinen, 2005, 2007; Pilnick, 2002;

Sarangi & Clarke, 2002; Sarangi, 2002; Sarangi et al., 2004, 2003; van Zuuren, van Schie, & van Baaren, 1997) and revealed other aspects, such as how information is provided and how a genetic or possible genetic diagnosis is addressed. However, the areas of paediatric and adult genetic counselling sessions remain under investigated.

In the vast majority of the process studies in genetic counselling initial or first sessions were examined, with only a few investigating second or follow-up sessions (Ellington et al., 2007; Sarangi et al., 2004; van Zuuren et al., 1997). First and follow-up sessions have different features; a first session will typically involve information gathering, while a second session will involve very little, if any, and focus more on the diagnosis. It can thus be assumed that by investigating different types of sessions different features of the genetic counselling process will be revealed.

As shown in the previous chapter, genetic counselling or genetic advice may be offered not only by genetic counsellors, but also by other professionals i.e., medical geneticists, genetic nurses, and midwives and other clinicians who may give genetic advice. As an introduction to their definition of genetic counselling, Resta et al. (2006) commented that the definition is for 'genetic counselling' and not for 'genetic counsellors'. Whether interactions conducted by professionals other than genetic counsellors are a true reflection of 'the genetic counselling process' is a valid question. Smets (2007) suggested that there is not much difference between the approach of genetic professionals and non-genetic professionals, as both share the principle of a patient-centered approach, have the same difficulties in eliciting a patient agenda and aim to enhance patient understanding. However, whether genetic counsellors and midwives practice a patient-centered approach in the same way, given the differences in their training and experience, is debatable. A

number of studies examined the genetic counselling process when conducted by midwives (Marteau et al., 1992; Pilnick et al., 2004; Pilnick, 2004; Pilnick & Zayts, 2011) and clinicians (Gordon et al., 2002; Pieterse et al., 2005, 2007; Pilnick & Zayts, 2011; Sarangi & Clarke, 2002; Sarangi, 2002). Some specifically examined sessions conducted by genetic counsellors (Armstrong et al., 1998; Benkendorf et al., 2001; Browner et al., 2003; Ellington et al., 2005; Ellington et al., 2006; Gordon et al., 2002; Hodgson et al., 2009; Sarangi et al., 2003). Others made no distinction between the counselling offered by medical geneticists and genetic counsellors (Babul-Hirji et al., 2010; Butow & Lobb, 2004; Duric et al., 2003; Ellington et al., 2007; Hunt et al., 2005).

Investigations into the genetic counselling process have used a number of different methodologies: as discussed, the first studies involved subjective comments on sessions (Kessler, 1981; Rapp, 1988) and later, sessions were observed and themes identified from the session transcripts (Gordon et al., 2002; Hallowell, 1999; Hodgson et al., 2009; Marteau et al., 1992; van Zuuren et al., 1997). These methodologies were valuable as they provided insight into the poorly understood genetic counselling process. However, more formalised methodologies were required and quantitative methods, including the Roter interactional score (RIAS) were developed. The RIAS involved scoring the sessions according to the information given and the amount of talk time by the counsellor and patient (Butow & Lobb, 2004; Ellington et al., 2005, 2007; Ellington et al., 2006; Lobb et al., 2002; Pieterse et al., 2005, 2007). This work contributed to quantifying what, and how often, certain elements occur during genetic counselling interactions. This overall description was necessary and helpful, but further investigations, examining the detail of the interactions were needed. Studies based on socio-linguistic methods, such as discourse analysis, allowed an in-depth examination of the session dynamics and tensions and an

examination of what the talk is doing rather than what the talk is about. This dimension provided a different perspective on the process of genetic counselling and made a significant contribution to the understanding of the process. These insights are discussed further in the following sections.

3.2 Structure in interactions

3.2.1 Overall structure

Genetic counselling sessions have been shown to have an overall structure (Armstrong et al., 1998; Babul-Hirji et al., 2010; Butow & Lobb, 2004; Hodgson et al., 2009). Sessions with pregnant Australian women, who have had genetic counselling because of a positive maternal screen for fetal anomalies, were found to comprise openings, screening test dialogue, diagnostic testing dialogue, explanation of the conditions being tested for and closings (Hodgson et al., 2009). Genetic counselling sessions with parents of children with a genetic disorder were found to consist of an opening, information gathering, scientific information, information delivery and a counselling phase (Babul-Hirji et al., 2010). In cancer sessions, the opening sequence consisted of determining the woman's reason for attending the session, then a family and personal history of cancer was collected, a discussion of the roles of genes and chromosomes in cancer development, and an explanation of the risks (Butow & Lobb, 2004). Psychosocial aspects were addressed at any time during the sessions. In new sessions with patients who might have genetic problems, the structure was described in terms of phases: an initial highly structured phase in which greetings were followed by drawing a family pedigree (Armstrong et al., 1998); and a second phase which was less controlled when the patient engaged with the genetic

information. These studies, although they did not reveal the detail of how sessions were structured, showed that there were different phases. Specific structural features have been revealed in medical encounters that were made possible because of the use of sociolinguistic methodologies. This information allows comparisons to be drawn between medical and genetic counselling sessions.

Various studies found that the overall structure, shown in genetic counselling sessions, resembles what is described in medical encounters (Byrne & Long, 1976; Heritage & Maynard, 2006; Waitzkin, 1991). In their study, Byrne and Long (1976) found a typical medical encounter to contain a number of events: (i) establishing a relationship (ii) attempts at discovering the reason for attendance (iii) verbal and/or physical examination (iv) considering the condition (v) treatment or further investigation and (vi) termination. Similarly, Waitzkin (1991) described the structure as: (i) chief complaint, (ii) present illness, (iii) history taking (past, family and social), (iv) systems review, (v) physical examination, (vi) other investigations, (vii) diagnosis and (viii) plan. Heritage and Maynard (2006) similarly found acute primary care medical visits to consist of: opening, presenting complaint, examination, diagnosis, treatment and closing.

A striking difference between counselling interactions and medical encounters were that the former were more fluid (Labov & Fanshel, 1977; Sheon, Lee, & Facente, 2010; Silverman, 1997). In their study on therapeutic discourse, Labov and Fanshel (1977) described the interaction as an artificial structure which is derived from sudden shifts of topics. In Human Immunodeficiency Virus (HIV) pre-test counselling sessions, a flexible structure was also found. It consisted of medical history taking (or rather what resembles a medical history taking), followed by discussion about sexual matters and then information

delivery (Silverman, 1997). Dreaded issues were introduced later on in the session and the session concluded with discussions about the availability of the test result. Sheon (2010) found that HIV counselling sessions (with men in the USA) consist of several tasks, namely: counselling (client speaks more than the counsellor in one turn), information delivery (risk assessment and health communication), data collection (standard survey regarding risk behaviour required by the particular institution) and sample collection (oral fluid swap and rapid test). These tasks were quantified by mapping when and how often each occurred in the session. It was found that they did not occur in a strict order and when the data collection task was removed from the session, the time the counsellors spent on counselling increased (Sheon et al., 2010).

It was particularly useful to consider HIV sessions due to the similarities between the process of genetic counselling and HIV counselling. The aims in HIV testing and counselling were reported to be to: prevent HIV transmission; and to support the individual affected with the condition (Chippindale & French, 2001). During the process the individual is provided with information regarding testing, so as to promote informed choice, information is obtained with regard to high risk behaviours, and patients receive support during the testing process. Counselling, both with individuals and couples, is required to assist the patient (and partner) to adjust to the news, if positive, as well as to promote low risk behaviour. These elements are present in genetic counselling interactions except that the focus is on a genetic condition. It was further thought to be worthwhile because HIV has high incidence in Africa, and particularly South Africa (as demonstrated in Chapter 2), and the counselling is provided to a very similar socio-cultural group as that using genetic counselling services.

It is clear from the research discussed above that order exists in institutional discourses. This is what distinguishes such discourses from everyday talk and informal conversations. This order, however, varies according to the types of encounters as shown in counselling and medical interactions (Heritage & Maynard, 2006). Such overall descriptions are valuable as they provide an overview and a context for the interactions. Although it is important to have an overview, closer examination focused on specific aspects is also required in order to gain a more detailed understanding of the nature of interactions.

3.2.2 Interactional structure

Socio-linguistic studies, specifically conversational analysis, have revealed interactional structures of the talk, such as how one action leads to another (referred to as sequence organisation) (Schegloff, 2007). The sequences in genetic counselling interactions have been found to be diverse (Babul-Hirji et al., 2010; Lehtinen & Kääriäinen, 2005; Sarangi, 2000). Babul-Hirji (2010) found that question and answer sequences, typically found in medical interactions, occurred during sections of the session in which the genetic counsellors' 'voice of efficiency' predominated and that open-ended, yes/no and polarized questions were often used. In contrast, during phases where the genetic counsellors provided information ('voice of educator'), the discourse was characterised by long monologues by the counsellors with acknowledgment tokens used by the patients (Babul-Hirji et al., 2010; Lehtinen & Kääriäinen, 2005; Lehtinen, 2005; Sarangi, 2000). Yet another sequence was identified during a phase which was termed the genetic counsellors 'humanistic voice' (Babul-Hirji et al., 2010). During these phases the patients talked while the counsellor limited her/himself to using minimal and supportive acknowledgments.

Much of this resembles the typical structure of medical encounters which has been described as a repetitious question – response – interpretation sequence (Mishler, 1984; Robinson & Heritage, 2005; Robinson, 2006; Robinson, 1998). Mishler (1984, p. 76) calls the structure of medical encounters 'the basic structural unit of discourse in medical interviews'. It was found that different question designs were used, most obviously open and closed ended questions. Question designs in medical encounters however are more complex than this and subtle changes are designed to elicit different information, such as gloss-for-confirmation, symptoms-for-confirmation questions (Robinson & Heritage, 2005; Robinson, 2006) and perspective display series (PDS) (Maynard & Frankel, 2006; Maynard, 1991). Question/answer sequences are not the only format in medical encounters; narratives of discovery where the patient talks and doctors acknowledge (Halkowski, 2006), and patient explanation followed by the doctor's con/disconfirming (Gill & Maynard, 2006) were also described.

Similarly in HIV counselling, different communication formats exist. The interview format, in which the counsellor acts as the questioner and the patient acts as the answerer, and the information delivery format in which the counsellor is the speaker and the patient is the recipient (Silverman, 1997). Although such main formats exist, there were found to be departures from it, such as when questions were initiated by patients. These were characterized by the roles being reversed so that the patient became the questioner and the counsellor became the answerer. Patients were also found to make conversational contributions which were characterized by the patient taking on the role of the speaker and the counsellor the recipient. These two basic formats can be distinguished in the HIV counselling sessions and take on specific characteristics depending on the topic (Silverman, 1997). When 'delicate objects' were discussed, counsellors showed empathy

by paraphrasing and repeating what the patient has said. In sections of the session, which were termed 'advice giving', the structure was found to be a combination of information delivery formats, interview formats and combined sequences (Silverman, 1997). Similarly, the structure of the discourse when counsellors needed to 'give bad news' involved perspective display sequences (Silverman, 1997).

In therapeutic interactions, the discourses were characterized as a 'request for action' sequence (Labov & Fanshel, 1977). Such requests were found to be relatively neutral and take on the form of challenges and eliciting narratives amongst others. The discourse consisted of different levels, and interview styles could be distinguished from narratives and discussions of everyday life (unemotional) and family life (emotional) (Labov & Fanshel, 1977).

As seen from the literature, it is crucial that when attempting to understand and evaluate genetic counselling interactions, the hybridity, comprising the interrelatedness of overall structural characteristics and unique sequences of different phases, be taken into consideration before any conclusions are drawn.

3.3 Analyses based on components identified from the overall structure

Although research has shown that genetic counselling sessions consists of specific phases, analysis of the detail is sparse. Little is known about how the different phases of a genetic counselling session are structured and how these may vary between different indications for referral, different professional approaches, or different settings in which sessions are carried out.

As discussed in the overview of previous research, it seems that genetic counselling sessions may follow, more or less, a similar structure to that of other medical encounters. According to one research group in the UK (Armstrong et al., 1998), the genetic counselling session was opened with preliminaries such as greetings, after which the family pedigree was drawn up. In another study on cancer genetic counselling sessions in Australia, the most common opening sequences involved determining the reason for the referral, followed by a discussion on the family pedigree and personal history of cancer (Butow & Lobb, 2004). Rapp (1988) observed that the genetic counsellors in her USA study set up the dialogue at the opening of the session by asking the patients (pregnant women in this case) 'do you know why you are here talking to me?'. None of these studies aimed primarily to investigate the opening sequence of genetic counselling sessions and as a result did not provide detailed information regarding openings.

On the other hand, the opening sequence of the medical encounter has been researched in depth (Byrne & Long, 1976; Heath, 1981, 1986; Robinson, 1998). Doctors and patients establish 'co-presence' (Robinson, 1998); greetings are exchanged, names are checked, spatial and physical orientations are established, patients are seated and doctors read the medical records and check their equipment (Heath, 1981; Robinson, 1998). Greeting and identity check sequences consist of at least two-parts, the doctor's greeting or proposal followed by the patient's greeting or confirmation or rejection of the doctor's proposal. The extent to which greetings are exchanged was found to be affected by the number of patients the doctor had seen before and how many were still waiting to be seen (Byrne & Long, 1976).

Byrne and Long (1976) found that greetings differed depending on whether the doctor remembered the patient and how accurate his medical records were. The nature of the records affected the opening questions as doctors who knew the patient might have started a session by telling the patient why they were there, for example, 'now, you've come for that prescription?' compared to 'you don't look like …., Miss umm umm', when the doctor expected to see another patient. Direct questions were found to be a feature of doctors who had short consultation times, while broad openings were typical of doctors who had fewer consultations. Doctors were found to offer observations by remarking that a patient seemed tense or looked like s/he had been crying. Some doctors were observed to encourage patients to keep talking, and a very small percentage (7%) of doctors was found to use silence for this purpose. These preliminaries precede what Heath (1981, 1986) called getting into the 'business at hand' or 'soliciting presenting concerns'.

Unlike medical encounters, in which different phases have been examined in detail, other phases of the genetic counselling interaction, such as obtaining the family history or closings have not been examined. Studies in genetic counselling, have focused on examining specific activities such as establishing an agenda, communication of information, risk communication, decision-making and non-directiveness.

3.4 Analyses based on specific phenomena in genetic counselling interactions

3.4.1 Establishing the agenda

Most research on the opening of genetic counselling sessions has focused on the reason for the visit or whether the patient's concerns were established. Results varied considerably,

and findings showed that genetic counsellors made no attempt to establish patient concerns in some sessions while in others, patients' agendas were sought in 95% of cases (Butow & Lobb, 2004; Pieterse et al., 2005; Smith, Michie, Allanson, & Elwyn, 2000). Smith et al. (2000) found that, at the beginning of the session there was no negotiation of the patient's concerns and that the clinician decided what needed to be discussed. This was based on sessions from only one clinician, but these findings were in keeping with those from the larger sample from which the particular clinician was selected. In addition, Butow and Lobb (2004) who studied sessions with different clinicians, also found that setting the agenda was counsellor/clinician driven. None of the studies provided more information regarding how the patients' concerns were elicited. There might be different strategies used by different professionals, and different strategies might be used depending on whether the session is new or a follow-up.

When the patient and the counsellor/clinician agenda were 'matched' the patients felt that their expectations were met (Lobb et al., 2002; Shankar, Chapman, & Goodship, 1999). Patients were more dissatisfied with the consultation when there was a lack of concordance with regard to the concern (Michie, Weinman, & Marteau, 1998); in a third of cases, the geneticist ascertained the patient's level and type of concern inaccurately and when geneticists and patients were non-concordant the counsellors were more likely to think that patients wanted information regarding risks. It is not known how narrowly the agenda established at the beginning of the session was followed throughout the session (Pieterse et al., 2005).

In medical encounters, both doctors and patients treat presenting current symptoms as important when soliciting presenting concerns (Robinson, 2006). Both treat responses that

do not contain current symptoms as incomplete. When doctors' moved to gathering information before the patient completed their presentation of current symptoms, the patient treated this as an interruption (Robinson, 2006). In turn, when doctors did not proceed to information gathering when patients completed their presentation of current symptoms, the patient indicated that they had completed their presentation. Typically, doctors initiated the stage of eliciting patient's reasons for attending the consultation with a question. By doing this, the doctor sets the general topic, which is the patient's problem (Mishler, 1984). The use of open ended or wh-type (what, where, when) questions was found to be effective in eliciting patient concerns (Marvel, Epstein, Flowers, & Beckman, 1999; Mishler, 1984). However, Robinson (2006) and Heath (1981) showed that a closed ended question in the right context can also be effective in soliciting concerns. Doctors use different question formats depending on whether the visit is a first, follow-up or chronic one (Robinson, 2006). First visit questions are understood to ascertain new concerns and can be open or closed. Questions take on slightly different formats when the patient is attending a follow-up visit. Doctors' questions communicate that they know something about the patient's concern and that they are aware that it is not a new concern. When eliciting chronic routine concerns, the questions are designed to indicate that the doctor knows that the patient is there to discuss his/her chronic condition.

In their questioning, doctors show a preference for the use of specific types of questions, such as question formats designed to elicit a 'no'-type response or a 'yes'-type response. By asking the patient "anything new?" which is designed to elicit a 'no'-type response, the doctor is communicating that the patient is there to discuss the chronic condition and that the doctor does not anticipate a new problem. Similarly using "so what's new?" which is

designed to elicit a 'yes'-type response communicates that the doctor anticipates the patient may have a new problem in addition to the chronic concerns.

There is some indication that neither doctor nor patient is open to presentation of a fuller agenda (Barry, Bradley, Britten, Stevenson, & Barber, 2000). Doctors may not be confident nor have the time to deal with the patients full agenda and patients may be concerned about what is appropriate. The doctor's behaviour can prevent the patients from voicing all their concerns resulting in an incomplete presentation of concerns. The reasons for not completing their concerns included that they were not asked, or they were redirected (Marvel et al., 1999). Redirections occurred by asking closed questions ("when do you have the pain?"), elaborators ("tell me more about the pain"), recompleters ("the pain") or statements ("the pain sounds serious") (Marvel et al., 1999). Similarly Waitzkin (1991) also found that doctors commonly interrupted patients when they presented their complaints. This prevents patient storytelling and as a result, some aspects of the illness will be excluded from the consultation. The interruptions happen even though these issues are important in the patient's experience. According to Waitzkin (1991) doctors may not want to hear patient stories as they do not contribute to making a diagnosis, and the patient's version of the story may be inconsistent or confusing, or the story may take too much time and may evoke unpleasant feelings for either or both the patient and the doctor.

The patients' behaviour may also prevent complete solicitation of presenting concerns. Patients are perceived to have limited autonomy in medical consultations as they may be allowed to make requests, but may not be permitted to suggest solutions to the requests (Barry et al., 2000). Patients voice only some aspects of their concerns, mostly the biomedical aspects, while the unvoiced concerns are the psychosocial aspects. According

to Barry et al. (2000), in the medical consultation the patient is purely a biomedical entity and they behave as they are expected to, rather than how they want to behave. Gender and cultural values may affect the patient's willingness to verbalize concerns at the opening and additional concerns may not occur to the patient until later in the consultation (Marvel et al., 1999). Marvel et al. (1999) pointed out that it may not always be necessary to solicit an exhaustive list of patient concerns at the beginning of the consultation as patients may delay discussing emotionally laden topics until the doctor has earned their trust.

Setting an incomplete agenda is thought to be associated with fewer patient concerns being elicited, more late arising concerns being voiced and missed opportunities to gather potentially important information from the patient. Research, such as that conducted by Marvel et al. (1999) and Robinson and Heritage (2005) provide insight into practice and can lead to opportunities for training doctors to be more effective in eliciting presenting concerns. Findings showed that doctors with more experience were more successful at obtaining a complete agenda from the patient, and that with training, practice can be improved (Marvel et al., 1999). The use of an open-ended opening solicitation or general enquiry question, such as "what concerns do you have?", followed by nondirective facilitating utterances (also called surveying patient concerns) such as "what else?" or "uh huh" repeatedly until all concerns were voiced, seemed the most useful technique (Marvel et al., 1999; Robinson & Heritage, 2005).

3.4.2 Information giving

The fundamental activity, of providing patients with relevant medical and genetic information in genetic counselling has been investigated by a few authors (Gordon et al.,

2002; Lehtinen & Kääriäinen, 2005; Lehtinen, 2005, 2007). During this activity, there were attempts from the genetic professionals (clinicians) to ensure the patients' understanding (Lehtinen, 2005). Studies also examined how clinicians manage providing information (Lehtinen & Kääriäinen, 2005; Lehtinen, 2007).

The clinicians were found to orientate toward ensuring that patients understand the information given and adjust to what the information means for them (Lehtinen, 2005). This understanding was achieved jointly by the patient and the clinician, and interactionally, by the patients producing candidate understandings at selective positions within the typical monologue of information giving by the clinicians. A candidate understanding was described as the patients stating what they had actually heard rather than just acknowledging that they heard the information. Instead of producing an acknowledgement token such as 'uh huh', the patients show what they have understood what was said. This usually took the form of a particle (i.e. so, in other words, so you mean) + a paraphrase (a summary of the information).

Clinicians not only ensure that patients understand the information, but they have to manage their information giving when the patients come with information that may be discrepant from what the clinician provides (Lehtinen & Kääriäinen, 2005; Lehtinen, 2007). The clinicians kept a delicate balance between acknowledging the patients' knowledge and maintaining their own expertise. They may manage the situation by accepting the information, and show that it is not discrepant with their information, or they reject the information indicating that it is 'wrong'. This is achieved by organizing all the knowledge into a coherent whole, offering evidence for their original information, and attributing causes to the patient's information.

Some insights were also gained as to how genetic counsellors provide information. One study examined the discussion of the procedural pain of an amniocentesis (Gordon et al., 2002). The authors identified three patterns of constructed dialogue in terms of form and content: the use of non-medical terms (colloquial); the use of similes; and downplaying the pain. In terms of function, the dialogue served to preserve the patient's positive face, to help with providing evidence and to maintain value-neutrality.

Information giving as an activity of providing large amounts of medical and genetic information to the extent it is seen in medical and genetic counselling encounters was not really found in counselling and therapeutic sessions. However, in HIV counselling where one of the activities included providing patients with information on the virus, testing and high risk behaviour, information giving sequences were reported (Silverman, 1997). Information giving was often found to be a monologue produced by the counsellors with the patients responding with acknowledgment tokens. This was termed an information delivery format. Although this format is typical, two types of deviations were found which included questions initiated by the clients and clients making a conversational contribution (Silverman, 1997).

3.4.3 Risk discussion, decision-making and non-directiveness

Risk discussion, decision-making and non-directiveness are distinct entities, but in an interaction, as shown in the previous chapter, it becomes difficult to separate the one from the other. These categories become artificial as they influence each other, and as a result the three concepts are discussed together here.

In examining risk communication in genetic counselling, not only the technical and clinical aspects of risk, but also the anxieties and interpersonal concerns raised by knowing the risk and being at risk, have been considered (Sarangi et al., 2003; Sarangi, 2002). A distinction is made between the risk of occurrence (the disorder will manifest) and the risk of knowing (undergoing tests that will clarify the risk of disease occurrence) (Sarangi et al., 2003). In predictive genetic counselling sessions (for Huntington disease and cancer), it was found that these risks become conflated and the one was understood in light of the other. It was further found that genetic professionals make use of six discourse strategies in the framing of risks: abstraction (statistical facts and figures such as 1 in 12); reformulation (presenting risk in a more context specific way and included the use of metaphors and visual aids); externalisation (general patterns, not the individuals' situation); localization (relevance and applicability to the patient situation); temporalisation (time axis in which risk becomes more or less relevant); and agentivisation (engagement with risk by screening and surveillance). Counsellors have been found to mitigate their probability statements and manage inexactness, range and degrees of confirmation, by contextualizing the information (Sarangi, 2002)

A number of studies have focused on non-directiveness. Research has highlighted the difficulties in understanding, maintaining and measuring non-directiveness (Benkendorf et al., 2001; Hallowell, 1999; Michie et al., 1997; Pilnick, 2002; Pilnick & Zayts, 2011; Sarangi & Clarke, 2002), particularly in clinical practice where an approach varies in different circumstances (Michie et al., 1997; Sarangi et al., 2004; Schwennesen & Koch, 2012; Weil et al., 2006; Williams, Alderson, & Farsides, 2002; Zayts & Schnurr, 2011).

In some research projects the behaviour of the counsellor has been studied and the language of the counsellor analysed for its features (Benkendorf et al., 2001), for its potential to initiate 'reflective frames' (Sarangi et al., 2004), or for the ways screening options are presented (Pilnick, 2004; Pilnick, 2008; Schwennesen & Koch, 2012). Reflective frames have been found to be initiated by using reflective questioning or nonspecific invites, by addressing awareness and anxiety, by discussing decisions about testing and the impact of results (Sarangi et al., 2004). Patients' responses to reflective frames show some misalignments for both questions about the decision to have testing and about the impact of the test result (Sarangi et al., 2005).

Sarangi and Clarke (2002) showed that in childhood testing, the parent's rights to test and child's rights to autonomy may become juxtaposed. Both professionals and parents use contrast to negotiate the outcome; the parents use contrast to justify their position, while the professional uses contrast to offer a preferred option without explicitly contradicting the parents. These strategies have developed partly due to the professional's commitment to maintaining a non-directive stance.

3.4.4 Counselling

To what extent 'counselling' occurs and to what extent genetic counsellors practice what Kessler identified as the 'Counselling model' in genetic counselling sessions has been debated, and as a result some researchers have attempted to examine this aspect (Butow & Lobb, 2004; Ellington et al., 2005; Ellington et al., 2006). Using coding systems such as RIAS, it was found that genetic professionals in cancer genetic counselling sessions spent little time on eliciting emotional responses from patients, seldom involved patients in the

sessions, and the sessions were largely educational in nature. However, both counsellors and patients devoted large amounts of time to providing biomedical information. Distinct patterns were evident in sessions: a client-focused psychosocial style; a counsellor-driven psychosocial pattern; biomedical question and answer pattern; and a client-focused biomedical pattern (Ellington et al., 2006). Teaching patterns were also characterized by higher verbal dominance by the counsellors compared to counselling patterns where counsellor verbal dominance was low (Roter et al., 2006b). The sessions have not been an 'either-or', but rather a combination of teaching and counselling approaches and counsellors had their own styles. Further, the presence of a companion in the session had an effect on the extent to which counselling occurred (Ellington et al., 2006).

Whether or not counselling actually occurs in genetic counselling interactions is one question, but what the characteristics are, and how emotional aspects are dealt with in the sessions are other perspectives to consider. These aspects do not seem to have been investigated in genetic counselling from a socio-linguistic perspective. In an identify and count study on breast cancer genetic counselling, it was found that the extent to which women provided emotional cues were influenced by patient characteristics, counsellor characteristics and an interaction between the two (Duric et al., 2003). The researchers found that patients gave at least one emotional cue during the session, but not all the professionals respond to these cues and a particular professional did not necessarily respond to all the patient cues. The more intense emotional cues were more likely to be addressed and, when professionals responded to emotional cues, patients gave more during the sessions. They also found that patients who received responses to their emotional cues experienced less depression after the sessions. Genetic professionals do influence the extent to which patients share their emotions. A balance can be achieved if patients are

given interactional space to verbalise what they think and to share their fears and needs (Brookes-Howell, 2006). The responsibility seems to be on the counsellors to attend to the emotional aspects as they direct the interactions. The fact that 'counselling' has been found to occur less often in genetic counselling sessions, may echo the difficulty of providing both education and counselling, as well as the lack of a clearly defined practice model which would clearly define the counsellor's role.

A better description of counselling, interactionally, can be found in the counselling literature. In HIV counselling during delicate object discussions, certain patterns were identified (Silverman, 1997). Counsellors encouraged patient narrative by showing empathy, and in the interaction this was characterized by paraphrasing and repeating what the patients had said. Further analysis showed that patients only experience empathy when they interpreted the counsellor's repeating of their response as an 'I hear what you say' rather than 'warrant (justify why) what you say'. Further understanding of what counselling talk looks like comes from examining troubles talk (Miller & Silverman, 1995). Trouble talk in counselling refers to patients talking about their life experiences which range from serious problems to mild issues. A specific question design is characteristic of such talk and includes: asking about dreaded issues; future orientated hypothetical questions such as 'how would others feel about….?'; and scaling questions such as 'how would you rank….?'. In psychotherapeutic discourses the therapist makes links between client experiences (Peräkylä, 2004), such as childhood, everyday life and the therapist-client relationship. An examination of the genetic counselling sessions' 'counselling phase' could compare to what extent there is overlap between the two disciplines, as well as what techniques have been developed in practice.

3.5 Asymmetry

A uniform observation of the communication in medical encounters is the interactional asymmetry which is characterized by doctors' actions being first (requesting) and patient responses being second (answering) (Robinson, 1998). Explanations for asymmetry can be found in the theory which claims that communication is socially organized. This implies that doctors are powerful and dominant and patients are disempowered and subordinate. As a result the interaction is a predestined product resulting in patient submission to doctor's power (Robinson, 1998).

Several studies found that the medical encounter permits the doctor control over the development of the interview (Heath, 1981, 1986; Marvel et al., 1999; Mishler, 1984; Roberts, 2000; Robinson, 2006; Waitzkin, 1991). The doctor's control is evident in that the doctor can redirect or focus the consultation before the patient gets to voice all his/her concerns (Marvel et al., 1999). The doctor achieves control by being the first and last speaker and thus being the one who decides what direction to take by steering the questioning and assessing the answers (Mishler, 1984). This allows the doctor to use his/her position as the speaker to control the interview by opening each cycle with his/her request or question. Doctors can selectively give attention to some topics and be inattentive to others. Through questioning, they can create a domain of relevance (to themselves and the patients) which Paolo Freire calls 'naming the world' (cited by (Mishler 1984), where the focus of the asymmetry or power is on biomedical aspects. The pattern suggests a particular voice which Mishler calls 'the voice of medicine' (Mishler 1984). The voice of the patient, 'the voice of the life world', is in the topics which patients

introduce into the interview because of their relevance. This voice of the life world is often not voiced in the medical encounter or if voiced, it is often ignored.

An alternative explanation is that the asymmetry is interactionally grounded (Robinson, 1998). This implies that the patient and doctor accept turn taking rules that are different from ordinary conversation. Both the doctor and the patient participate in organizing the turn taking. However, both hold the doctor accountable and the doctor is treated as being responsible for the next activity including soliciting an appropriately fitted concern (Robinson, 2006). Similarly, the patient's display of recipiency (showing the doctor that s/he is ready to voice a concern) is evidence that both parties hold the doctor accountable (Heath, 1986). Asymmetry is therefore co-constructed by both patients and doctors and is inevitable in the encounters (Pilnick & Dingwall, 2011). Not only is there asymmetry of topic as it is the patient that is sick and not the doctor but there is also asymmetry of task since the doctor has to diagnose and manage and as a result needs to ask questions and examine. The authors suggests that "…asymmetry lies at the heart of the medical enterprise: it is founded in what doctors are there for" (Pilnick & Dingwall, 2011, p. 1374).

Similar asymmetry has been found in genetic counselling interactions as the entire consultation has been found to have a tightly controlled agenda and neither the counsellor nor the patient wants to or is able to disturb it (Armstrong et al., 1998). As found in medical encounters, the voice of the patient is not always heard and the counsellors have control of the session (Babul-Hirji et al., 2010; Hodgson et al., 2009). Different voices were described during different stages of the consult in which the genetic professionals oscillate between: the voice of educator; efficiency and control; compassion and empathy; while the patients oscillate between: the voice of story-teller; social communicator;

complier; and apologizer (Babul-Hirji et al., 2010). Such different patterns were also described by Roter et al. (2006b) and included clinical teaching, psycho-educational teaching, supportive counselling and psychosocial counselling.

3.6 Nonverbal communication

As with verbal communication researchers have employed different methodologies to examine non-verbal behaviour. Nonverbal behaviour was measured by observing video recordings of nurse patient interactions (Caris-Verhallen, Kerkstra, & Bensing, 1999). The process involved clearly defining nonverbal behaviours and noting the duration and frequencies of these. Others also 'counted' the number of occurrences of non-verbal behaviours based on previously identified behaviours (Duggan & Parrott, 2001). For these purposes, instruments to measure nonverbal behaviours exist, i.e. the relational communication scales for observational measurement (RCS-O) (Gallagher, Hartung, Gerzina, Gregory, & Merolla, 2005) and nonverbal communication in doctor–elderly patient transactions (NDEPT) (Gorawara-Bhat, Cook, & Sachs, 2007). As with verbal communication, such methodology provides a good basis for unravelling non-verbal behaviour but it does not allow the details and associations between verbal and non-verbal features to emerge.

Examining non-verbal communication from a sociolinguistic perspective showed that, in particular, gaze and posture played a role in medical interactions (Heath, 1986, 2002; Robinson, 1998). During the opening sequence of a consultation, non-verbal communication encourages activities and signals when to move from one phase to another. During the preliminaries, the doctor and the patient prepare for 'the business at hand' by

assuming appropriate spatial and physical alignment (Heath, 1986; Robinson, 1998). Looking at or looking away from one another affects the interaction as the doctor can determine when the patient is ready to begin and withholds the start of business until the patient has sat down and assumed a 'face to face' orientation. The patient is often uncertain when the doctor is ready to begin, for example when s/he is still reading medical records, and sits waiting for the doctor to initiate talk.

The patients may display both availability and recipiency which allows the doctor the opportunity to begin the consultation. Showing such availability for the consultation to begin is what Heath (1986) calls a display of recipiency. Robinson (1998) also found that patients show their availability by directing towards the doctor their posture and gaze which is called a frame of dominant orientation by Robinson (2006). In his analysis, Heath (1986) found that the display of recipiency was associated closely with the doctor's speech. This display shows availability and an interest in receiving a response and gives the doctor the opportunity to respond with an action. By encouraging the doctor to begin the patient receives the floor to disclose why s/he is there. The close connection between the doctors' spoken words and the patients' display of recipiency, suggest that the first might elicit the other and as a result the patient gently pushes the doctor to the 'business at hand'.

Heath (1986) also found that a display of recipiency plays a role when the patient is responding to a request from the doctor. Patients were found to pause during speech in their turn until the doctor looked up at the patient from his notes (display of recipiency). This was found to take place as a pivotal three-action sequence. A pause is produced to encourage gaze realignment, then such realignment is followed by a new or continuation of speech. By encouraging the listener to realign gaze, the speaker shows that being looked at

is important, as it shows that the listener is attending to and receiving the speaker's activity. Therefore, it can be suggested that when the doctor reads the medical records, the patient perceives this as his/her attention being with the medical records and not with what the patient is saying. Robinson (1998) on the other hand, explains that when doctors read the medical records they engage with the 'patient in bureaucracy' and not the 'patient embodied' but that both imply being engaged with the patient. Engagement is when gaze and body orientation are focused on the patient or on medical records. He argued that the move from engaging with patient embodied during the greeting to the patient in bureaucracy is necessary in order to discuss the patient's reason for the visit.

Robinson's (1998) work showed that patients and doctors use gaze and body orientation to communicate engagement and disengagement with different activities and therefore with each other. They use different segments of the body (head, torso and lower body) to engage simultaneously with different activities and they use their lower body to indicate a dominant and longer term engagement (frame of dominant orientation). Non-verbal behaviours such as head nodding, smiling and gaze, were found to be related to effective communication and that task orientated communication was associated with instrumental touch and negatively related to head nodding, smiling and gaze (Caris-Verhallen et al., 1999). Physicians' use of facial reinforcers (nodding and animated facial expressions) during introductions was positively related to the patient sharing more about themselves and the difficulties of their illness (Duggan & Parrott, 2001).

Non-verbal communication is thought to be linked to a patient-centered medical interaction as it was shown that displaying attention to the patient by directing gaze and posture to the patient during critical moments of patient narratives meant that patients felt heard

(Ruusuvuori, 2001). As a result non verbal behaviour was also shown to result in higher patient satisfaction (Mast, 2007). However, the link between non-verbal behaviour and patient satisfaction is more complex than just gaze and posture as both physician and patient characteristics seemed to play a role.

3.7 Multicultural genetic counselling interactions

A major limitation in research on process studies is the deficit of studies in non-Western and multicultural and multilingual settings. There have been very few studies on the process in non-Western cultural settings. A study on women of Mexican-origin living in the USA revealed more miscommunications in the sessions (Browner et al., 2003) and it was found that women and the doctors in a prenatal setting had conflicting goals regarding the women's pregnancies (Hunt et al., 2005). Ellington et al. (2007) provide a description of pre- and post test breast cancer session of an African American family. Research in Hong Kong found that socio-cultural circumstances affected the genetic counselling process (Pilnick & Zayts, 2011; Zayts & Schnurr, 2011). In South Africa, information is available on the interactional dynamics of a single prenatal genetic counselling session (Tovell, 2004). Multicultural genetic counselling interactions are considered in more detail under intercultural communication in Chapter 4.

3.8 Summary

This chapter summarized findings from interactional research in genetic counselling and selective findings from the medical and counselling literature, in particular HIV

counselling. This review has allowed a glance into "The Black Box of Genetic counselling" (Biesecker & Peters, 2001, p. 195).

Some studies described the overall interaction in counselling sessions, whilst others examined one aspect in the finest detail. Different settings were investigated and the process was studied while being conducted by differently trained professionals. Certain aspects, particularly non-directiveness, have been over investigated, while other aspects such as negotiation of agendas and management of psychosocial talk have been under investigated, and most of the research has been conducted in Westernised settings.

Chapter 4 Intercultural Communication

Intercultural communication is defined here as the communication between individuals from diverse cultures and languages. As the genetic counselling interactions in the study take place in such a setting, these concepts needed to be considered.

This chapter explores culture mainly from a medical sociological and educational perspective with an emphasis on literature concerning cultural aspects in genetic counselling. As will be seen, this provides a background perspective, but examining intercultural interactions is a difficult task and requires careful consideration.

4.1 Defining culture

The concept of culture is complex and multidimensional; it is not a concrete entity but rather 'loosely shared mental categories' (Clarke, 1997). Wang (2001, p. 208) defined culture as follows:

"Broadly speaking, cultural systems connect people and groups who identify or associate with one another through common purposes, needs, or perceived similarities. Based upon explicit (e.g. tangible features such as clothing, food, festivals, and behaviours) and/or implicit information (e.g., intangible aspects such as conscious and unconscious values, assumptions, attitudes, beliefs and feelings) group identities (e.g., racial (phenotypic), socioeconomic status, religious reference groups, etc.) endured over time and space while varying in number, intensity, and resilience of belongingness, self-investment, and degree of group acceptance"

To expand further on this description of culture, common assumptions and agreements among sociologists are as follows (Gilbert, Selikow, & Walker, 2002):

- Culture is not individual but takes place in a social context
- The groups to which the term 'culture' applies vary greatly. There is, for example, 'Asian culture', as well as 'deaf culture' for people who have hearing impairments
- There is diversity amongst the individuals of one particular culture
- Culture defines what is acceptable in a particular community
- It distinguishes humans from animals and is linked to symbols and language
- It shapes behaviour and is closely linked to shared traditions, customs and beliefs
- It is a collection of non-physical traits, such as values, beliefs, attitudes, behaviours, customs, social and political institutions, arts, crafts, and science
- It varies from community to community and is a process that is not fixed but continuously changes
- We are not born with, but learn culture through a process of socialization or transmission from generation to generation
- Culture is viewed, by those who practice it, as normal or taken for granted, but may be seen as bizarre or strange by those from different cultures.
- Culture is a relative concept, and must be studied in terms of its own values and meanings

There are many different cultures in the world, each having its unique values, customs and beliefs but at the same time sharing some values with other cultures. People have different ways of viewing culture and five typologies have been distinguished: Universal, Ubiquitous, Traditional, Race-based, and Pan-National (Lewis, 2002; Wang, 2001). Cultures can also be grouped together and described in terms of a worldview or paradigm.

The Western worldview underpins the dominant biomedical approach in Western medicine which values individual autonomy and self-determination and believes that disease is caused by specific agents (Lewis, 2002). This worldview is only one way of representing and treating biological reality but because it is such a predominant paradigm, other ways of viewing the world are sometimes overlooked and this can be referred to as an Eurocentric approach. Other world views for example the traditional African worldview embraces a holistic and anthropocentric ontology where man forms an inseparable whole with the cosmos, and everything (including God, spirits, and nature) is seen in its relation to man (Van Dyk, 2001). Physical characteristics, behaviours and defects may be viewed in terms of religious, ethical or moral transgressions (Finkler, Skrzynia, & Evans, 2003; Finkler, 2005).

4.2 Culture in genetic counselling

As discussed in chapter two, genetic counselling practices are based in Western cultural and health philosophies and adhere to the principles associated with the biomedical model of disease causation (Lewis, 2002). Cultural worldviews that do not value the principle of autonomy and the importance of understanding the cause of disease are seen as different. The very 'idea' of genetics is rooted in Western medicine (Finkler, 2005). This cultural encapsulation (Lewis, 2002), or ethnocentrism, when discussed in relation to cultural psychology (Burman, 2007), results in other cultural worldviews being compared to western worldviews and viewed as having a disadvantage that needs to be overcome. The following quote from a reflection on a case study on 'an uneducated Spanish couple' illustrates this: "The broader lesson of this case study is that uneducated people of lower socioeconomic background most certainly can learn and benefit from genetic counseling

provided the level of discourse is tailored for their needs" (Applebaum & Firestein, 1983, p. 155).

The call to address cultural aspects in genetic counselling was made in the early 1990`s when Wang and Marsch (1992, p. 91) described how the ethno-cultural values held by Asians may work against the norms generally employed by geneticists and genetic counsellors in the USA. They said "….it is essential, therefore, that professionals offering genetic services acknowledge the impact of ethnicity and culture on the ethical principles generally utilized in such services if ethically and culturally appropriate services are to be delivered."

Greb (1998) and Weil (2000) summarized the myriad of ways in which other cultural beliefs may affect genetic counselling. The list below is a combination of the writings of the two authors.

- The relationship toward nature - How do individuals think about natural forces and events?
- Time orientation - What is important, planning for the future (future and goal orientated) or living in the present (past orientated), using every minute to do something or less concern for the passage of time?
- Family relationships - Who is regarded as family? What roles do they play? Who is regarded as 'sister'?
- Gender roles - What is the role of a man and a woman? Is the family matrilineal or patrilineal?
- Marriage - Does 'family well-being' take preference over individual needs? For example, are marriages arranged and/or consanguineous?

- Role of children - What is expected from boys and girls? What are the expected roles of the parent and the child?
- Bereavement - How do people deal with bereavement, birth, death etc?
- Rituals surrounding birth and death - Are there rituals? If so what are they?
- Religion and superstitions - What does their religion permit or not permit them to do and what rituals do they need to do?
- Health and illness - What are their explanations of body, mind and spirit?
- Concept of self - What is the patient's view? Is it individualistic (autonomy and achievement) or collectivist (honour or duty), or a combination of both?
- Non-verbal behaviour - Cultural practices may differ with regard to eye contact, facial expression, touch, proximity, giving and receiving information and gestures.
- Language - Ability to communicate in a common language promotes a sense of cultural identity and greatly facilitates the exchange of information, ideas and values. The absence of a common language creates a major barrier to communication.
- Socio-economic status - Differences in education, financial resources and security, occupational status, medical aid, and disability benefits affect worldviews.

The points highlighted by the authors are valid and may indeed affect the counselling session. However, care should be taken when ascribing difficulties in multicultural sessions due to the differences in cultures. As will be shown in the following sections, culture and multicultural interactions are complex and require more than such simplistic assessments.

4.3 Research regarding culture in genetic counselling

Research on culture in genetic counselling has focused on how other cultures differ from Western culture. This approach not only emphasises a focus on attributing a "cultural meaning" to aspects but also foster a Eurocentric approach. A large number of studies have been performed on how a selected cultural group in a specific area viewed a particular issue. There are studies on patients belonging to specific cultural groups, such as couples in the United Arab Emirates (UAE) (Al-Gazali, 2005), Bedouin and Jewish communities in Israel (Raz & Atar, 2003), orthodox Jews in America (Mittman, Bowie, & Maman, 2007), Somali immigrants to the USA (Greeson, Veach, & LeRoy, 2001), African American, Hispanic groups, and Whites in the USA (Browner & Preloran, 1999; Cohen, Fine, & Pergament, 1998; Gammon et al., 2011; Long, Thomas, Grubs, Gettig, & Krishnamurti, 2011; Saucier et al., 2005; Singer, Antonucci, & Hoewyk, 2004), Asian-Pacific and Latin American immigrants in San Francisco Bay (Mittman et al., 1998), African-Americans, Latinos, Israeli Muslims (Neter et al 2005), Palestinians and Palestinian Americans (Awwad et al 2008), Chinese Australians (Barlow-Stewart et al., 2006) and women with mental retardation (Finucane, 1998). Culturally diverse groups (Catz et al., 2005) have also been studied.

These studies aimed to assess the selected group's attitudes, values and beliefs, with the focus on examining principles important to the Westernized view of genetic counselling. In one study, only half of the couples in the United Arab Emirates acknowledged a genetic basis for their child's condition and only 10% remembered the risk given (Al-Gazali, 2005). Differences were observed when African-Americans, Latinos and non-Hispanic Whites were compared, and African-Americans were less knowledgeable and less concerned about genetic risks compared to the White samples (Akinleye et al., 2011).

Similarly Catz et al. (2005) found that knowledge about genetics and genetic testing is lower in Hispanic than in other patients. Differences in the utilization of genetic testing between African-Americans, Latinos and non-Hispanic Whites were found to be due to different preferences, values and beliefs, differential access (Singer et al., 2004) and the role Latinos' male partners played in the amniocentesis uptake rate (Browner & Preloran, 1999). Lower uptake of amniocentesis has been found amongst Hispanic patients compared to Caucasian, and African patients (Saucier et al., 2005) and some of the differences could be ascribed to lower socio-economic status and education level (Al-Gazali, 2005; Saucier et al., 2005). Whether acculturation can explain some of the differences in beliefs between members of the same culture further shows an ethnocentric approach in research on genetic counselling and culture (Awwad, Veach, Bartels, & LeRoy, 2007; Barragan, Ormond, Strecker, & Weil, 2011; Finucane, 1998). A study on Mexican women's health practices (accessing general practitioners) in USA showed that women could be separated into those who were more acculturated to Western American culture and those who were true to their Mexican culture (Barragan et al., 2011). Women who were more acculturated placed less value on their Mexican beliefs and traditions while the less acculturated women valued and practiced their beliefs more.

An ethnocentric approach is also evident in research regarding the impact of culture on genetic counselling. The challenges of developing education programmes on cancer genetics for African American women (Kendall et al., 2007) and Chinese American women (Sim, Zhou, Hom, Chen, & Sze, 2011) stem from the goal of educating these patients about concepts important according to the Western principles followed in genetic counselling. Similarly, the experiences and challenges of providing culturally appropriate genetic services are associated with this Eurocentric approach (Middleton, Robson,

Burnell, & Ahmed, 2007; Saleh, Barlow-Stewart, Meiser, Kirk, & Tucker, 2011), as is the assessment of the genetic counsellor supervisors perceptions of multicultural competence and the effect of these perspectives on their ability to evaluate genetic counselling students (Kyung Lee, McCarthy Veach, & LeRoy, 2009).

The reality is, however, that patients from different cultural groups do access Western genetic counselling services (Singer et al., 2004; Weil, 2001). In other medical practices, it was found that women valued and made use of Western medicine and that many accessed both traditional and Western services (Barragan et al., 2011). The challenges encountered when working with a diversity of patients forced genetic counselling professionals to undertake research so that the issues in intercultural encounters could be better understood. The studies undertaken have provided insights into: perceptions of disability (Greeson et al., 2001); causes of birth defects or genetic disorders (Cohen et al., 1998); perceptions of prenatal genetic counselling (Awwad et al., 2007); attitudes towards termination of pregnancy (Neter, Wolowelsky, & Borochowitz, 2005); perceptions of reproductive technology (Mittman et al., 2007); and the influence of religious and spiritual beliefs on amniocentesis decision-making (Seth et al., 2011).

While patients from other cultures appear to value genetic counselling services, there may be aspects preventing them from utilizing services (Butler et al., 2010; Catz et al., 2005; Singer et al., 2004). Western culture remains the dominant culture in many respects and therefore it holds economic, political and scientific power and has knowledge which puts patients from different cultures at a disadvantage (McInnes, 2011). "You know as well as we know that what is just is arrived at in human arguments only when the necessity on both sides is equal, and that the power-full exact what they can, while the weak yield what

they must." (Thucydides, Book V, as quoted by (Singh, Lele, & Martohardjono, 1988). In order to provide adequate genetic services, it is believed professionals need to do more than understand that there are cultural differences and aim to address how the sessions are approached from a cultural perspective.

4.4 Culture and South Africa

Many patients in the South African health care setting value collective thinking rather than individual thinking and have an external locus of control with a belief in fatalism (Hammond-Tooke, 1989; Kromberg & Jenkins, 1997; Penn & Watermeyer, 2012). The idea of Ubuntu 'a person is a person because of another person' is advocated in health care (Berg, 2003). This collective approach can be seen in practice when patients consult with family members regarding decisions to be made (Penn & Watermeyer, 2012).

There is evidence in the literature that some South African patients attribute disease to mystical causes, to not performing cultural rituals or by being involved in taboo practices, as such practices can anger the ancestors (Hammond-Tooke, 1989; Kromberg & Jenkins, 1997; Kromberg & Jenkins, 2012). Levy (1990, p. 187) from his post genetic counselling interviews found evidence for this when a patient stated: "I made a terrible fault by looking at 'police file' on TV and saw a lot of horrific things, this is what caused me to have such a baby." and "I still have to slaughter something and ask my forefathers if I can go for sterilization"

In some cases the cause of genetic disorders, as reported by a group of grandmothers was thought to be due to several factors. These included; lifestyle, such as wearing tight clothes during pregnancy; behaviour such as laughing at others; social problems such as domestic

abuse; not following cultural rituals; religious reasons such as punishment from God; something 'being wrong inside'; and/or the mother's age and the mixing of blood (Penn, Watermeyer, MacDonald, & Moabelo, 2009). Many caregivers of children with haemophilia were not sure or did not understand the cause of the condition (Solomon, Greenberg, Futter, Vivian, & Penn, 2012). They had different views of what they thought caused haemophilia and some said that not performing cultural rituals was the cause. These caregivers understood inheritance in terms of physical, behavioural and moral characteristics being passed down through generations and that the stronger characteristics in the parents would be passed to the child. In contrast they also thought that 'all things come from the mother's blood' and that the baby 'eats from her' (Solomon et al., 2012). Other causes mentioned were related to hormones being secreted from the father during intercourse, something the mother ate, or an injection given during pregnancy (Solomon et al., 2012)

Research has also provided some insight into other practices and beliefs which have an impact on genetic counselling. There are cultural practice and taboos regarding termination of pregnancy, infanticide, selection of partners, polygamy and polyandry (Kromberg & Jenkins, 1997). There are, for example, several beliefs about birth, miscarriage, and infant deaths, when a fetus is regarded as being alive and what is regarded as appropriate disposal of a fetus or stillborn infant (Jewkes & Wood, 1998). Such disposal depends on the status the fetus is awarded, and the stronger the ties with the community the more of a person they will be considered to be and the more a proper burial will be required. The birth of a child is very important for the clan, for the woman's status as an adult, and as a contact between the two families, since children are seen as helpers and they have the responsibility of taking care of their parents in their old age (Berg, 2003). It is very

important for the father of the baby to acknowledge paternity, but this does not necessarily mean marriage. Berg (2003) described the case of a mother who attempted to kill her baby due to the father not acknowledging paternity, and the professionals' lack of understanding of the issues involved. Strong indigenous cultural beliefs and knowledge regarding AIDS were found to still exist in rural Kwazulu Natal (Liddell, Barrett, & Bydawell, 2006), while infanticide was said by a group of grandmothers not to be widely practiced anymore, because the younger generation delivered their babies in hospital (Penn et al., 2009)

As diseases are thought by some individual to be caused by supernatural phenomena, different types of traditional healers are believed to be able to treat such ailments (Kale, 1995). Inyangas (herbalists) treat with herbs, while Isangomas (Diviners) can access and plead with the ancestors and Umthandazi (faith healers) treat by prayer and holy water (Kale, 1995). In 1995, it was found that 80% of the South African population consulted traditional healers (Kale, 1995). In Kwazulu Natal, one study showed that 70% consulted traditional healers as their first choice with sangomas being consulted the most (Puckree, Mkhize, Mgobhozi, & Lin, 2002) and another that 84% of HIV positive men had consulted with a traditional healer (mostly herbalists) in 2007 (Babb et al., 2007). Most South African patients however make dual use of both Western and traditional medicine (Berg, 2003; Kromberg & Jenkins, 1997; Penn et al., 2009; Solomon et al., 2012). The reasons are not fully understood and one study found that women valued Western care for delivery but not for pregnancy management (Myer & Harrison, 2003).

As South African has 11 official languages, language differences play a major role in the provision of genetic counselling services. For example, difficulties in language and terminology between Western English speaking doctors and Xhosa speaking patients led to

misunderstanding and compromised care in one paediatric setting (Levin, 2006). Communication difficulties due to language issues were reported by patients, nursing and medical staff and the professionals often felt helpless in their efforts to assist the patients (Deumert, 2010). Language differences can partially be overcome by the use of interpreters. However, making use of interpreters results in a host of other problems and it is extremely rare to have officially trained translators employed at health facilities. As a result, translating occurs ad hoc and falls onto untrained personnel, mostly nursing and other staff (Penn & Watermeyer, 2012; Penn, 2007), but also fellow patients, cleaners or car guards assist with translation as we have experienced in our clinics. A further difficulty is that the words used in genetic counselling are unfamiliar for the translator as there are no words for DNA, genes, chromosomes, genome, genetic predisposition or Down syndrome in the local African languages (Kromberg & Jenkins, 1997; Penn et al., 2009; Solomon et al., 2012). There are also no words for genetic disorders in general and genetic disorders were described as such as 'God's creature' or 'family child' or 'disabled child' or 'cripple', by a local group of grandmothers (Penn et al., 2009).

How this array of factors influence the genetic counselling interaction in South Africa is not well understood and most of what is known is from an analysis of one prenatal genetic counselling session with a woman who had a previous abnormal baby (anencephaly) (Penn & Watermeyer, 2012; Tovell, 2004). Cultural issues were not found to be explicitly discussed during this single session, but they seemed to frame some of the discussions especially during history taking. Although there seemed to have been an understanding of cultural factors, the counsellor did not address or explore these further in the session. Discussions about termination of pregnancy and a blood test, though sensitive, also did not explore the cultural connotations these might have not did the woman introduce any

cultural connotation. Defining an issue as 'cultural' and therefore worthy of exploration is difficult because of the complex nature of culture. Further, the researcher believes this approach does not contribute to multicultural counselling as it categorizes people due to their differences.

4.5 Culturally appropriate genetic counselling

With the available information the challenge is to find ways in which professionals can be more culturally competent in providing genetic counselling to patients from diverse cultures. Wang and Marsh (1992) in the 90's called for professionals to acknowledge the impact of ethnicity and culture in genetic counselling. They found shortcomings in sessions with patients of Asian culture in terms of autonomy, informed consent and non-directiveness.

The training of professionals in cultural competence has received much attention and it was said that training should not only include knowledge of relevant ethno-cultural groups, but also encourage self-awareness and understanding of the professionals own ethno-cultural views, and an understanding of institutional and social barriers (Weil 2001). The need for professionals to become culturally competent led to the development of "The Handbook of Cross-Cultural Genetic Counseling" (Wang 1994), as well as the outlining of a number of skills and techniques which would help develop multicultural competence (Oosterwal, 2009; Wang, 2001; Weil & Mittman, 1993; Weil, 2001). A website (http://www.geneticcounselingtoolkit.co) dedicated to multicultural genetic counselling was also developed. The underlying assumption of the *Handbook of Cross-Cultural Genetic Counseling* was that counsellors understood themselves and could use this knowledge as an essential counselling tool. In order to become multiculturally competent

self-awareness and an understanding of one's own cultural code, together with an attitude of humility and appreciation of the diversity of patients and the ability to use the patient's cultural codes as a resource, was thought to be crucial. An understanding of racial-cultural group dynamics, various cultures and counselling skills, how to establish and maintain trust, how to pay attention to a patient's mistrust and their decision-making process, how to use the non-directive approach and when, and the use of translators, were also found to be important (Oosterwal, 2009; Wang, 2001; Weil & Mittman, 1993; Weil, 2001).

Wang (1998) evaluated a multicultural education curriculum for effectiveness in increasing cultural competence using the Multicultural Awareness-Knowledge-and-Skills Survey. He found the handbook of cross-cultural genetic counselling to be effective in enhancing measured multicultural competence. An important finding, was that the complexities of practicing multiculturally were not always addressed and the students in the study reported that "their clients did not reflect the information the student had read in the literature" (Wang, 1998, p. 105). As a result, the students were frustrated when trying to apply what they had learned. Students viewed the aspects regarding knowledge and awareness in the Handbook as very interesting intellectually, but not necessarily practical or relevant to genetic counselling. A contributing factor to the difficulties of putting theoretical principles into practice may be the lack of clarity in the definitions of 'ethno-cultural groups' which are often defined only in terms of country, heritage and geographical location and then cultural counselling is addressed only from this perspective (Wang, 2001; Weil, 2001). A culturally encapsulated perspective may also be one of the possible contributors as may, a lack of understanding of all the issues involved in multicultural genetic counselling practices (Browner et al., 2003).

A change in perspective with regard to cultural issues from cross-cultural to multicultural practices, highlighted some of the issues regarding practical implementation (Wang, 2001). In cross-cultural practice, the emphasis is on culture specific group information, while in multicultural practice the emphasis is on recognizing that intellectual understanding of visible racial-cultural groups does not necessarily translate into adequate multicultural competence. A cross-cultural practice works from a culturally encapsulated perspective (Lewis, 2002). Working in a multicultural context, the emphasis is not on only identifying differences between different cultures (cross-cultural approach), but by using an approach which reflects sensitivity to cultural influences (multicultural approach), thereby recognizing that culture is a fundamental part of the individual (Penn, 2002). Middleton et al. (2005) also state that learning about other cultures (cross-cultural approach) might be impractical and not the only way to become culturally competent. They state that it is more useful to be aware of what types of questions to ask and to be aware that there are differences between people (multicultural approach). "In order to dislodge the misunderstandings of their clients, counselors must give clients the opportunity to air their own views, however contrary to those of genetics professionals these may be" (Browner et al., 2003, p. 1933).

In this overview it was argued that the focus of research to ascertain differences between groups in order to provide culturally appropriate genetic counselling does not capture the complexities of cultural influences during interactions. Instead, as Browner et al. (2003) suggested, concentrating on the person and their views irrespective of their culture might be more valuable. Interactional multicultural studies need to focus on what occurs during the interactions and be careful not to ascribe cultural meanings to concepts and interactions without sufficient evidence.

4.6 Research examining interactions

Studies examining multicultural genetic counselling interactions are few. One study examined intercultural discourse from a perspective of identifying miscommunication (Browner et al., 2003). In the sessions of prenatal genetic counselling for a positive maternal screen, in Mexican-origin women, areas of miscommunication were shown to be caused by: the professional's use of medical jargon; the professional's adherence to non-directiveness; inhibitions of the professionals due to a lack of cultural sensitivity; difficulties relating to translation; and problems regarding trust. The authors also found that many women did not explain their own theories or ideas about the causes of genetic conditions and were sceptical of genetic testing. Similarly, in earlier work, Rapp (1988), who analysed observer field notes of antenatal sessions in women of Latina origin, also found miscommunication.

The emphasis on differences between cultures is evident from other studies and although the interactions were not approached from a miscommunication perspective, these studies also hint at misunderstandings. In one study on antenatal sessions with women of Latino origin, the women were most concerned about the health of their baby and rarely engaged with the clinical and risk constructs presented to them, while the professionals focused on communicating clinical information without regard for the women's lived experiences (Hunt et al., 2005). Roberts et al (2005) argued for intercultural communication to be approached from a different perspective. According to these authors, the patient and practitioner talked themselves into an intercultural encounter and miscommunication was due to language issues i.e. pronunciation, word stress, intonation, speech delivery, grammar, vocabulary, lack of contextual information and style of presentation. Similarly,

Piller (2007) found that linguistic misunderstandings are often mistaken for cultural misunderstandings. Piller (2007, p. 221) states "The key question of Intercultural Communication must shift from reified and inescapable notions of cultural difference to a focus on discourses where 'culture' is actually made relevant and used as a communicative resource".

It is however, difficult to examine intercultural interactions, and studies approached from a descriptive point of view need to be carefully designed. Unique findings did not seem to emerge from Ellington et al (2007) research on African-American women at risk for breast cancer. They found that the women in both pre- and post- test sessions contributed to 40% of the conversation and that there were differences between pre- and post-sessions and in discussions between sessions when the women had a positive or a negative result. These results were found to be very similar to the research findings in cancer genetics session where the patients and professionals were from the same culture (Ellington et al., 2005; Ellington et al., 2006; Lobb et al., 2004; Pieterse et al., 2005). In one non-Western setting, Hong Kong, it was found that the interactions were influenced by patients' socio-economic circumstances and that these were drawn on to help patients make decisions (Pilnick & Zayts, 2011). The providers further developed specific strategies in their attempts to adhere to non-directiveness (Zayts & Schnurr, 2011). The reason for the differences between the studies discussed above, could be due to the methods used. Ellington et al. (2005, 2006) evaluated their sessions by making use of the RIAS scoring system to code sessions while Pilnick and Zayts (2011) used socio-linguistic methods to analyse their data. Methodology plays an important role in evaluating intercultural discourses and as Piller (2007, p. 221) states "Methodology and the philosophical approach to interactional multicultural research need careful attention in order to examine and understand the intricacies involved in these

encounters". As argued by Koole and ten Thije (2001), intercultural communication should be analysed in the same way as other interactions and the emphasis should be on the common ground created by the participants. Phenomena can only be ascribed to 'culture' if the participants make it relevant.

4.7 Summary

This chapter is a summary of the relevant literature on intercultural communication. The researcher attempted to define culture and presented an overview of cultural beliefs in South Africa. Studies regarding genetic counselling practice for people from different cultures started to appear in the early 90's and the chapter describes the Eurocentric approach in these investigations. A distinction was made between cross-cultural and multicultural approaches and it was shown how the latter approach appreciates the person rather than the culture to which the person belongs. The relevance of research findings regarding incorporating culturally sensitive practices into genetic counselling was discussed. Finally the difficulties in examining intercultural encounters were highlighted.

Chapter 5 Methodology

This chapter will describe the methodology employed in performing the present study. It contains a description of the setting, details of the sample and the ethical considerations. In addition, the theoretical framework that informed the research design and data analysis process will be outlined.

There is some research available in the field of genetic counselling to draw on when considering applying concepts in practice. However, as discussed in the introduction and literature chapters of the thesis, emphasis has been on patient perceptions and theoretical concepts, leaving the area of interactional studies under investigated. The understanding of the process of genetic counselling therefore remains limited, with even less being understood about multicultural interactions.

It is was therefore anticipated that research into the process of genetic counselling in the South African context, utilizing qualitative methodology, would make a significant contribution to the existing research in this area.

5.1 Study aims and objectives

When this research project was conceptualised, as mentioned in chapter one, the researcher was questioning the effectiveness of the genetic counselling services offered to women in state hospital services as the uptake of prenatal genetic diagnosis appeared to be low. The researcher's initial assumptions were that the women in the state hospitals have different attitudes and beliefs concerning childbearing, having a child with abnormalities, prenatal

diagnosis and termination of pregnancy. From these initial ideas, the researcher became more interested in what occurred in these prenatal genetic counselling interactions. As a result, the following research question was formulated:

> *What are the structural, interactional and analytic features of the multicultural antenatal genetic counselling sessions conducted by genetic counsellors from one unit?*

The study objective, therefore, was to investigate the genetic counselling process in multicultural encounters in prenatal genetic diagnosis sessions in antenatal clinics situated in tertiary state hospitals in Johannesburg. Specifically the aims were to describe and explain:

a. The genetic counselling process in these sessions.
b. The characteristics of the interactions between genetic counsellors and patients.
c. The features of the verbal and non-verbal interactions.
d. Some of the phenomena encountered during the interactions.

5.2 Research design

5.2.1 Qualitative approach

A qualitative research approach was selected for the study as with such an approach, meaning, experience and understanding can be investigated, resulting in rich, thick descriptions of the studied phenomena (Mouton & Marais, 1996). In qualitative research

the phenomenon is studied 'from the inside', whether it is the view of participants or the nature of the interactions (Flick, 2002).

The suitability of qualitative methods for research in the field of genetic counselling has been discussed in detail in the previous chapters. Beeson (1997) highlighted the value of such research and felt that genetic counsellors were in a strong position to make good use of qualitative methods: "You are the link between very different social worlds; you move back and forth between the sharply focused work of molecular genetics and the complex and highly emotional social worlds of the families of your counselees" (Beeson, 1997, p. 25).

Biesecker and Peters (2001, p. 195) compared the process of genetic counselling with a 'black box' stating that we are only beginning to get a 'glimpse' of its contents. They advocated that carefully designed process studies can shed light on the components of the sessions, the communication patterns and interventions used. It was shown that process studies have elucidated several aspects of genetic counselling interactions, such as non-directiveness and decision-making (Sarangi et al., 2004) and how counsellors take on different 'voices' in the session (Babul-Hirji et al., 2010).

Further motivation to employ a qualitative approach was based on the success of a study which examined a genetic counselling interaction in an intercultural setting in Johannesburg (Penn & Watermeyer, 2012; Tovell, 2004). This study was based on a single genetic counselling session and used conversation and thematic content analysis to explore the characteristics of the interaction. The methods proved effective in revealing several significant communication characteristics and the dynamics of the session. This

research was conducted through the health communication project (HCP) based in the School of Human and Community Development of the University of the Witwatersrand. The HCP has performed research in several areas of health interactions and has identified communication as the most common difficulty encountered by health care professionals in the multicultural setting of South Africa. The HCP mainly draws on qualitative research methods as a means of data collection and analysis, to examine health care interactions, and the unique challenges of these interactions have been found to be amenable to these approaches.

5.2.2 The design

The researcher opted to use more than one method to collect the data. Collecting data from more than one source has been successfully undertaken in the South African context, by the projects conducted through the HCP. In addition, approaching the phenomenon from more than one angle allows for richer more trustworthy descriptions and a better understanding of the phenomenon under investigation (Creswell, 2009; Silverman, 2004), as multiple methods of analysing data allows the different realities of doctors, patients and researchers to be brought together (Barry, 2002). Interpreting and cross-checking the data in different ways adds to the validity of the study.

The data utilized in this study included:

- recording of genetic counselling sessions:

  The genetic counselling sessions were video- and voice-recorded.

- semi-structured interviews:

A set of guiding questions were used to conduct interviews with the patient and genetic counsellor participants separately after the genetic counselling sessions

- ethnographic observations:

  Ethnographic approaches were used to describe the setting of the research. The researcher made use of observation methods and written field notes to describe the physical setting and 'culture' of the antenatal clinics where the research was carried out. The descriptions provided a context within which the results of the genetic counselling interactions and the post counselling interviews could be understood.

The analytical framework was developed by engaging with the literature, data analysis sessions and discussions with the project supervisor, researchers in the health communication field and discourse analysts. Data analysis involved transcribing, translating (where necessary) and analysing the recorded material. Reading, watching and listening to the recordings allowed for ideas and themes to be developed based on the theoretical framework. Transcriptions of the genetic counselling sessions and interviews commenced soon after the first interview and continued throughout the data collection period. Several months after data collection was completed, the checking and editing of the transcripts continued.

The first phase of analysis involved obtaining a gestalt of the nature of the genetic counselling sessions. This led to describing the overall structure of the session which then allowed for the identification of specific aspects for further analysis.

In the initial planning of the project, the interview data were to be used to verify the findings from the analysis of the sessions. However, the interview data yielded poor

results and it was not possible to analyse these in detail. Though the data had limited use, some of the comments made by the genetic counsellors were included in the results as a (very limited) way of strengthening some arguments. In the interviews the counsellors commented on their perspectives and when these emerged in the sessions, it was included in the discussions.

The quality of interview data is dependent on the facilitator's skills and experience in probing and facilitating discussions during the interview process. However, the poor data yielded in the interviews with the women in the study is thought to be linked to other factors. The experience of researchers in the HCP is that patients in the setting are generally not forthcoming in one on one discussions and that focus group discussions yield richer data. Further, from the individual interviews in which the patients were asked to comment on the service they received, it was found that they only made positive comments about the professionals and the service. In addition they generally appeared passive in their post-session interactions, a feature that was confirmed during data analysis as will be shown in the result chapters.

5.3 The setting

The research was performed at two large tertiary level hospitals in Johannesburg: Rahima Moosa Mother and Child Hospital (RMMCH) (previously known as Coronation Mother and Child Hospital) and Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) (previously known as Johannesburg Hospital).

The two hospitals were the sites where the Division of Human Genetics holds prenatal genetic diagnosis counselling clinics. The staff of the Division run weekly genetic counselling clinics at these (and other) hospitals. By the time data collection started, the prenatal diagnostic genetic counselling clinic at Chris Hani Baragwanath Hospital was no longer operating efficiently and as a result, this site could not be included. All but two data sets were collected at RMMCH. This hospital maintains a well organized, comprehensive antenatal service and as a result, eligible patients were consistently available over the data collection period. The service at CMJAH is less structured and as a result patient referrals to this service was erratic resulting in only two sessions being recorded at that clinic.

5.3.1 Rahima Moosa Mother and Child Hospital (RMMCH)

RMMCH is situated in a suburb (Coronationville) in Western Johannesburg. It is a state (public) hospital that provides paediatric and antenatal services mainly to patients from the surrounding areas of Coronationville and Lenasia. As with other state hospitals, patients are from the lower socio-economic groups who do not have access to private health care. It has both inpatient and specialist clinics and treats between 25 000 and 30 000 patients a year. Although the hospital offers a consistent and comprehensive service to mothers and children, similar to the state health system in general in South Africa (discussed in chapter 4) the hospital is plagued by a number of challenges which includes financial difficulties and shortage of beds, facilities and staff.

The Division of Human Genetics has a weekly genetic counselling clinic at RMMCH. The genetic counselling clinic is situated in the Specialist Clinic which, at the time of data collection was staffed by three nurses and one administrative assistant. The cardiologists

and the geneticists share the rooms in the clinic. It has a waiting area, a total of seven consulting rooms, an administration/tea/weighing room and the nurses' station is in the passage. The patient files are kept at the clinic in cabinets in the consulting rooms.

The genetics staff see prenatal as well as paediatric cases. The patients are required to be at the clinic at 7am on the day of the appointment and numbers are assigned in the order in which they arrive. While waiting for their names to be called, patients can watch television. The women, their children and other family members and friends sit in the waiting room. The clinic administrative staff make bookings, arrange follow-up appointments and other referrals, file patient records and are responsible for the general running of the clinics. A list of names of the booked patients for the genetics clinic is faxed through to the Division of Human Genetics the day before the clinic.

The genetic staff allocated to the clinic include two medical geneticists and two genetic counsellors. In addition genetic counselling students, medical genetics registrars and undergraduate medical students (sixth year) of the University of the Witwatersrand attend the clinic and observe cases. The medical geneticist in charge of the clinic assigns cases to counsellors and clinicians, who start seeing patients as soon as the formalities are completed.

The genetic counselling sessions usually take about one hour but can range from 45 to 90 minutes. Once cases are assigned, counsellors take their patient files and other written documentation and study the notes. The counsellors and doctors usually go to the waiting room and call the patient; greet them outside and invite them into the

counselling/consulting room for the session. At the end of the session they walk with the patients to the nurses' station to arrange follow-up appointments and/or other referrals.

5.3.2 Charlotte Maxeke Johannesburg Academic Hospital (CMJAH)

CMJAH is situated in Parktown, in Northern Johannesburg. It is a state (public) hospital, with 1088 beds, which services patients mostly from Gauteng province but also neighbouring provinces. As with RMMCH, patients accessing the service are generally from lower socio-economic groups who cannot afford private health care services. The hospital offers both in-patient and specialist out-patient services and serves as a referral hospitals for other hospitals in the region. It is the main teaching hospital of the University of the Witwatersrand and the University medical school is located in the hospital. Though CMJAH is a tertiary hospital that provides specialist services in all areas of medicine the hospital has the same staffing, financial and management challenges, as other state health services in South Africa.

The Division of Human Genetics has several genetic clinics at the hospital, including a weekly prenatal diagnosis clinic, which is held on the day that a fetal medicine specialist is available at the clinic. During the time of data collection the clinic had moved to a temporary location due to renovations. The area consisted of a large open space which was used as a waiting area. There were three rooms, one room led into two other rooms, available for consulting patients. The two inside rooms were used by HIV counsellors and genetic staff had access to the outside room. The inside rooms could only be used if they were not being used by the HIV counsellors. Thus the genetic counsellors had many interruptions as various patients and staff passed through.

At the time of data collection, there were two sonographers who performed the routine ultrasound evaluations, one antenatal nursing sister and three fetal medicine clinicians who worked on different days. The nursing sister co-coordinated the bookings for the sonographers, the fetal medicine clinicians and genetic counselling clinic. The number of patients referred varied a great deal as the hospital did not consistently provide a comprehensive antenatal service and the fetal medicine experts were not always available. This resulted in only two sessions being recorded at CMJAH.

At the time the genetic counselling clinic was staffed by two genetic counsellors, students and registrars. The counsellor in charge of the clinic phones for the patient list or sometimes the nursing sister phones to inform the counsellor in charge of cases booked for the day. Similar to the procedures at RMMCH, patients, once they arrive at the clinic, report to the nurses' station and the nurse collects their antenatal cards and hospital file. The counsellors arrange the necessary documents in their consulting room and then call the patient for the session.

5.3.3 Patient referral procedure

The women seen for prenatal genetic counselling at the two clinics described above were referred by medical practitioners, fetal medicine specialists, nursing staff and/or sonographers at the antenatal and ultrasound clinics of the hospital. There were also referrals from nursing staff at the surrounding feeder clinics of the respective hospitals and private medical practitioners. Women were referred for genetic counselling if they were at an increased risk of having a baby with an abnormality, and/or:

- Were of advanced maternal age (over 35 years of age),
- Had abnormal ultrasound findings (fetal abnormalities or markers) or
- Had a significant family history (previous abnormal child or genetic condition in the family).

In the state service, any woman who is over 35 years of age or who has a history of a genetic disorder is referred for genetic counselling. These referrals are usually made by the nursing staff and medical practitioners in the antenatal clinics. Women who are less than 22 weeks pregnant at the time they book for antenatal care receive a prenatal ultrasound evaluation by the sonographers. Women found to have fetal abnormalities or markers are referred to the fetal medicine specialists who, after assessment, refer them for genetic counselling.

5.4 The participants

5.4.1 Patient participants

The patient participants were women referred for genetic counselling. All but two of them were South African citizens from the Black African population group. One woman was from the Democratic Republic of the Congo and her first language was Ibo and one was South African of mixed ancestry who spoke Afrikaans. All the women could speak English, and were from lower socio-economic groups. There were 17 women who participated in the study, but one was accompanied by her partner.

Table 5.1. *Summary of the characteristics of the 17 patient participants*

Session	Pseudonym #	YOB	First language	Marital Status	Employment	Education	Child	Pregnancy	Gest	Amnio
P01	Mary	1968	Sotho	Married	Unemployed	Gr 12	1	Unplanned	21w	No
P02	Dineo	1969	No Info	Married	Employed	No info	1	Unplanned	16w	No
P03	Ursula	1967	Tswana	Traditional	Unemployed	Gr 10	2	Unplanned	17w	No
01	Nompilo	1969	Zulu	Single	Employed	Gr 12	1	Planned	23w	No
02	Christinah	1972	Tswana	Single	Unemployed	Gr 12	2	Unplanned	22w	Yes[@]
05	Thembi	1973	Sotho	Married	Employed	Gr 7	1	Planned	23w	No
06	Johanna	1972	Afrikaans	Single	Unemployed	Gr 10	3	Unplanned	32w	Not offered
07	Phumla	1972	Ibo	Married	Employed	Tech	2	Planned	22w	Yes*
08	Rosie	1965	Xhosa	Married	Employed	Gr 11	3	Unplanned	12w	No
09	Lerato	1970	Zulu	Single	Employed	Gr 8	3	Planned	20w	Yes*
10	Ayanda	1968	Xhosa	Married	Employed	Gr 10	3	Planned	16w	No[$]
11	Nonhlanhla	1972	Tswana	Single	Employed	Gr 12	0	Planned	18w	Yes[@]
12	Bethinah	1968	Zulu	Married	Self employed	Gr 9	4	Unplanned	28 w	Not offered
13	Cynthia	1966	Xhosa	Traditional	Unemployed	Gr 12	1	Planned	16 w	No
14	Harriet	1969	No Info	Single	Employed	No Info	3	Planned	15 w	No
15	Bongumusa	1969	Sotho	Divorced	Unemployed	Form3 (Gr 10)	4	Unplanned	20 w	Undecided
16	Wilhelminah	1969	No Info	Single	Employed	No Info	1	Unplanned	26 w	Not offered

The women were given pseudonyms to protect their identities
* Initially requested an amniocentesis but did not have the test
$ Had an infant with Down Syndrome – passed away
@ Amniocentesis outcome: Christinah normal boy and Nonhlanhla a normal girl

In the post session interviews, the women were asked about their ages, first language, marital and employment status, level of education and number of children. The researcher used the information from the sessions as well as the patient files to obtain information as to whether the women elected to have an amniocentesis performed and if available, the outcome of the pregnancy. The information included is typical of the information obtained in a genetic counselling session (Harper 2010). Table 5.1 is a summary of the characteristics of the 17 patient participants.

5.4.2 Genetic counsellor participants

The counsellor participants were the genetic counsellors of the Division of Human Genetics of the NHLS and the University of the Witwatersrand allocated to the clinics.

Six genetic counsellors conducted the genetic counselling sessions. Each counsellor conducted between two and four sessions. The counsellors were referred to as counsellor A, B, C, D, E and F respectively and pseudonyms were given to each to protect their identities. The researcher purposely did not provide a detailed table which linked the counsellors with their individual demographic information as this would compromise their confidentiality. The counsellors were all white females conversant in English, but some also spoke Afrikaans. At the time of data collection they were between 25 and 51 years of age and they had between one and 20 years experience in genetic counselling. Counsellors A, B and C were inexperienced (Inexp) while counsellors D, E and F had more than 5 years experience (Exp).

Counsellor A – Sharon

Counsellor B – Bronwyn

Counsellor D – Jacquie

Counsellor E – Natasha

Counsellor C – Trisha Counsellor F – Charlene

Most of the counsellors had completed their Masters degree in genetic counselling through the Division of Human Genetics of the University of the Witwatersrand and had completed an internship or were in their first post graduate year as interns. One genetic counsellor completed her degree at another university, but had done an internship in the department. Another counsellor had a nursing background and had worked in the field of genetic counselling in the Division of Human Genetics for more than 20 years. All the counsellors were therefore familiar with the model of genetic counselling promoted in the Division (described in Chapter 2).

5.4.3 Genetic counselling sessions

Although women with different indications for genetic counselling were eligible to participate in the research, in all but one, the indication was advanced maternal age (AMA 35 years of age or older). In the one case, the woman had a previous infant with an unconfirmed abnormality. Also in another session an interpreter was used as the woman could not speak English. Both these sessions were excluded. In addition there were three sessions recorded as part of the pilot study during the time of developing the question guides. These three sessions were included in the final study as they met the inclusion criteria (p.110). The three sessions were numbered P01, P02 and P03 (P refer to "pilot").

5.5 Data collection procedure

Data collection involved the provision of information sheets, obtaining informed consent (from the patients and the counsellor), conducting and recording the genetic counselling

sessions, conducting and recording the post-session interviews, ethnographic observations of the setting, and maintaining self reflection (researcher). The researcher had assistants to help with obtaining informed consent, conducting the post-session interviews and doing the transcriptions and translations.

5.5.1 Research assistants

The researcher is the genetic counselling manager (and genetic counsellor by profession) of the Division of Human Genetics and speaks English and Afrikaans only. Due to concerns about coercion of subordinate staff, it was not advisable for the researcher to conduct the counsellor participant post-session interviews. The researcher also did not perform the patient post-session interviews, as the researcher could not communicate with the patient participants in their first language (with the exception of one woman). Three research interviewers were therefore employed to assist.

The Division of Human Genetics had a Medical Research Council (MRC) Community Genetics researcher seconded to the unit. She was a professional nurse by training and had research experience. Her first language is IsiZulu but she is also fluent in Sepedi and Setswana (languages used by the majority of the local population). The MRC researcher's role was to approach the women in the clinics to request their participation in the research, obtain informed consent, conduct the post-session patient interviews and assist with transcription and translation.

Two experienced genetic counsellors who were trained by and worked in the Division of Human Genetics were employed to do the counsellor participant post-session interviews.

They were selected to assist with the research as they were experienced in interviewing skills, had an understanding of the setting and the process of genetic counselling and were not employed by the Division of Human Genetics at the time the research was conducted.

The researcher also had four other assistants, a psychology student, a genetic counsellor and two typists, who helped with transcription, translation and editing. The psychology student was in her final year of study and was a Sepedi speaker conversant in isiZulu and Setswana. She transcribed and translated the post-session patient participants' interviews. The psychology student, genetic counsellor and one of the typists assisted with transcription of the genetic counselling sessions. The second typist assisted with formatting the typed transcriptions in MS Word. The use of research assistants particularly in transcribing is discussed in more detail on p.117.

5.5.2 Procedure

Informed consent forms were designed for the patient (Appendix A) and counsellor participants (Appendix B). The MRC research assistant obtained informed consent from them to participate in the research, in their home language.

Selection depended on the patients' suitability and willingness to participate. The number of women booked on any counselling day varied greatly, from no patients to around six patients.

Upon arrival at the respective clinics, the researcher or genetic counsellor/s at the clinic identified women who met the eligibility criteria for participation. Each woman was then

approached by the MRC community genetics researcher and was taken into one of the rooms where the research was explained and consent (or refusal) was obtained without the researcher or the genetic counsellor/s being present. The patient participants received an information sheet (see Appendix C) to keep and the consent form was completed. The consent form made provision for the collected information to be used only for research or for teaching and training purposes. Concurrently, the researcher or genetic counsellor/s set up the recording equipment in the genetic counsellor's room. If consent was obtained, the counsellor took the patient into the counselling room to initiate the session.

The eligibility criteria for inclusion in the study were as follows:

- Women, over 35 years of age who were pregnant and had an increased risk of having an infant with a chromosomal abnormality.
- Pregnant women who had an increased risk of having a baby with a chromosomal abnormality as a result of a screening test, or an abnormal NT in the fetus in the first trimester or a positive Down syndrome screen in the second trimester.
- Pregnant women who had had three or more miscarriages in the first three months of pregnancy
- Pregnant women who had been exposed to drugs, medications, alcohol or infections during pregnancy
- Pregnant women who had had a child with, or a family history of a genetic disorder e.g. Down syndrome, haemophilia, albinism, cystic fibrosis
- Pregnant women who had had a child with or a family history of a birth defect e.g. neural tube defects, cleft lip and palate, clubfoot, congenital heart disease

Women who had a fetal abnormality or markers detected on ultrasound were excluded because of the acute emotional reactions associated with hearing the unexpected news that their baby had an abnormality. The researcher believed that it would have been unethical to burden a woman with a research project at the time of such grief.

5.5.3 Recordings (Sessions)

Once informed consent was obtained and the participants agreed to take part in the research, their genetic counselling session was video and voice recorded. The researcher (or, in some instances, the genetic counsellors) assisted with setting up the recording equipment. The sessions were recorded using both video (Sony Handycam DCR SR45E) and audio (Sony ICD-SX56) recorders. The sound quality of the audio recording was better than the video recordings and was used to check unclear sounds from the video recordings. The genetic counsellor participants operated the equipment themselves and started and ended the recordings.

In total, 19 genetic counselling sessions were recorded (three during the piloting process P01,P02,P03)). Two sessions were excluded (reasons explained in previous section) and therefore, the final data set consisted of 17 genetic counselling interactions (sessions). The total recording time was 14 hours, 54 minutes and 38 seconds.

5.5.4 Interviews (post-session)

After the genetic counselling sessions, post-counselling interviews were conducted with the patient and genetic counsellor participant separately using question guides (Appendix

E, F). In the majority of cases, the interviews with both patient and counsellor participants took place at the clinic after the genetic counselling sessions. However, if the genetic counsellor had to see other patients, her interview was conducted later in the Division of Human Genetics.

Of the 19 recorded sessions where post-session interviews could be conducted with the patient participants, only 12 post-counselling patient participant interviews were included. One patient participant left the clinic before she could be interviewed, in another case there was a problem with the recording and the data were lost, for the three pilot sessions the interviews were not included as the researcher was still developing the question guides and two further sessions (the mediated session and the session where the indication for the referral was not AMA) were excluded.

In the case of the post-counselling interviews with genetic counsellor participants, 14 interviews were included. Of the 19 sessions, two sessions were excluded (mediated session and session where the referral was not AMA) and no counsellor participant interviews were conducted after the three pilot study sessions.

Complete data sets for the study, which included a video recorded genetic counselling session, an audio recorded patient participant interview and an audio recorded genetic counsellor participant interview therefore totalled 12.

5.5.5 Ethnographic observations

The researcher used her observations made from working as a genetic counsellor in the clinics, as well as being present in the clinics during data collection and when working as

a genetic counsellor to write the description of the research setting. Members of staff from the Division of Human Genetics and the respective hospitals were also consulted regarding hospital procedures. An ethnographic description of the waiting room of the RMMCH can be found in Appendix G.

5.5.6 Self-reflection

Self-reflection occurred throughout the research and I kept notes of my own ideas and beliefs about what I had observed or heard. In addition, discussions with the research supervisor, mentor and other colleagues provided opportunities for challenging preconceived ideas. I presented preliminary data from the study at conferences and received valuable comments from the audience which further challenged and shaped research ideas. I continued to practice as a genetic counsellor throughout the project, and was constantly aware of the effect the two activities, the practising of and analysing the practice of genetic counselling, had on each other.

5.6 Pilot study

The methods to be used in the study were tested before data collection commenced. It was particularly important in developing the question guides which would be used in the patient and counsellor participant interviews.

Two question guides were developed, one for the patient participants and one for genetic counsellor participants. The researcher constructed the question guides by considering the objectives of the project and consulting with the supervisor. The question guides were

used to perform pilot interviews with one counsellor and two patient participants. The researcher and the MRC research assistant conducted the interviews. These interviews were recorded and the researcher, her supervisor and a colleague (experienced in the genetic counselling field) amended the question guides.

The interviewers, MRC research nurse and two genetic counsellors, received training from the researcher on the use of the question guides before the first interviews. The researcher and the interviewers listened to the recording of the first interviews together and discussed whether the questions asked and the interview process met the aims and objectives of the project, and further changes were subsequently made. The final versions of the semi-structured interview schedules appear in Appendix C and D.

Two short demographic questionnaires were developed, and aimed at collecting information typically relevant in genetic counselling. For the patient participants, the information required included: date of birth, ethnicity, first language, marital status, employment status, income, highest level of education, area where participants live, number of children, whether the pregnancy was planned or not, ultrasound information and gestation at time of counselling (Appendix H). For the genetic counsellor participants, the information included date of birth, ethnicity, first language, other languages, years in the genetic counselling field, qualifications and background (Appendix I).

The pilot study also involved testing whether the data collection process was effective. When the pilot interviews were conducted with the participants, the process of obtaining informed consent, setting up the recording equipment and recording the sessions were

tested. The impact this would have on the genetic service at the clinic was also considered. It became apparent that only one session could be recorded on a particular day and when the clinic was particularly busy, the counsellor interviews had to be conducted at the counsellor's office after the clinic as the counsellor had to continue to provide a service.

Data collection required very careful logistic co-ordination. For a genetic counselling session to be included in the research, there had to be an eligible patient participant, a genetic counsellor participant, a genetic counsellor post-session interviewer and the MRC community genetics interviewer as well as the researcher, suitable rooms and video and voice recorders. As only one video recorder was available, two sessions could not be recorded simultaneously. Two voice recorders and two suitable rooms had to be available as the post-session interviews with genetic counsellors and patient participants occurred simultaneously. The genetic counsellors had to continue seeing other patients after their research sessions and could therefore not always wait for the post-session patient interviews to be completed before they were interviewed.

5.7 Analysis framework

5.7.1 Approach

The analysis is a hybrid approach which draws on principles of discourse analysis. There is strength in drawing on different perspectives as Wood and Kroger (2000, p. 25) state: "We propose, if you like, a kind of made-to-order rather than off-the rack discourse analysis, a bricolage, in recognition of the different concerns of researchers".

Discourse analysis was selected to investigate the genetic counselling interactions as it is based on the premise that language 'is the medium for interaction' and therefore can be studied to reveal the 'way of doing things' (Wood & Kroger, 2000). The researcher was interested in how the genetic counselling interactions occurred and what could be understood about the way these were conducted. Therefore, the methods on which the analysis of the data was based included Conversation analysis (CA), Theme-orientated discourse analysis (TODA) (Roberts & Sarangi, 2005) and methodological considerations in multicultural discourse analysis (Koole & Ten Thije, 2001).

5.7.2 Transcription

Data analysis starts with producing transcripts of the recorded material. Simply put transcription is, a process of producing typed manuscripts of recordings of interactions. In reality, it is a complex process which allows all the nuances of the recording to be available as a script. It is a process of 'translating speech into language' (Ten Have, 2007). The process is vital to the analysis but is not a substitute, as the recordings are the data for discourse analysis and not the transcripts.

The software programme Soundscriber (http://wwwpersonal.umich.edu/~ebreck/code/sscriber/) was used to facilitate transcribing the video recordings and the software with the electronic voice recorders (Sony digital voice editor 2) was used to transcribe the audio recordings. These allowed for the recording playback to be manipulated, using speed control and playback loops.

Video recordings of the genetic counselling sessions were downloaded to a computer as windows media player files and the audio recordings of the session and the post-session interviews with the participants were downloaded as digital voice files using the software provided with the voice recorders. Transcripts were typed in MS word documents.

It is debatable whether the analyst should do his/her own transcribing or whether this should be done by research assistants (Wood & Kroger, 2000). The argument is that it is only after repeated listening to the recordings and reading of the transcripts that the analyst becomes aware of phenomena in the data (Ten Have, 2007). However, as transcription is a laborious process, with one hour of recording taking up to 20 hours to transcribe, the researcher chose to obtain assistance. As discussed in section 5.1.1, research assistants helped with the transcribing. The researcher however, still listened to, viewed the recordings and edited the basic transcripts produced by the research assistants. As this required repeated listening and viewing of the videos, it allowed the researcher to engage with the material from the beginning while saving some time in producing the transcripts. For the patient participant interviews however, the researcher had to rely on the research assistants as these interviews were not conducted in English.

When producing a transcript, it is important to note that there is no perfect transcript (Wood & Kroger, 2000). It has been questioned whether all details such as pauses, intonation, overlapping speech, laughter, breathing (inspiration and aspiration) and emphasis need to be included (Sidnell, 2009; Wood & Kroger, 2000). Jefferson (2004) argues that the nuances allow the details to be explored which can be easily missed by just ensuring that words and turns are transcribed, and that it is in the detail that new and interesting phenomena are discovered in the ways in which conversation is organized.

However as Ten Have (2007) points out, it not only takes time and practice to make transcriptions, it also takes time and practice to learn how to read them. It may not be ideal to produce a transcript at the level of detail required by the Jefferson conventions. A balanced needs to be found, and especially with novice researchers it is useful to start with a simplified version and add detail as necessary (Wood & Kroger, 2000). As a result, the researcher's approach involved producing basic transcripts with detail added to selected sections. The first step involved transcribing the content and the participants' turns. This was done by listening and re-listening to the recordings several times. Once the basic transcripts were completed, the researcher checked and added detail. This round involved checking the accuracy of the turns, overlapping speech and pauses. The basic transcripts of all the genetic counselling sessions and interviews were formatted by adding line numbers, margins, spacing and font before printing. The completed printed transcripts were used for the analysis. Sections identified from the first line analysis were then further transcribed by the researcher and detail, such as emphasis and intonation and breathing (inspiration and expiration) was added. The transcription symbols used were based on Jefferson's transcription conventions as found in Schegloff (2007). The list of transcription conventions used can be found in Appendix J (an insert is included in the thesis for easy reference).

Thus far, only the transcription of verbal elements has been considered, by only including the verbal elements, the detail that could be discovered from the non-verbal interaction would be missed. However transcribing non-verbal elements is a challenging task. More importantly, as discussed in the background chapter, it is even more difficult to analyse or make claims based on the non-verbal aspects. In exploring non-verbal aspects, some researchers have identified specific phenomena which they wanted to study further (Ten

Have, 2007). Heath (1986) developed a system of non-verbal transcription conventions. The participant's non-verbal actions were denoted above the verbal elements. They involved gaze and body orientation amongst others. With regard to the non-verbal elements, the researcher based the transcription on Heath's conventions (Appendix J), but only gaze and body orientation were denoted in this study. As will be shown the predominant orientation in the all 17 sessions were that the two participants faced each other. In the result section of the thesis select comments will be made on non-verbal behaviours based on what emerged from the data and what the researcher thought to be significant.

5.7.3 Data analysis

The researcher approached the analysis without having any conscious preconceived ideas of what the data might show. This is referred to as 'unmotivated looking' (Flick, 2002; Ten Have, 2007). The researcher was conscious of this frame of mind or 'open-mindedness'. The balance between open-mindedness and drawing on the researcher's skills and experience was however considered. Entering the analysis process without any preconceived ideas would allow the researcher to engage with the data and allow patterns and themes to emerge. As the researcher is a practicing genetic counsellor, this complete 'blank slate' state was impossible. In attempts to keep the balance, emphasis was placed on maintaining a reflexive stance during the research process.

Data analysis started with the production of transcripts as described in the previous section. Making observations is achieved by looking closely at the data which can be done by the researcher reading and viewing the data, as well as in data sessions where a group

of analysts watch and discuss the data together (Sidnell, 2009; Ten Have, 2007). By the time the transcripts were in a hard copy format, the researcher had read and viewed the sessions several times and some features were noted. The researcher took one genetic counselling recording to a data analysis session with her supervisor and a researcher experienced in discourse analysis. The video was viewed and interesting features were noted and discussed. The researcher then repeated the process with all the sessions, made observations and took notes.

From these initial observations particular phases in the interactions were observed. Based on research by Sheon et al. (2010) this allowed a 'sequence map' to be constructed in which the phases were differentiated from each other by means of colour. One session was selected and independently rated by the researcher and another professional in the field of genetic counselling. Both identified the overall structure and the boundaries very similarly. Any disparities were discussed and taken into consideration when the researcher applied the process in identifying the phases in the other genetic counselling sessions. Once the overall structure of the session was identified, specific sections were chosen for further analysis.

Data analysis drew on different approaches of which the focus was on discourse as a topic, i.e. describing what the discourse was doing, what function it had and how these functions were accomplished. Discourse approaches differ with regard to whether the focus is in the detail of the conversations or in some aspect of the particular practice. Different approaches have different strengths and the analysis borrowed from a number of these. Researchers in the critical discourse tradition approach their analysis from the stance that the broader social and cultural contexts influence the interactions between the participants

(referred to as macro), while researchers in the conversation analysis tradition argue that social and cultural influences are only relevant when the participants in the interaction show these are relevant (referred to as micro) (Korobov, 2001). Scholars in these two disciplines are very clear on the distinction between their approaches and this tension between the two has been the subject of many debates. The researcher felt both these approaches were essential in understanding the genetic counselling interactions. As a result the analysis process in the present study is explained as a top down approach which refers to the macro aspects and a bottom up approach which refers to the micro aspects.

As the study progressed and the different components of the genetic counselling sessions were noted, the researcher became aware that different methods captured different aspects, nuances and essential elements of the phenomenon examined. For example, when the overall structure of the sessions was considered, a framework drawing on conversation analysis seemed to be most effective in revealing the interactional hybridity. During an examination of the opening phase, a framework based on conversation analysis seemed to be powerful in unpacking the dynamics of this phase. When examining the decision-making sequences, which was less structured than the openings because of the nature of this phase, an approach drawing on principles of both conversation and theme orientated discourse analysis was used. The difference between directive and non-directive strategies and an exploration of counsellor strategies seemed particular relevant dimensions to explore during this phase. Similarly, in the counselling phase which looked at segments of the interview where there was more patient involvement, with the counsellors acting as responders, the same combination approach was used. At first glance this analysis method may appear fragmentary, but in the philosophy of qualitative research, the data drove the

method of analysis and, as many writers have observed, examining the complexity of interactions demand complex and multilayer aspects.

5.7.3.1 Conversation Analysis (CA)

CA as a particular type of analytical work, developed in the early 1960's by Harvey Sacks, Emanuel Schegloff and Gail Jefferson (Ten Have, 2007), has a strong focus on analysing the detail of the conversation resembling a micro analytical approach (Wood & Kroger, 2000). CA reveals information regarding turn-taking (who speaks first) and turn-design (how speakers design the turn), the sequence organization (how one thing leads to another) and repair organization (how mis-hearing or misunderstandings are dealt with) (Schegloff, 2007).

CA was originally developed as a pure science with the aim of uncovering aspects of sociality. It was later used to study talk in institutional interactions and to identify how these interactions were organized (Ten Have, 2007). Some features of institutional talk make studying it different from studying any kind of talk as there are, setting specific rules that impose more restrictions in institutional talk. The institutions and their structures have been criticised for these restrictions saying that they limit people's expression of freedom. Some have been very critical of, for example, doctor-patient interaction. Mishler's study (1984) in which he describes the voice of the life world and the voice of medicine is an example of such a critical view. On the other hand, CA researchers argue that such restrictions may be functional in some way in these institutional settings (Ten Have, 2007). There is also debate as to the 'generality of such institutional properties'. While institutional talk has several characteristics unique to itself which influence

interpretations, others have warned that researchers must be conscious of not ignoring the detail of the interactions and what these might reveal and how this can add to interpretations.

It was important to base the analysis of the data in this study on CA principles as this provided a way of examining the detail of the genetic counselling conversations. Therefore the analysis was approached by making observations with regard to the organization of the talk on the selected sections of the data, specifically examining (Sidnell, 2009):

- Turn-taking organization – what is specific about the turn-taking
- Overall structural organization – an overall map of the typical phases
- Sequence organization – how one action leads to another (sequentially organised)
- Turn design – what talk is designed to do and ways in which this is achieved
- Epistemological and other asymmetry – asymmetry of participation, knowhow, knowledge, and right of access to knowledge.

5.7.3.2 Theme-orientated discourse analysis (TODA)

Roberts and Sarangi (2005) developed a theme-orientated approach to discourse analysis in the medical field. The motivation for this approach came from the fact that discourse analysis is daunting as it involves analysis of vast levels and types of language and knowledge. In addition, the themes in discourse analysis align with the concerns of professionals working in their respective fields. Aligning the discourse analytical themes with the professional concerns provides opportunities for "joint problematization of health-related concerns" (Roberts & Sarangi, 2005, p. 639). Although the findings from

such efforts will not necessarily lead to solving problems, it does provide a new way of examining a particular problem.

The theme-orientated approach links analytic themes of discourse analysis to the most relevant focal themes of professional concerns in medicine. The analytic themes suggested by this approach include:

- Interactive frames and footing – what is relevant and appropriate
- Contextualization cues and inferences – what is meaningful in the context
- Face and facework – strategies related to politeness
- Social identity – age, gender race etc
- Rhetorical devices – use of language to influence or persuade

The focal themes suggested by this approach include:

- shared-decision making and
- mis-communication in intercultural interactions.

The theme-orientated approach suggested by Roberts and Sarangi (2005) is an applied approach to discourse analysis. The approach in this analysis of medical interactions lends itself to describing and understanding interactional phenomena in medical encounters in a way that makes the findings relevant and practical to the professionals working in the field.

The researcher also considered some of the analytic themes suggested by Roberts and Sarangi (2005) in their theme-orientated approach to discourse analysis. The researcher

considered interactive frames and footing, contextualization cues and inferences, face and facework, and social identity and rhetorical devices, as well as shared-decision making.

5.7.3.3 Methodological considerations in intercultural communication studies (ICC)

Koole and ten Thije (2001) argue for a methodology of analysing intercultural communication in the same way as analysing ordinary communication. Intercultural communication is often analysed as communication between different cultures and this could result in miscommunication. Rather than using the term intercultural communication, the authors use *intercultural discourse* which implies that the participants create a shared common ground of meaning and practices. Their proposed analysis therefore aims at the reconstruction of the common ground, which may be characterized by, but is not necessarily miscommunication.

The method proposed by Koole and ten Thije (2001) is focused on the common ground constructed by the participants as well as aspects of this. The common ground is termed 'discursive interculture'. Their approach considers intercultural communication as ordinary communication and they argue that for the communication to occur in the first place, the participants must share some common knowledge. This shift in emphasis implies that information can be shared and that the participants can learn from each other. In the analysis, miscommunication is seen as a 'lack of sharedness' and this becomes important in understanding the interaction. How the participants deal with the lack of sharedness, whether they adapt or whether they retain it, are strategies in the interaction. "Using this focus, analysts can move from the perspective of communicative actions as being shaped by culture to seeing them as shaping culture" (Koole & Ten Thije, 2001, p. 585).

A key consideration in approaching the analysis in the present study was how to include a multicultural perspective. An observation made early on in the analysis was that obvious 'cultural differences' were not apparent. The argument of Koole and ten Thije (2001) regarding analysing intercultural communication in the same way as ordinary communication was considered throughout the analysis. Attention was paid to how the participant's reconstructed a common ground of meaning and practices, which may not necessarily be miscommunication, and how sharedness in creating a common ground and a lack of sharedness could result in miscommunication, as well as how the participants deal with these phenomena in the interactions.

The researcher did not follow specific steps in the analysis as none exist (Heritage & Maynard, 2006; Sidnell, 2009; Ten Have, 2007; Wood & Kroger, 2000). "Analysis essentially consists of a detailed and repeated reading of the discourse against the background of the discourse-analytic perspective" (Wood & Kroger, 2000, p. 95). The analysis approach taken was a repetition of interpretation and pattern analysis. The analysis involved a continuous moving from a 'bottom-up' to 'top-down' and 'top down' to 'bottom-up' approach, considering specific sections individually and the discourse as a whole. This was repeated a number of times until the researcher was satisfied that there was sufficient evidence for the claims. During the analysis, the researcher looked for patterns, made claims about these and provided evidence in the form of excerpts from the data. The excerpts contain details of verbal elements and selected non-verbal elements (appendix J). In the transcripts "C" is for counsellor and "P" is for the woman, in one session where the woman's partner attended clinic with her, he was represented as "P1". Even though not all the transcribed elements are commented on in all the excerpts, it was a

deliberate decision to include these due to uniformity and in keeping with the principle of transparency. Figure 5.1 shows the data analysis process.

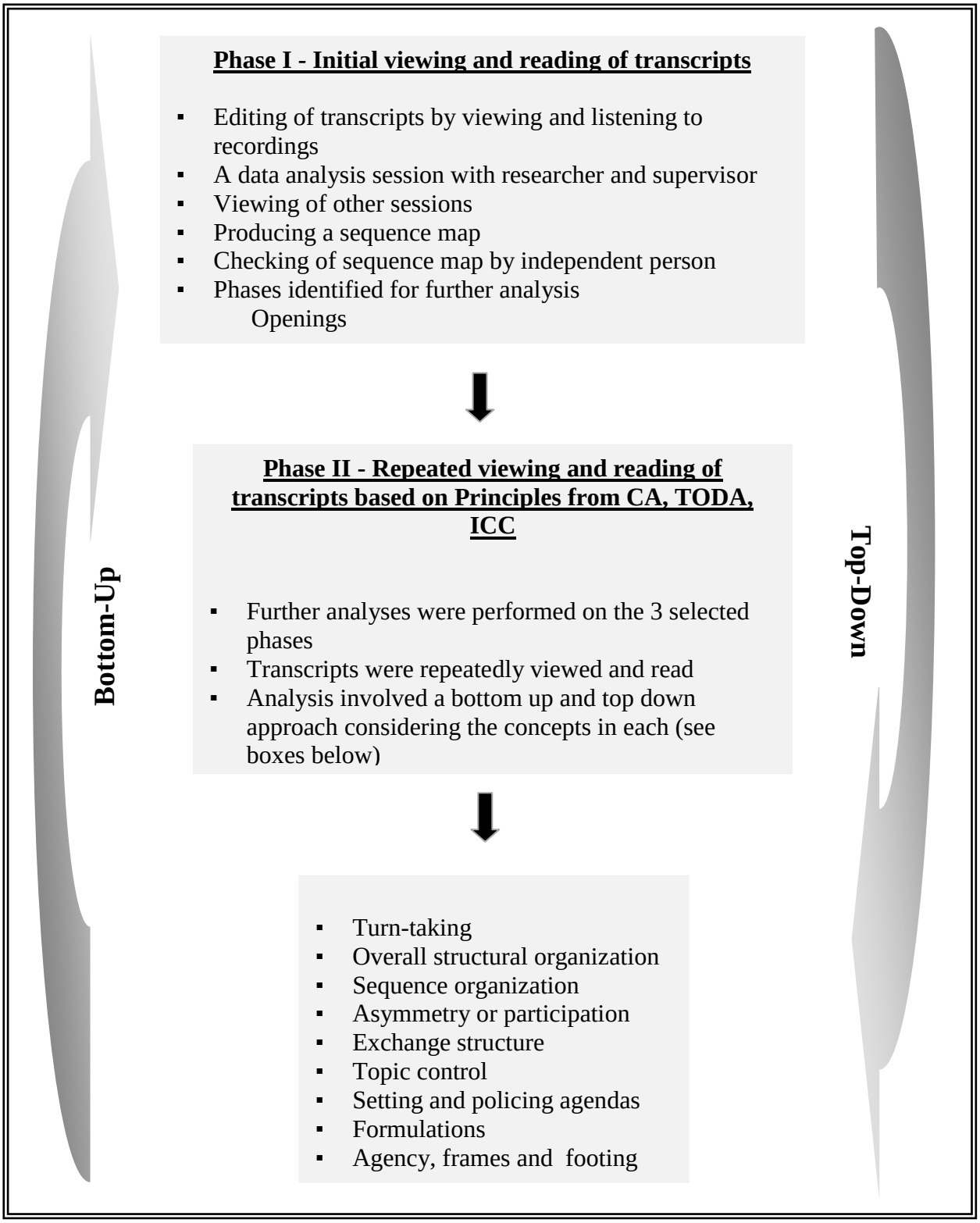


Figure 5.1. *Visual representation of the data analysis process.*

5.8 Rigour

Reliability and validity are as important in qualitative research as in quantitative research. The term rigour, or trustworthiness, of qualitative research refers to the worth of the research outcomes (Brink, 1999; Burns & Grove, 2001).

There is disagreement about what defines good qualitative research and also whether criteria for this should even exist (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). Emden et al. (2001), in a study attempting to identify when qualitative research is good and whether its claims should be taken seriously enough to change teaching and clinical practices, or serve as an example of good research, concluded that for qualitative research to be of high value it has to:

- pay attention to detail with honesty and trustworthiness (process)
- be written with impact, effect, meaning and believability (writing)
- relate usefully to practice and other/ongoing research (outcome)
- show that quality is important, consensual and achievable (excellence).

The researcher considered these points throughout the research process. As discussed in the previous sections, the philosophical perspective, process of data collection, methodological approach and how the paradigm translated into an analytical framework were described.

In this study the researcher collected data from different sources i.e. the counselling sessions, interviews with the participants and ethnographic observations. This

triangulation of data sources is a way of verifying outcomes and makes for more trustworthy results (Creswell, 2002; Silverman, 2004).

In discourse studies, the reliability is greatly affected by the quality of the transcripts, as the transcript is a translation of the features of the actual interaction (Silverman, 2004). For this study, to ensure the best transcripts possible, the sessions were both video and voice recorded. These recordings provided additional sources from which inaudible words or phrases could be checked. The process of transcribing was done by research assistants and the researcher. The research assistants produced basic transcripts ensuring accuracy in terms of content and turns. The researcher edited the basic transcripts by systematically checking first for content, followed by turns and overlapping talk, followed by pauses. Details such as intonation were added next by first recording all the rising intonations, then all the falling intonations and then emphasis. For the interview data, only turns and content were important. All transcripts were produced by the research assistants and checked again by the researcher for the transcriptions of the counsellor participant interviews. The community genetics researcher checked the transcripts for the patient participant interviews that were not in English.

The interpretations of qualitative data are influenced by the researcher's understanding of ideas and concepts. Dixon-Woods et al., (2004) suggested that clear research questions, sufficiently supported claims and clearly integrated conclusions add to the validity of a study. The development of ideas on the study material was shaped by data analysis sessions and discussions with the supervisor and other experts in the field. Excerpts from the sessions, thus allowing others to evaluate the claims made, illustrated the researcher's observations and interpretations of the phenomena.

The partiality of the researcher was acknowledged from the onset of the study. The researcher is a practicing genetic counsellor and trainer of genetic counselling students. As a result, the researcher had preconceived ideas about how genetic counselling has been and should be conducted. The researcher was aware of the tension between practicing as a genetic counsellor and evaluating the practice. Being a counsellor might have affected the way the results were interpreted, while concurrently being a researcher may have affected the interactions with patients. A major limitation in an analysis is a failure to depart from old ideas (Burns & Grove, 2001). In an attempt to address this, reflective notes were kept and ideas, thoughts and challenges were addressed by discussions with the research supervisor, an experienced mentor in the field of genetic counselling and the counselling skills supervisor.

5.9 Ethical considerations

5.9.1 Obtaining consent

The study was submitted for consideration to the Committee for Research on Human Subjects (medical) of the University of the Witwatersrand for clearance of research involving human subjects, and or patient records (see Appendix K). Permission to perform the research in the respective hospitals was obtained from the hospital superintendents (Appendix L, M).

Informed voluntary consent was obtained from each study participant. The patient participants were considered a vulnerable group as they were receiving a service and could have felt compelled to give consent. Tovell (2004) reported that in her study, informed

consent was initially obtained in English by the genetic counsellor, but that the potential participant later refused to participate when the interpreter, who spoke isiZulu, requested consent. This highlighted the importance of language and professional roles when attempting to obtain true informed consent. This was carefully considered and therefore informed consent was obtained in the participants' own language. Obtaining consent in the home language seemed effective as some of the women felt comfortable in declining to participate in the research.

The genetic counsellor participants were subordinate to the researcher and this raised concerns about coercion. This was addressed when ethics approval for the research was sought. At the time of protocol submission and ethics approval, three of the participating genetic counsellors appeared before the University of the Witwatersrand's ethics committee to clarify how they felt about participating in the research. The genetic counsellors then made the decision to participate and it was a mere formality to obtain their informed consent when suitable patients were identified. One genetic counsellor however chose not to participate in the research. During data collection, the genetic counsellors were approached by the community research assistant in the week of the clinic to ask if they would participate, as she knew who was allocated to the clinics. Part-time genetic counsellor interviewers conducted the post-session interviews and they had the informed consent form which the counsellor participants had completed.

5.9.2 Confidentiality

Due to the pitfalls of qualitative research in which small samples from small groups are used, there is a risk that the participants might be identified. This was kept in mind and

every attempt was made to protect the participants' identities in the write-up of the project. However, there is only one site in Johannesburg (the Division of Human Genetics of the NHLS and Wits) that employs genetic counsellors and it is therefore impossible to provide total anonymity to the genetic counsellors involved in the research.

The risk of breach of confidentially was higher for the genetic counsellors than the patient participants. In an attempt to protect the identity of the former group, pseudonyms were mentioned in the sessions when names were used, the counsellors were coded as counsellor A, B, C, D, E and F and only the researcher had access to this information. It is also for reasons of confidentiality that in the results section a summary of counsellor information was not included. The researcher felt that if for example counsellor A was shown to have 5 years of experience, the counsellors and others in the field would be able to identify this counsellor. Instead counsellors were grouped as either experienced when they had more than 5 years experience or inexperienced if they had less than 5 years experience.

In further attempts to maintain confidentiality, access to the video and voice data was only made available during select research and data analysis discussions with a few experienced colleagues and was not shown to other audiences. Only excerpts of the transcripts of sessions were included in presentations to wider audiences at conferences.

5.10 Summary

In this chapter the setting, participants and methods were described in detail. The research was conducted at two academic hospitals in Johannesburg with women of advanced

maternal age. The genetic counselling interactions of 17 women were recorded and interviews were conducted with the women and the genetic counsellors after the sessions.

The methodological approach was a qualitative hybrid design based on principles of discourse analysis. The sessions were analysed in their entirety and different phases were identified. Three phases were selected for further analysis; openings, decision-making and counselling segments. The analysis involved a continuous 'bottom-up', 'top-down' approach considering the turn design, topic control, agency and intercultural discourse amongst others.

Finally, this chapter contains a description of how the rigour, validity and reliability of the study were considered as well as the ethical issues encountered by the study.

Chapter 6 Results I - Overall Description of the Sessions

The first phase of analysis involved examining the genetic counselling session in its entirety. The analysis was approached with the aim of obtaining an overall impression of the sessions. This initial phase of analysis involved watching the video recordings, reading the transcripts and describing the interactions. This was largely a descriptive process drawing on some principles of CA (Sidnell, 2009) and TODA (Roberts & Sarangi, 2005). CA's focus on the micro analysis of sequences was particularly suitable to explore the structure of the sessions while TODA allowed focussing on different functions.

It became apparent that the genetic counselling sessions had a clearly discernible structure. The structure consisted of different components which could be distinguished from each other based on the goal each was attempting to achieve in the session (function) and it was evident that the different phases had unique interactional structures (Sarangi, 2000; Sheon et al., 2010). The phases were mapped along a continuum in which each phase was demarcated by a different colour, resulting in what Sheon et al. (2010) referred to as a 'sequence map'.

As stated in chapter 5, the excerpts shown are uniform with regard to the transcription conventions used. The transcriptions show the detail seen in traditional CA conventions. Due to the hybrid nature of the analysis, not all the features captured in the transcripts may be commented on as only those aspects relevant to the particular analysis focus will be

discussed. This choice was deliberate as it not only presented uniformity but is in keeping with the principle of transparency.

This chapter is a discussion of the findings of the key characteristics of the different phases of the sessions which are presented in the form of excerpts as illustrations. In the excerpts where names and other possible identifying information are shown, pseudonyms were used to protect the individuals' identities and these pseudonyms were kept throughout the thesis when referring to the individual women (P), a partner (P1) and counsellor (C).

6.1 The overall structure

All 17 genetic counselling sessions appeared to be similar in terms of the overall structure. This clearly discernible structure was a key finding and little variation was observed between the sessions of the different counsellors or between different sessions of a specific counsellor. The researcher watched the sessions and made observations of what occurred during the sessions. During this process, it became evident that the sessions followed a particular order specifically with regard to four of the six identified components. Four phases followed a particular order: the opening phase occurred at the beginning of the session, followed by the information gathering phase, then the information giving phase and the session ended with the closing phase. Two other components, the decision-making sequence and the counselling segments were less structured and could be seen as more artificial.

The decision-making sequences were defined as such by the fact that the counsellors and women talked about aspects related or relevant to the decision of having or not having an

amniocentesis. As a result this phase was more flexible and was seen to occur after or during information giving but before the closing phase. The counselling segments were identified because of the obvious contrast to the rest of the session in that the women took up more interactional space. These were found to be particularly flexible and occurred during any stage of the session. The researcher identified the phases and together with an experienced genetic counsellor refined how these should be demarcated. It is acknowledged that there is overlap between what was called a decision-making sequence and a counselling phase and that some of the segment could very well fit into either category.

The six identified components of the genetic counselling sessions were found to be:

- opening phase
- information gathering phase
- information giving phase
- closing phase
- decision-making sequence
- counselling segments

Figure 6.1 shows the sequence map. For each of the sessions, the time taken is shown as minutes (m) and seconds (s) and the number of lines is shown as (L). It illustrates the order in which the different components (opening, information-gathering, information-giving and closing) occurred in each of the sessions and it shows that the decision-making and counselling segments did not occur in any particular order. From the sequence map it was possible to create a schematic representation of the structure of the genetic counselling sessions. This representation is presented in figure 6.2. The outer circular structure illustrates the flow of the session with the opening followed by information

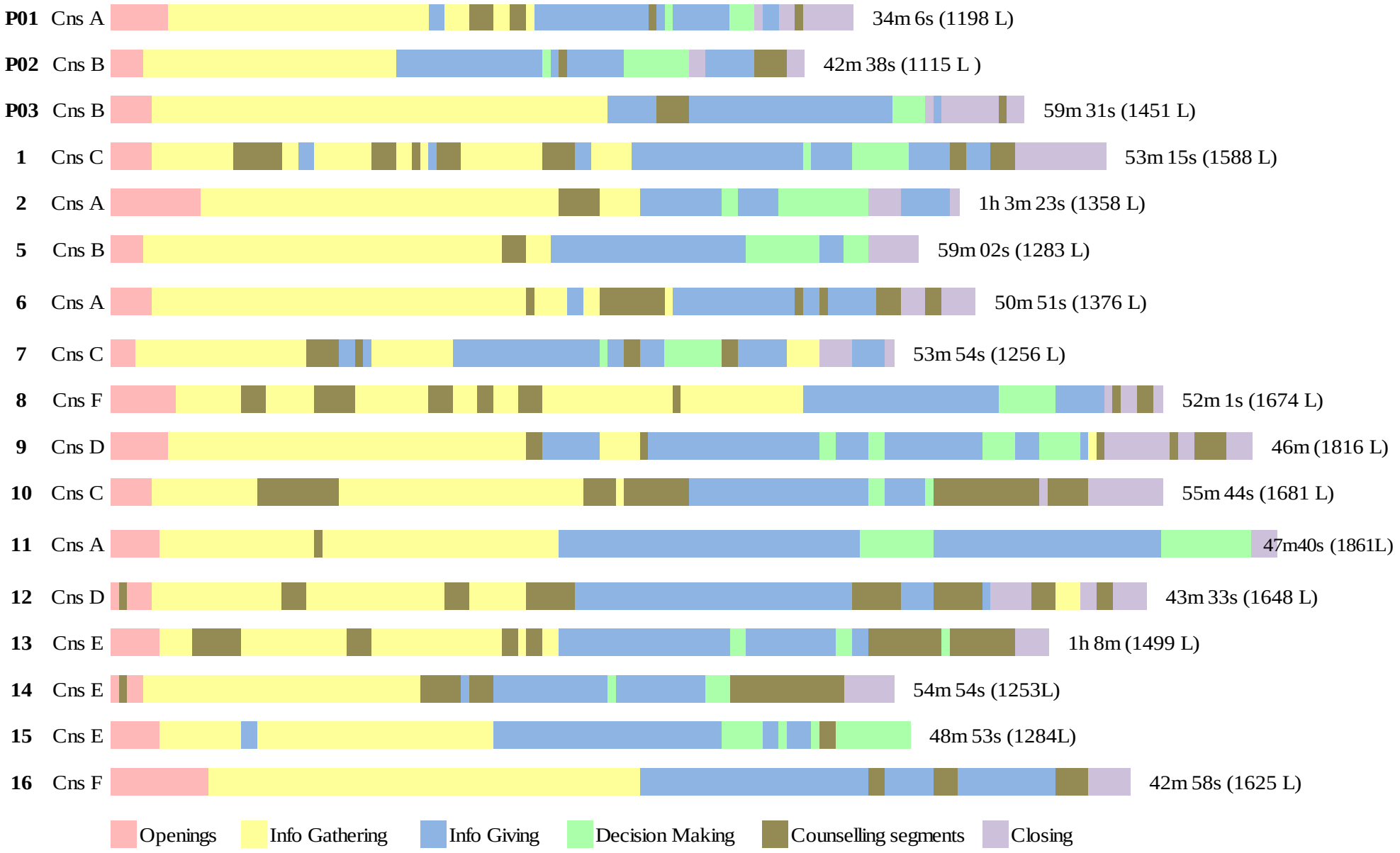


Figure 6.1. *Sequence map of the 17 genetic counselling sessions.*

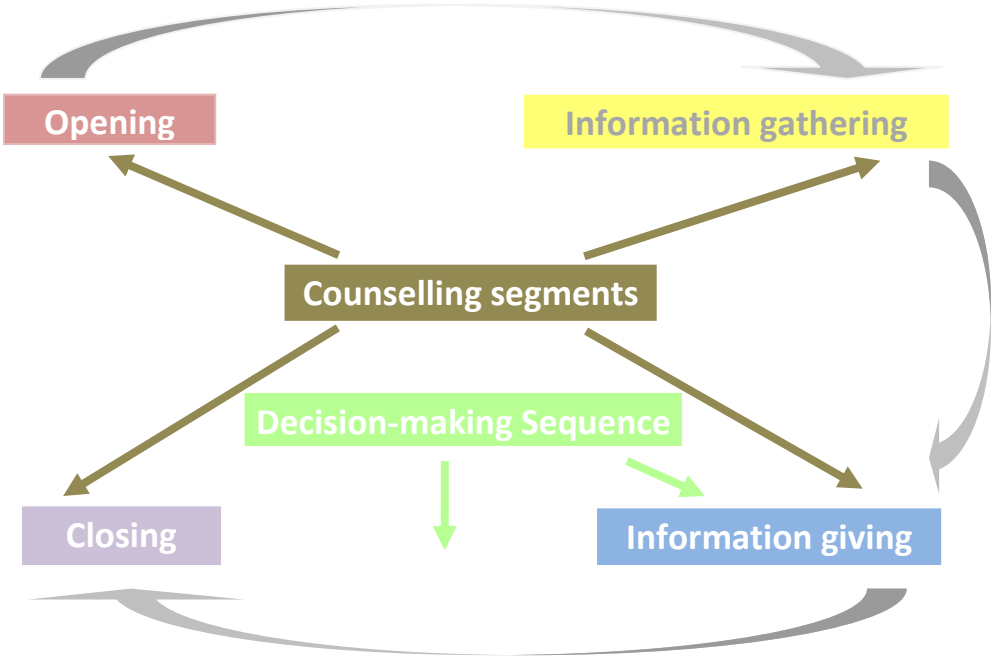


Figure 6.2. *Visual representation of the phases of the genetic counselling sessions*

gathering, then by information giving, and by a closing. In the centre of the diagram is the decision-making sequence with two arrows extending to the information giving and between the information giving and closing phases, indicating that decision-making sequences occurred during or after information giving. The second component in the centre is the counselling segment with four arrows extending to all four outer phases, illustrating that counselling segments occurred at any stage of the session.

6.2 Arrangement of the counselling rooms

The arrangement in the counselling rooms was very similar across all 17 sessions. Depending on the space in the rooms, the counsellors and the women sat opposite each other, facing each other directly, or they sat at the corner of the desk. Figure 6.3 shows

these two predominant positions. However, there were some subtle variations with regards to the distance between the counsellor (C) and the woman (P), the angle of the chair and whether the desk was on the right or left hand side of the counsellor. Appendix N shows the set up in each of the sessions.

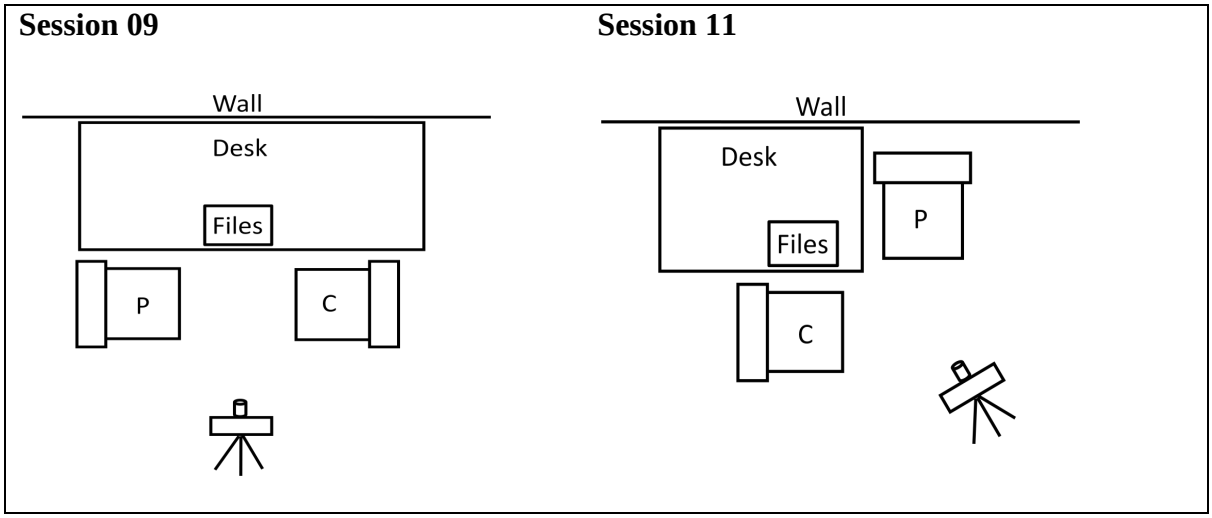


Figure 6.3. *Set up in the counselling rooms*

For most of the session the counsellors and the women remained in these positions and their dominant frame of orientation (Robinson, 2006) was with their bodies and gaze directed at each other. During the opening and information gathering phase, both the women and counsellors often directed their gaze at the files placed on the desk or on the counsellor's lap. Similarly during the information giving phase their gaze was occasionally directed at the pictures/graphics which were either on the desk or on the counsellor's lap. The counsellors were found to be either engaging with the 'patient in bureaucracy' (Robinson, 1998) when focusing on the records or the 'patient embodied' when they assumed a face to face orientation. In contrast, during the decision-making phase and counselling segments their gaze was almost exclusively directed at each other.

The features described above serve to provide a general impression of the non-verbal interactions in the genetic counselling sessions of the study. The focus on positioning, gaze and orientation allowed the researcher to access some of the non-verbal features in the sessions. However, this description is superficial and cannot depict the complex interplay between verbal and non-verbal elements.

6.3 The components of the genetic counselling sessions

6.3.1 The opening phase

The opening phase represents the first few minutes of the interaction. It was the initiation of the genetic counselling session and contained a number of activities. These activities included: introductions, greetings and reference to the current research project, invitations to ask questions, an attempt to establish the reason for referral and an explanation of what the session was going to entail.

The current section will illustrate the different activities which occurred during the openings. However, the emphasis will be on providing an overview of the phase and the different sequences observed. The details of other emerging features will be discussed in chapter seven. Excerpts are shown to illustrate the features. The excerpts show the details of the verbal features of the talk as well as gaze and the orientation of the counsellor (C) and the woman (P). An insert with the transcription conventions used is included.

The first activity during the opening was an introduction. Excerpt 6.01 is an illustration of a typical introduction and shows the counsellor opening the session by introducing herself. This is followed by a question to the patient regarding the pronunciation of her name.

Both the counsellor and the woman looked at each other during the introduction while they both focussed on the file when the counsellors asked how to pronounce the woman's name.

Excerpt 6.01, Session 11, Couns A Inexp – An introduction

		_____
1	**C:**	Okay (2.0)
		_____
2		so my name is ↑Sharohhn (1.0)
		____
3	**P:**	uhm
		_____
4	**C:**	and I'm from the genetics department (1.0)
		_____
5	**P:**	((nods))
		- -
		file
6	**C:**	Okay >how? do you say your name< (.)
		- - - - - - - - -
		file
7	**P:**	Nonhlanhla

The next excerpt (6.02) illustrates another activity namely the counsellor's attempt to establish the reason for the referral. The excerpt shows the counsellor asking the woman why she thought she was referred and the woman replying that she was referred for counselling. Here the woman directed her gaze at the file when she was explaining why she was referred.

Excerpt 6.02: Session 15, Couns E Exp – Reason for referral

		- - - - _____
		file
26	**C:**	Okay - hmmn Bongumusa do you know why? you are here?
		_____
27		today? (2.0)
		____ -
		file
28	**P:**	yes? they told me ah (.) I have to come for (.) ah
		- - - - - - - - - ____
		file
29		what counselling

Following on from the attempt to establish the reason for referral, the counsellor explained what the session was going to entail, as can be seen in excerpt 6.03. The excerpt is taken from the same session as excerpt 6.02, a few turns later. The explanation of what is going to happen in the session was done over a number of turns in which the woman responded with acknowledgments. Both the counsellor and the woman looked at each other during the counsellor's explanation.

Excerpt 6.03: Session 15, Couns E Exp – Reason for attending clinic

38	**C:**	okay - so Bongumusa - at this? clinic we see all women,
39		that come to ((name)) hospital? - who are older than
40		thirty (.) five years
41	**P:**	>Yes<
42	**C:**	to talk about what are the <problems that can happen in a
43		pregnancy> (.) when a woman is older (.) and what are the tests
44		that we can <do> to <offer>you (.) to look for those problems (2.0)
45		oka:y.
46	**P:**	Ja

Others, who have studied genetic counselling interactions, have reported similar activities during openings to those observed in the current study; greetings (Armstrong et al., 1998; Hodgson et al., 2009) and establishing the reason for the referral (Armstrong et al., 1998; Babul-Hirji et al., 2010; Butow & Lobb, 2004; Rapp, 1988). These activities resemble those that have been described in medical encounters: greetings (Byrne & Long, 1976; Heath, 1981; Robinson, 1998), checking names, seating patients, reading medical records and checking equipment and were referred to as the preliminaries (Heath, 1981, 1986) which were found to precede establishing the reason for the visit (Byrne & Long, 1976; Heath, 1981, 1986). In this respect, genetic counselling resembles medical interactions

more than counselling encounters which have been described as consisting of an artificial structure (Labov & Fanshel, 1977; Silverman, 1997). The opening sequences in the genetic counselling sessions can be described as helping the patient and the counsellor establish who they are talking to, the reason for them being in the interaction and what the women can expect from the session.

When examining these different activities, different sequences were apparent. In CA terminology this is referred to as an adjacency pair which is characterized as comprising a minimum of two turns (Schegloff, 2007). Such adjacency pairs are described as consisting of first pair parts (FPPs) and second pair parts (SPPs) which are related to each other, for example, a question requires an answer. Several distinct sequences were evident in the opening. In excerpts 6.01 and 6.02 a similar organization was seen and in both excerpts the counsellor asked questions (excerpts 6.1 lines 6 and excerpt 6.2 lines 26-27) and the woman provided answers. In CA terminology this is a 'question and answer sequence' (Schegloff, 2007) and in HIV counselling it is referred to an 'interview format' (Silverman, 1997). One of the sequences observed during the openings is therefore a question/answer sequence:

FPP Question by counsellor

SPP Answer by woman

Another sequence was evident as seen in Excerpt 6.03. Here, there was an explanation given or information being communicated by the counsellor while the woman responded with acknowledgments. CA refers to this as 'tellings' (Schegloff, 2007) while in HIV counselling it is termed an 'information delivery format' (Silverman, 1997). As with question/answer sequences, the term explanation/acknowledgment sequences will be used

when referring to 'tellings'. Thus another sequence was evident during the openings which occurred when the counsellors communicated information. These were explanation/acknowledgment sequences:

FPP Explanation/information by counsellor

SPP Acknowledgment by woman

6.3.2 Information gathering sequence

The information gathering phase, which followed on from the opening, was characterised by the counsellor obtaining different kinds of information from the patient. It typically involved obtaining information for the patient records such as name, date of birth, address and contact details. Information regarding biological relationships and family members' health took up the largest proportion of this phase. The transition from the opening phase to the information gathering phase was identifiable as this occurred after the counsellor had explained what was going to happen during the session. It was mostly signalled by a transition marker such as 'okay' or 'all right' followed by an introduction to information gathering with a statement such as 'let me just get some information from you'. This phase ended when all information was obtained and was characterised by the counsellor posing several questions to the women to which the women provided answers. The counsellors obtained different types of information from the women. Excerpt 6.04 is an example of obtaining demographic information. It shows the counsellor asking about the woman's date of birth and her employment status. This information is recorded in the patient folders.

Excerpt 6.04: Session 16 Couns F Exp – Demographic information

		– –
		file
162	**C:**	0Okay0(.) and your date? of birth?
		_____
163	**P:**	Twenty one November 1969
		– –
		file
164	**C:**	0 Twenty one November 1969 0 s:o how old are you now.
		– – – – – – – – – – –
		file
165	**P:**	I'm thirty-nine
		– – – – – – – – –
		file
166	**C:**	thirty-nine.
		– – –
		file
167	**P:**	uhm
		– –
		file
168	**C:**	0okay0 turning fourty in November
		_____
169	**P:**	Ye:s mam
		– –
		file
170	**C:**	Wilhelmina? are you? working? at all?
		_____
171	**P:**	Yes? I'm? working? in the crèche?
		– – – – – –
		file
172	**C:**	crèche
		___
173	**P:**	yes
		– –
		file
174	**C:**	okay? what kind of work do you do in the crèche
		_____
175	**P:**	I'm cooking
		_____
176	**C:**	okay?

In excerpt 6.05, information regarding biological relationships was obtained. Details regarding the woman's family history, such as number of siblings, uncles, aunts, cousins, nephews and nieces and their health were also collected. The counsellors used the information to draw a family pedigree in the patient folder. The excerpt shows the counsellor asking about the woman's brothers and sisters.

Excerpt 6.05: Session 06 Couns A Inexp – Biological relationships

		_ _ _

discussing the woman's biological ties, while in excerpt 6.06 line 643 the counsellor's comment 'now tell me about this pregnancy' sets up the frame for a discussion on the woman's current pregnancy.

The sequence of the information-gathering sequence was more uniform than the opening phase, in that it did not matter whether information was gathered on demographics, family, medical or pregnancy history. All were characterised by a question or statement posed to the women in various ways, and them providing answers to these that were specifically related to the demographic and clinical information. The sequences began with a request for information from the counsellor and ended when the counsellor had obtained all the necessary information. The counsellors made use of several question formats: closed ended questions or, in CA terminology, 'yes/no interrogatives' which require a yes or a no answer (Schegloff, 2007) as well as open ended questions or, in CA terminology, 'wh-interrogatives' which refer to questions which contain a who, where, what and when. Such questions require more than a yes/no answer and, depending on which 'wh' were used, they require a specific answer for example *who* requires a reference to a *person* (Schegloff, 2007). Examples of yes/no interrogatives can be seen in excerpt 6.04 line 170, excerpt 6.06 lines 643-644 and examples of wh-interrogatives can be seen in excerpt 6.4 line 174 and excerpt 6.5 line 342-343. There were also examples of polarized questions such as those occurring in Session P01 lines 90-91: Couns A "C:…Is this your married name or is it your family name? P: my family name.". Another request for information which had a different format was distinguished as a 'b-event statement' (Labov & Fanshel, 1977). These are declarative statements made by one of the participants of which the other participant has knowledge. Examples include excerpt 6.05 line 345 and excerpt 6.06 line 646.

The sequence of the information gathering phase can be summarized as consisting of distinct question/answer formats:

FPP Question (yes/no, wh-type, polarized) by counsellor

SPP Answer by patient

As well as:

FPP Statement (b-event) by counsellor

SPP Answer by patient

The excerpts are self-explanatory in terms of what their function is: obtaining identifying demographic information for record keeping purposes; asking about the patient's family history and drawing up the family pedigree to establish whether there are any inherited genetic conditions which might impact on the risks to the current pregnancy; as well as gathering information about the current pregnancy. All these functions have been described previously (Armstrong et al., 1998; Babul-Hirji et al., 2010; Butow & Lobb, 2004; Tovell, 2004). This activity resembles medical history taking in physician patient interactions (Boyd & Heritage, 2006). Even in counselling discourse, specifically HIV counselling there is an activity which resembles medical history talking (Silverman, 1997). This type of history taking is a fundamental element of the medical encounter as doctors require information about the patient to make a diagnosis and prescribe treatment.

Genetic counselling interactions are similar to medical encounters in this respect as they also require information about the patient and her medical history. In addition, genetic counselling encounters have more emphasis on obtaining information on the biological relationship and conditions in the family, and this emphasis was observed in the interactions in the present study.

Yes/no and open question formats were reported in genetic counselling interactions (Babul-Hirji et al., 2010; Tovell, 2004) as were polarized questions where the patient was given two options from which to choose (Babul-Hirji et al., 2010). The sequences of the genetic counselling interactions is similar to those described in medical history taking during medical encounters (Boyd & Heritage, 2006) and the question answer sequences evident in counselling discourse (Silverman, 1997). The similarity is not unexpected as in any activity where information is requested from one participant by another, the sequence is expected to take the form of a question and answer format. The resemblance between genetic counselling interactions, other medical encounters and HIV sessions is not surprising as in all these encounters medical information is obtained.

As explained in the introduction section of the chapter, non-verbal elements examined in the study included gazes and body orientation. As the transcripts showed the counsellors' gazes were often directed at the files during this phase particularly when they were recording the information and wrote or drew the family pedigree. When questions were asked the counsellors mostly looked at the women, but when they were writing or drawing they mostly looked at the files. Similarly with the women, their gazes were also either directed at the counsellors or the files.

6.3.3 Information giving sequence

Providing information took up the second largest proportion of time of the genetic counselling session as seen on the sequence map. During the openings, after the counsellors attempted to establish what women knew about why they were referred, the counsellors spent time explaining to the women what they would be discussing in the

session. It was during the information giving sequence of the session that the concepts that the counsellors' referred to during the opening phase were explained. The women were given information regarding biological processes, sperm and egg, genetic mechanisms, normal chromosomes, chromosomal abnormalities associated with advanced maternal age, risks, invasive testing options, such as amniocentesis, and ultrasound.

There were other instances during the sessions where patient-specific information was communicated in response to information obtained from the women relating to other health or genetic issues. These instances were not regarded as being part of the information-giving phase.

Information-giving was characterised by the counsellors providing information and the woman acknowledging both verbal and non-verbally that she had heard what was communicated. Similarly, as seen during the information gathering phase, the counsellors announced that they would now provide the woman with information. This framing was characteristic in all the sessions. A typical introduction which illustrates such a frame is shown in Excerpt 6.07.

Excerpt 6.07: Session P02 Couns B Inexp – Frame

452	**C:**	(0.6)
		_____
453		okahhy (.) >alright< so:? Dineo let's move (.) on to talk more about (1.0)
		_ _ _ _ _____
		files
454		why we're here today.
		____
455	**P:**	Uhm
		_____ _ _ _ _ _____
		Desk
456	**C:**	and why we are talking today okay. So what do you know
		_____
457		about these problems that can happened in a pregnancy
		_____
458		when moms are older

When information was being communicated, large amounts of information were typically communicated as shown in excerpt 6.08.

Excerpt 6.08: Session P02 Couns B Inexp – Large amount of information

		– – –

When smaller amounts of information were communicated, the features as shown above were still present with the exception of the length of the talk by the counsellor. Excerpt 6.09 shows a shorter information-giving sequence.

Excerpt 6.09: Session P02 Couns B Inexp – Shorter information-giving sequence

		Picture *picture*
554	**C:**	okay you'll see that there are <u>two</u> of each kind so there're
		picture
555		<u>two</u> number 1, two of number 2
		picture
556	**P:**	Uhm hu?
557	**C:**	all the way through
		picture
558	**P:**	okay
		picture *picture* *picture*
559	**C:**	okay one number one(.) comes from mother, one number one comes from
		picture
560		father (.)
		picture
561	**P:**	Ooh?

As the two excerpts show, the concepts explained were very complex. The counsellor did most of the talking while the patient used acknowledgement tokens and head nods to communicate that she was participating in the interaction and accepting the information being communicated. The counsellors made use of pictures/graphics to illustrate what they were discussing and both the counsellor and the woman's gaze was often directed at these pictures when the counsellor was busy explaining. Providing long monologues of information were reported in other genetic counselling interactions (Babul-Hirji et al., 2010; Hodgson et al., 2009; Lehtinen & Kääriäinen, 2005; Lehtinen, 2005, 2007), medical (Gill & Maynard, 2006; Halkowski, 2006) and counselling encounters (Silverman, 1997). The activity of providing information during genetic counselling encounters therefore resembles other interactions where information is communicated.

Another feature of the information sequences included occasional comprehension checks by the counsellors. The counsellors interrupted their information-giving by checking whether the woman had questions or whether they understood what was being explained. Excerpt 6.10 shows such a check. When the patient was invited directly by the counsellor's question in line 586, 'questions so far?', she responded by saying (line 587) 'No so far I'm listening'. In only nine instances the women responded to such invitations.

Excerpt 6.10 Session P02 Couns B Inexp - 'check'

		_ _ _

Excerpt 6.11: Session 11 Couns A Inexp - Initiation

		_____
1110	**C:**	The baby would (.) they would lose the baby from the test
		_ _ _ _ _
		file
1111	**P:**	>Uhm<
		_____
1112	**C:**	The other ninety-nine?
		_ _ _ _ _ _
		file
1113	**P:**	>Uhm<
		_____
1114	**C:**	no problem (.) will be fine
		_ _
		file
1115	**P:**	so how many (2.0) women (.) I'm the first? one you you have told
		_ _ _ _ _ _ _ _ _ _ _ _ _
		file
1116		me about this or.
		_____ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
1117	**C:**	We:ll your chance is one out a hundred ninety-nine
1118	**P:**	>Uhm<

Conversational contributions from patients in the form of questions have not explicitly been reported in genetic counselling interaction studies. In one of the transcripts in Babul-Hirji et al. (2010), which were used to illustrate the counsellor's humanistic voice, the patient asked a question.

If the sequence of the information-giving phase is considered, three distinct organisations are evident. For the most part the phase consisted of the counsellor providing information and the patient responding with acknowledgements i.e. information/acknowledgment sequences.

FPP explanation/information by counsellor

SPP acknowledgement by patient

In addition, although less frequently, there was a question by the counsellor, checking whether the patient understood or whether the patient had any other questions. Here the sequence was a typical question/answer sequence.

FPP question by counsellor

SPP answer by patient

Further, there was sometimes a question from the patient with the counsellor providing the answers. This resulted in a sequence organization that resembled the question/answer formats except that the patient was the asker and the counsellor the answerer. It was a mirror of the interview formats as found in HIV sessions (Silverman, 1997). The sequence thus looks as follows:

FPP question by patient

SPP answer by counsellor

6.3.4 Closing sequence

The closing phase signalled that the session was coming to an end and contained several activities. The closing phase followed on from the information-giving phase and the counsellors used this phase to ensure that everything that needed to be addressed during the session was covered. It contained summaries of what was discussed and women were given an opportunity to ask more questions which were answered. The closings also contained discussions of which the content was unique to that particular session. The counsellors also made sure that the women understood what the plan was for her directly after the session, including her appointments. The women were given the counsellors' telephone numbers and were invited to contact them if they had more questions, wanted to arrange an appointment or if they were concerned about their babies after birth. In those

sessions where the woman agreed to an amniocentesis, a consent form was completed. The counsellors made notes in the patient files and thank you and goodbyes were said.

This phase was characterized by marked variation in length and the closing of the session was (mostly) signalled by the counsellor asking a question such as 'anything else' or 'do you have any more questions for me?'. Other ways in which the counsellors initiated the closing phase was a reference to the plan after the session such as 'so you want to go back' and 'alright so I will try and organise..'. Other ways included 'let's do the consent', or 'how do you feel about what we've discussed', or 'so what I understand from you....'. Excerpt 6.12 illustrates the signalling of the closing stage of the session.

Excerpt 6.12: Session 05 Couns B Inexp – Closing stage

1205	**C:**	°oka::y°? (2.0)
1206		>Thembi is there anything else you want ask me now.<(2.0)
1207	**P:**	°until now no°
1208	**C:**	its oka::y
1209	**P:**	°uhm°
1210	**C:**	all right so let's go and you have to talk to Thandi

This excerpt shows how the counsellor moved into the closing stage of the session by using the transition marker 'okay'. The counsellor then asked the woman whether there was anything else she wanted to know.

Excerpt 6.13 shows the counsellor providing the woman with more information. As with the information-gathering and information-giving phase, several frames exist within the closing phase. In the example below the counsellor announces that she is going to give

the woman her card and thereby give her contact information should the patient need to speak to her again.

Excerpt 6.13: Session 10 Couns C Inexp – More information

1624	**C:**	>okay I want to give you my card.<
1625	**P:**	yes
1626	**C:**	this is so that you can phone me (.) if there is [any problems?]
1627	**P:**	[if there's any] problems
1628	**C:**	If you think of more que:stio:ns?
1629	**P:**	yes [I can phone]
1630	**C:**	[you can phone.]
1631	**P:**	yes

Another activity was also seen in closings as shown in excerpt 6.14.

Excerpt 6.14: Session 10 Couns C Inexp – Patient and her partner's discussion

1514	**P:**	then he said okay? Carry? on go? you'll >tell me when you
1515		come back how you <fou::nd> it and all that I said °okay° let me
1516		the problem is I want to know
1517	**C:**	[ri::ght]
1518	**P:**	[I] want MORE knowledge
1519	**C:**	to understa::nd.

Excerpt 6.14 shows that the woman shared information with the counsellor regarding discussion with her partner about attending the clinic.

The sequence of the closing phase consisted of many different types. As the excerpts illustrated, there were questions by the counsellors/answers by the women sequences such as excerpt 6.12 line 1206

FPP question by the counsellor

SPP answer by the patient

The counsellors often explained or provided more information, for example about contacting the counsellor after the session and so there were information/acknowledgement sequences shown as in excerpt 6.13 line 1624-1628

FPP information by the counsellor

SPP acknowledgment by the patient

The women also made conversational contributions and there were information/acknowledgement sequences as shown in excerpt 6.14 line 1514-1516:

FPP information by the patient

SPP acknowledgment by the counsellor

Very few studies have examined session closings and those that have, do not provide details. The activities during the closings in the present study were found to be similar to those described in one other genetic counselling interaction (Hodgson et al., 2009) and in primary care consultations (West, 2006) in which summarizing, making arrangements, announcing closure, farewells and inviting questions were described. There was no reference made to women making conversational contributions during closings in these studies. Women's conversational contributions were regarded as counselling segments and these are examined in more detail in chapter 9. It was also noted that, unlike the information-gathering and giving sequences the counsellors' and the women's gazes were almost exclusively directed at each other throughout the closings.

6.3.5 Decision-making sequence

The decision-making sequence of the session is defined as the stage at which the counsellors engage with the women regarding the decision about whether or not to have an amniocentesis. During these decision-making sequences, the counsellors engaged with the women regarding amniocentesis, ultrasound, and the possible outcomes. This sequence was flexible and was found to occur after either some of the information or all of the information had been discussed. The length of the sequences varied between the counsellors and the sessions.

Decision-making sequences were characterized by questions posed to the women to which they provided information rather than just yes or no responses. The women typically came to a decision after the counsellor had asked several questions. As a result, the decision-making sequences consisted of several cycles. The cycles began with a question from the counsellors focussing on the women's thoughts regarding the information. Excerpt 6.15 illustrates an initiation of the decision-making sequence wherein the counsellor asks the woman what she thought about the amniocentesis. The excerpt starts at the point where the counsellor had completed explaining the amniocentesis test. The counsellor then invites the patient to share her thoughts about the information just explained (the test) by the use of a wh-type interrogative. The question is designed as a perspective-display series (PDS), which invites the woman to talk about her thoughts, or attitude rather than just providing a yes or no answer. The woman responded by sharing that she is scared of doing the test.

Excerpt 6.15: Session 1 Couns C Inexp – How does this test sound to you?

1199	**C:**	how? does this test sound to you.
		picture
1200	**P:**	Eish (.) I am scared of this test really
		picture
1201		(2.0)
		picture
1202		yo? (1.0)
		picture *picture*
1203	**C:**	it does it look scary. - what, what scares you about this?

The counsellors in turn dealt with the women's answers in different ways as illustrated in excerpt 6.16. One way in which the counsellors responded was to provide the woman with more information specifically to clarify misunderstandings or to provide the information needed for her to come to a decision. Excerpt 6.16 shows information being communicated during the decision-making phase. Here the patient's comment 'this needle', in line 1250, is met with an explanation of the technical aspects of the amniocentesis procedure.

Excerpt 6.16: Session 1 Couns C Inexp – Information being communicated

1205	**C:**	what do you mean?
1206	**P:**	This needle,
		down
1207	**C:**	The needle doesn't touch, the baby. >what they do is you?<
1208		Know? the sonar?
1209	**P:**	Ja
		down
1210	**C:**	They look on the sonar
1211	**P:**	O::h
1212	**C:**	as they doing it
1213	**P:**	Ja
		picture *picture*
1214	**C:**	so it >doesn't go anywhere< near baby it just goes into the water
1215		(3.0)

During the decision-making sequences the women also made conversational contributions. As seen in excerpt 6.17 a woman responded to the counsellor's explanation (shown in the previous excerpt 6.16) by volunteering and sharing her thoughts and feelings and subsequently her decision.

Excerpt 6.17 Session 1 Couns C Inexp – How does this test sound to you?

		– – –

The decision-making phase had several different sequences. There were question/answer sequences, as seen in excerpt 6.15, where the counsellor asks what the woman thinks about the test. The questions/answer sequences were specific in that the woman shared information (PDS (Maynard, 1991) or initiating a reflective frame (Sarangi et al., 2004)). The sequence is therefore:

FPP Question by counsellor

SPP Answer by patient

Whereas in excerpt 6.16 the counsellor provided the patient with more information regarding the needle and here the sequence was an explanation/acknowledgement:

FPP explanation by counsellor

SPP acknowledgement by patient

There was also another type of sequence where the woman's talk was predominated by sharing or asking a question and the counsellor answering or acknowledging. This resulted in a mirror of the information delivery formats as seen in HIV sessions (Silverman, 1997). The sequence in these instances was as follows:

FPP Information by patient

SPP Acknowledgement by counsellor

Coming to a decision regarding having an amniocentesis performed or not was central to these sessions. This was the goal of the interactions and the counsellors stated during the openings that the woman would be given information about a test and that she would be required to make a decision regarding whether or not she wanted this performed. The

brief overall description in the above sections does not capture the complexity of the process of how the woman came to a decision. With regard to non-verbal behaviour, the counsellors mostly directed their gaze at the women, but both the counsellors and the women also direct their gaze at the files or pictures during parts of the discussions.

6.3.6 Counselling segments

In contrast to the other phases observed, counselling segments occurred throughout the session. The content or turn length of the segments varied considerably. The segments were characterized by the women sharing information and as a result, the sequences consisted of more talk from the women than the counsellors. The counsellors' responses consisted of minimal encouragers, paraphrasing, mirroring and questioning.

The topics discussed during these segments, in contrast to the rest of the session, included aspects of the women's life, such as personal experiences, beliefs, concerns and feelings. They did not include the genetic and medical aspects of being at an increased risk for fetal chromosome abnormalities due to maternal age. The focus of these segments was issues of interest to the woman and they did not always function to promote empathy. As a result, and in keeping with Kessler's terminology the word counselling was the preferred term (Kessler, 1997a). Kessler explained the counselling model as a process whereby the counsellors addressed the patient's fears, hopes and defences etc. These counselling segments therefore were concerned with the psychosocial aspects of genetic counselling. The focus of this section is to show one such a segment to illustrate its content and sequence (excerpt 6.18).

Excerpt 6.18: Session 10 Couns C Inexp – Empathic segment

289	**P:**	[it was very] very very difficult for me to:
290		accept <u>it</u> like (.) even >after like I (get birth) it was ectopic
291		and operation< (.) it was <u>hurting?</u> inside like I <u>did</u> it purposely
292		you see (.) but I know? that I didn't do it maybe God (.) ((cries))
293		saw that (.) I couldn't (.) go through with that <u>pain</u> you see ((cries))
294	**C:**	uhm (.) so it was for you it was a really ha:rd <u>emotional</u> ti:me
295	**P:**	°it was emotional time°
296	**C:**	and I can see it still upsets you?
297	**P:**	it's still(.) it's °still upsets me a lot°
298	**C:**	what was the ha:rdest part of that time for you?
299	**P:**	to lose the baby.
300	**C:**	° to lose the baby°
301	**P:**	because (.) after? I found out that I was (.) pregnant >I learned to as< (.)
302		accept it because I didn't want a baby< (.) you see (.)
303	**C:**	right
304	**P:**	so I learned to a accept it <u>when</u> I learned? to accept it then
305		that's happened it was very (.) <u>hurt</u>ful for me

The patient's talk is in response to the counsellor's question 'how was that time for you?'. In contrast to the rest of the phases, the woman shares a large amount of information. The counsellor uses her turn to acknowledge what the woman is saying and encouraged her to talk more with the use of counselling skills (Egan, 2001; Veach et al., 2003) such as paraphrasing (line 294), statements (296), questions (line 298), mirroring (line 300) and minimal encouragers (line 303). Throughout the exchange, both the counsellor and the woman looked at each other.

In genetic counselling studies, this type of interaction has been found, but it is not referred to as a counselling segment per se. It has in some cases been referred to in terms of voices, such as the 'humanistic voice', because the patients do more talking and the counsellor listens and responds with minimal response tokens (Babul-Hirji et al., 2010). Others have looked at whether and how often counsellors addressed emotional aspects (Butow & Lobb, 2004; Duric et al., 2003; Ellington et al., 2005; Ellington et al., 2006). As seen in HIV counselling sessions, in the counselling segments in this study, the counsellors were found to encourage the women's narrative (Miller & Silverman, 1995; Silverman, 1997).

The sequence of the counselling segments was characterized by more talk from the women. Such conversational contributions from the patient resemble a mirror of the information delivery formats as defined by Silverman (1997). The counsellors however, do not only respond by encouragers, but use several techniques such as paraphrasing and mirroring what the woman had said. The sequence was as follows:

FPP Information by patient

SPP Acknowledgement/response by counsellor

The extent of 'counselling' in genetic counselling has been questioned and how much, and if, counsellors use the counselling model has been queried (Butow & Lobb, 2004; Roter et al., 2006b). As counselling sequences were found to occur in these sessions and because there were questions regarding how genetic counsellors addressed the psychosocial aspects, further analysis of the counselling segments were warranted. This detailed analysis can be found in chapter 9.

6.4 Discussion

6.4.1 Thematic mapping

The process of sequence mapping (Sheon et al., 2010) allowed the 17 prenatal genetic counselling sessions to be characterized in terms of functional units and different discourse features. This approach resulted in six components being differentiated: an opening, information gathering, information-giving and closing phase, a decision-making sequence and counselling segments. Research on genetic counselling encounters has confirmed similar structures (Armstrong et al., 1998; Babul-Hirji et al., 2010; Butow & Lobb, 2004; Hodgson et al., 2009). Although the various studies described the components slightly differently, from the results of the present study there is clear overlap. The components identified in the current study can be aligned with the definition of genetic counselling (Resta et al., 2006): The *information gathering phase* aligns with 'interpretation of family and medical histories'; the *information giving phase* aligns with 'education about inheritance, testing, management, prevention, resources and research'; and *decision-making* and *counselling segments* align with 'counselling to promote informed choices and adaptation'. The overall mapping therefore provided some evidence for how the goals as set out in the definition of genetic counselling, are realised in practice.

The mapping further allowed the different phases to be characterised by specific discourse types. A discourse type is a way of characterizing forms of talk, for example, medical history taking or troubles telling (Sarangi, 2000). The discourse types were described in terms of their sequence (Schegloff, 2007) and it was found that the sequence was different

depending on the phase of the session. Different sequences occurred: question/answer; and information/acknowledgement sequences, where the counsellors asked the questions and provided the information. Similar sequences occurred, but where the roles were reversed and the women made conversational contributions and asked the questions, while the counsellors provided the information. What was shown was that the information gathering sequence consisted of a question by the counsellor and answer by the woman. In contrast, information giving was characterized by information provided by the counsellor and acknowledgment by the woman consistent with other research in genetic counselling (Babul-Hirji et al., 2010; Lehtinen & Kääriäinen, 2005; Lehtinen, 2005). Such sequences have also been described in medical (Halkowski, 2006; Mishler, 1984; Robinson, 1998) and other counselling (Silverman, 1997) interactions. Openings, closings and decision-making sequences consisted of both question-answer and information giving/acknowledging sequences, while the main discourse type in counselling segments were conversational contributions by the women, in that they provided the information and had acknowledgment from the counsellors. In terms of non-verbal features, differences were evident when examining the different phases. Although it was found that the counsellors and the women mostly directed their posture and gaze towards each other, their gaze were often directed at the patient files during information gathering and towards the pictures/graphics during information giving sequences, while their gaze was almost exclusively directed at each other during decision-making sequences and counselling segments.

The different phases or components of the session can be said to represent activity types while at an interactional level they show various discourse types. An activity type is regarded as characterising a setting such as a medical consultation or a university seminar

and a discourse type on the other hand is regarded as a way of charactering the form of talk such as medical history taking or troubles telling (Sarangi, 2000). The overlap between activity types and discourse types results in interactional hybridity. Within this framework, analysts are able to identity sections of activity types or discourse types for further analysis. However, as revealed by the overall description of the sessions in the present study, an analysis of a specific section does not represent the entire interaction and conclusions should not be drawn in isolation.

6.4.2 Ordered structure

The highly controlled structure was a very strong feature of the sessions in the present study and seems to be unique when compared with existing literature on genetic counselling. Except for openings and closings, when (or if) other components occurred during a genetic counselling session they were reported to be less rigid and interspersed (Armstrong et al., 1998; Babul-Hirji et al., 2010; Hodgson et al., 2009). For example, Hodgson et al. (2009) who studied genetic counselling sessions with women at an increased risk of having fetal abnormalities due to a screening test, found the screening test, diagnostic testing dialogue, and explanation of the conditions being tested for to be interspersed. Similarly Babul-Hirji et al. (2010), who studied genetic counselling sessions where a new diagnosis was communicated to parents found interspersed explanations. In cancer sessions, less structure was observed when the patients engaged with the genetic information (Armstrong et al., 1998). In contrast, analysis of a single antenatal genetic counselling session in South Africa, showed the session as comprising an introduction (reason for referral and 'what is going to happen'), family history, patient counselling and education, decision-making and referral, procedure and/or follow-up arrangements, which also revealed a tightly controlled agenda (Tovell, 2004).

Although an 'order of business' is necessary, as this is what distinguishes institutional talk from informal interactions (Heritage & Maynard, 2006), such a highly structured agenda was not seen in other interactions. The tightly controlled agenda found in the present study was evident not only in the strict order of the different components, but also in some of the techniques used by the counsellors, such as framing. The structure seems to serve a specific purpose in these sessions in that the counsellors use it as a way of guiding the woman through the genetic counselling process. This practice may be linked to the fact that all the women were referred to the clinic, resulting in the counsellors assuming that they were unfamiliar with the service.

6.4.3 Agency

The genetic counsellors had control over initiating the phases of the sessions as they were the first speakers. The counsellors therefore steered the interaction and chose which topic to initiate, how many questions to ask, before accepting the answer, and when to move to another topic. In addition, the women's voices hardly seemed to be heard. When the counsellors invited questions, the women in the majority of cases did not answer, and they made very few conversational contributions.

Such features in interactions have been reported as representing the 'Voice of Medicine' (Mishler 1984). This voice of medicine results in power asymmetry in that the doctor holds the power while the patient has little agency. There is debate relating to whether the power asymmetry is interactionally grounded rather than created (Pilnick & Dingwall, 2011).

In this context, it is argued that the power asymmetry is more than interactionally grounded. As both parties adhered to the structure, it seemed to flow without any disturbance. Even when the counsellors provided the women with interactional space by inviting decisions, they generally did not take these opportunities. The women usually remained passive and there were only 20 instances when they responded by initiating a question when given the opportunity. A major consideration was the fact that these women did not request the service but were referred in terms of hospital protocol. This power asymmetry might be linked to the socioeconomic groups to which these women belonged and their general lack of experience with participation in making health care decisions.

6.4.4 Phases for further analysis

The preliminary analysis as shown above provided a description of the overall sessions. During this process, three components were found to be particularly interesting: the opening, decision-making and counselling segments. A decision was taken to analyse the data further based on the phases identified. Further analysis could have been directed by other phenomena such as communicating information or risk communication. Using the phases as a starting point for analysis, risked producing an analysis that may be too restrictive as it may be forced to keep within the structures identified. The analysis however developed in this way as the researcher wanted to investigate what the interactions looked like rather than examining specific phenomena identified in other research.

The opening phase was thought to be particularly interesting as the reason for the interaction was established and it set the tone for the rest of the session. The way in which the women and the counsellors oriented towards a particular agenda was revealed. In the openings, it was clear that the women did not request the consult but that they had been referred. As a result, further analysis of the opening phase seemed worthwhile and these findings are discussed in chapter 7.

Decision-making was a pivotal activity in the sessions as the women needed to decide whether or not they wanted an amniocentesis performed. Therefore, the decision-making sequences, which revealed the ways in which the women moved towards making a decision, were analysed further and this is discussed in chapter 8.

The counselling segments were in contrast to the rest of the session as the women made some significant conversational contributions. As a result the counselling segments, in which the women discussed their fears, concerns and experiences, was worthy of further attention and this analysis is discussed in chapter 9.

6.5 Summary

This chapter described the overall structure of the 17 sessions and illustrated the strict order in which the components occurred, with openings followed by information-gathering, information-giving and a closing. Two other phases, decision-making and counselling appeared to be less organised with decision-making sequences occurring during or after information giving, and counselling segments appearing at any stage in the session. It was possible to identify each phase by the function it had during the session

and within this framework, it was possible to examine the sequence organization. The non-verbal features were described in terms of an overall impression and showed that the participants gaze was mostly directed at each other or the files or pictures on the desk or the lap of the counsellors. This revealed the hybrid nature of genetic counselling sessions as an activity type. The rigid structure is suggested to have been deployed to assist the counsellors to complete the session and the researcher suggests that this is a unique feature associated with the context and setting of the study and the institutional discourse. Finally, the three phases that were selected for further analysis were outlined.

Chapter 7 Results II - Analysis of the Opening Phase

The preliminary analysis of the opening phase revealed several features, which suggested the need for further analysis. In particular, how the counsellors established why the women were referred required further analysis. Further examination of the openings revealed more structures within the opening phase and this chapter begins by describing these elements followed by an analysis and discussion of the interactional features of the openings.

7.1 The overall structure of the opening phase

As shown in the previous chapter, the opening phase was the beginning of the genetic counselling session and took on average 2 min 38 seconds, ranging from 1 min 42 sec to 3 min 43 sec. The elements contained in the opening phase included:

- an introduction sequence,
- a greeting sequence,
- reference made to the current research project,
- setting an agenda,
- an explanation of the reason for referral,
- an explanation of what to expect in the session,
- an invitation to ask questions, and
- an offer of observation

Table 7.1. *Summary of the sequences in the opening phase*

Opening sequences	**SESSIONS**															
	P01 01:42 CnsA	**P02** 02:11 CnsB	**P03** 02:12 CnsB	**01** 01:34 CnsC	**02** 03:43 CnsA	**05** 02:17 CnsB	**06** 01:45 CnsA	**07** 01:35 CnsC	**08** 02:32 Cns F	**09** 02:04 CnsD	**10** 01:54 CnsC	**11** 02:15 CnsA	**12** 01:42 CnsD	**13** 02:59 CnsE	**14** 01:52 CnsE	**15** 02:11 CnsE	**16** 03:33 Cns F
Introduction sequence	N	Y	N	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y
Greeting sequence	N	N	N	N	N	N	N	Y	Y	N	Y	N	N	N	N	N	Y
Reference to research	N	Y	N	Y	Y	N	N	N	N	Y	Y	N	Y	Y	N	N	N
Inviting questions	Y	Y	Y	N	Y	Y	N	N	Y	N	N	N	Y	N	N	Y	Y
Offer observation	N	N	N	N	N	N	N	N	N	N	N	N	N	N	N	Y	N
Setting agenda	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Explanation of reason for referral	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Explanation of what to expect in session	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Y – Yes
N – No

There were some differences between the sessions regarding the occurrence of some of the elements and not all were included in all sessions. The introduction sequence, greeting sequence, reference to the research, invitation to questions and offers of observation did not occur in all sessions, while an attempt to set an agenda and an explanation of what to expect from the session occurred in all the sessions with very little variation between them. Table 7.1 is a summary of which elements of the opening sequence appeared in each of the sessions, how the length of the phase and who the counsellor was.

As discussed in the previous chapter, the openings of the genetic counselling session in the current research were found to be very similar to the openings of medical encounters (Byrne & Long, 1976; Heath, 1981, 1986; Robinson & Heritage, 2005; Robinson, 2006; Robinson, 1998) and other genetic counselling encounters (Armstrong et al., 1998; Babul-Hirji et al., 2010; Butow & Lobb, 2004; Hodgson et al., 2009). Further examination of the structure of the openings and the distinct elements that this revealed, allowed more in-depth comparison with medical encounters. In these encounters, the openings have been divided into the 'preliminaries' and 'soliciting presenting concerns' (Heath, 1981, 1986).

In the genetic counselling interactions in the present research, the introductions, greetings and reference to the current research project were aligned with the 'preliminaries'. The preliminaries consisted of an introduction sequence, a greeting sequence and a reference to the current research project. An introduction sequence occurred in 13 of the 17 sessions. In the four sessions where there was no introduction sequence, it was very likely that this took place before the recording of the session started. A greeting sequence only occurred in four of the 17 sessions. This "how are you" typically involved the counsellor asking the woman how she was with the woman replying. A greeting in these genetic counselling

sessions is thought to function as a way to establish rapport, rather than an attempt to solicit a concern. The counsellors referred to the current research project in seven of the sessions. Introducing the research into the session, may indicate that the counsellors were conscious of aspects that might have influenced the session and actively attempted to address these. The preliminaries therefore allowed the counsellors and the women to establish co-presence (Hodgson et al., 2009; Robinson, 1998) as they covered introductions and greetings, and talked about the current research project. This initial interaction also assisted the participants in building a relationship (Byrne & Long, 1976; Hodgson et al., 2009).

The structure of the genetic counselling session opening, based on its contents, is illustrated in figure 7.1

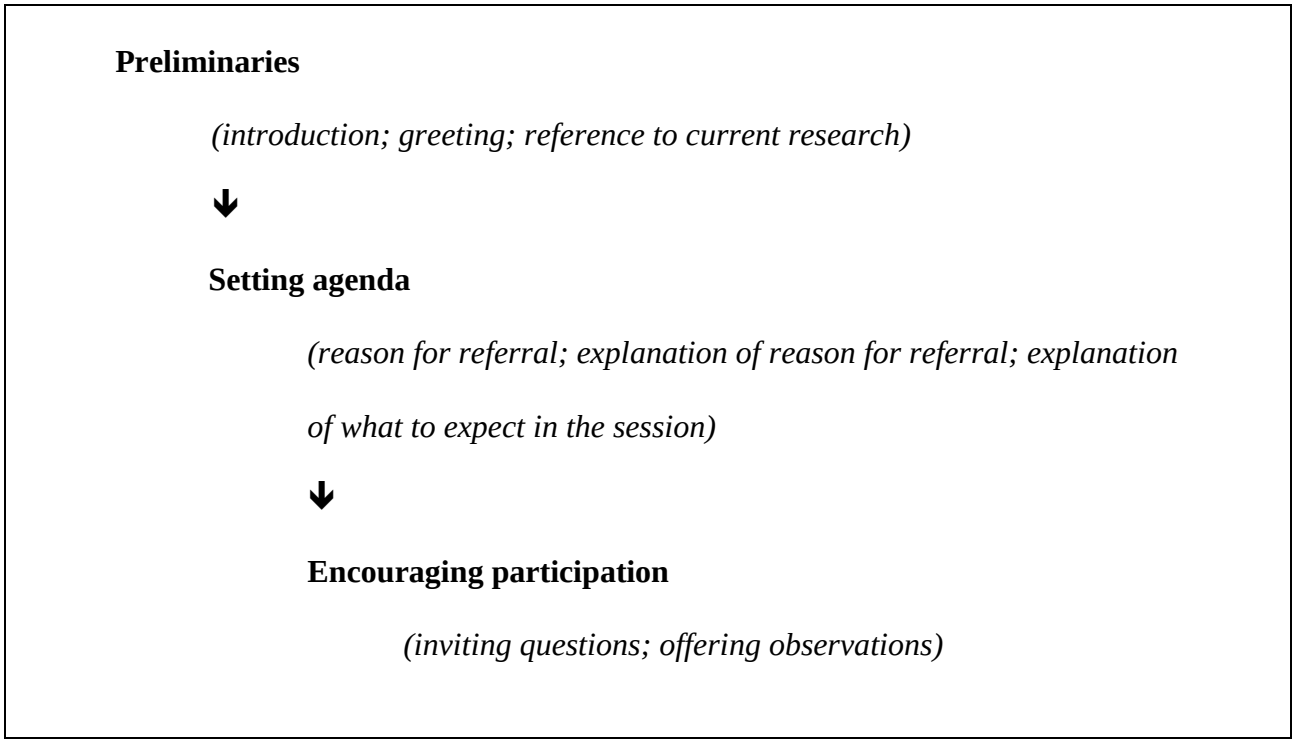


Figure 7.1. *Diagram of the structure of the opening phase.*

Setting of an agenda, explanations of the reason for referral, and what to expect from the session align with 'soliciting presenting concerns'. This is where the counsellors establish the reason for the referral and explain what to expect from the session. In addition, in medical encounters it was found that patients were encouraged to keep talking by the doctor offering observation and by the use of silence (Byrne & Long, 1976). Similarly, in the current research, the women were encouraged to ask questions and the counsellors offered observations.

7.2 Setting an agenda

Setting an agenda for the genetic counselling session was an explicit and deliberate process occurring in all 17 sessions. Setting the agenda involved: the counsellors asking the women why they were there, the women's responses, the counsellors' explanations of the reason for the referral and expectations for the session.

From a content perspective, the opening questions from the counsellors could be divided into four groups: 1) 'did the doctor explain to you' (six sessions); 2) 'do you know why….' (six sessions); 3) 'what did the doctors tell you' (three sessions) and 4) 'other' (two sessions). The women responded to the counsellors' opening questions regarding their referral either by saying: 'it is because of age' (11 sessions); that she did not know (5 sessions); or she gave another reason (2 sessions). In all cases, the counsellors responded to the women's answers, regarding why they were there, by referring to advanced maternal age as the reason for the referral. When the women said it was '*because of age',* the counsellors confirmed that this was correct. When the women *did not know* why they were referred, the counsellor, in some cases, explored further by enquiring how the

woman was referred (the sequence of events and details of who referred and when) before ultimately explaining the reason for the referral. In two sessions in which the women gave *other reasons* for referral, the counsellor stated that it was advanced maternal age.

There was little variation between the sessions regarding the counsellors' explanation of advanced maternal age and included the following details: advanced maternal age being 35 years and older, increased risk for abnormalities, the availability of testing, the gestational age at which testing is performed, the woman has a choice, the associated problems, and the associated risk. The explanation of what to expect in the session were either a statement such as: 'I just want to get your details', or a discussion of what to expect step by step. The explanation outlined most of the agenda items: obtaining personal details, obtaining information regarding the woman's family and medical history, drawing a pedigree, and providing information on chromosome abnormalities, risks and available testing.

In examining the openings more closely a key feature of the opening phase was that setting an agenda did not necessarily allow the women's concerns to emerge. In medical encounters where doctors elicit patients' presenting concerns (Byrne and Long 1976; Heath 1981; Robinson 2006), different question formats were found to elicit different types of information (Robinson, 2006). What medical practitioners did however, was ask the patients why they were there and how they could be helped. The question formats used by the genetic counsellors, in the present study, elicited from the women what they were told about their age as being the reason for the referral. The format did not allow the woman to talk about what they thought about their age that resulted in referral. The women answered as to whether they knew why they were referred and not as to what they

were concerned about. The women's answers therefore provided counsellors with information regarding who referred them, how they were referred and what they were told about the referral.

The way in which the counsellors framed their questions showed that they knew that the women attended the sessions because they had been referred, from a medical professional, generally a doctor, and that they should have been given information about the necessity for referral. The way in which the questions were asked provided the women with a frame in which they could provide answers such as in excerpt 7.01, where the counsellor frames that she is now going to ask the woman a question (line 8).

Excerpt 7.01: Session 01, Couns C Inexp – Do you know why they've referred you?

		_ _ _

The excerpt shows that the counsellor's question is designed in such a way that it provided the woman with an opportunity to answer in relation to her knowledge regarding the referral. The woman's response (line 10) shows that she orientates to the question being about whether she knows why she was referred. Her 'no' reply indicated that she did not know the reason for referral. The counsellor pursues this further by asking 'did they mention anything to you' (line 11). Even when the counsellor attempted again in line 11 by putting the emphasis on the word 'mention', the focus was on whether or not the woman was given relevant information. The woman's response (line 12) suggests that she also orientated towards the information that should have been conveyed when she replied she didn't 'even know about this genetic counsellor'. The emphasis on the word 'know' suggests that information was not conveyed. Further, in the counsellor's b-event statement (lines 20-21) she again placed emphasis on the fact that the woman did not get an explanation of why she was referred when she said 'they didn't explain why'. The emphasis on the 'why' illustrates that the reason is important and that the counsellor expected the woman to have been given some relevant information.

The excerpt illustrates the emphasis on eliciting what the woman knew about the referral. The excerpt also illustrates that the counsellor knows that the referral is from a doctor as shown in lines 8 (they've) and 11 (they) when she started off referring to 'them' and then clarified in lines 16 (the doctors) that by 'they' she meant the doctors. Further evidence can be seen in excerpt 7.02 where similar features were present.

Excerpt 7.02: Session P01, Couns A Inexp – You weren't too sure

1	**C:**	Alright so (name) said to me, (.) that you
2		weren't too? sure about why the doctors
3		wanted you to come to see us today.
4	**P:**	Yes.
5	**C:**	okay,
6	**P:**	yes.
7	**C:**	Did they say anything to you?
8	**P:**	No
9	**C:**	No? so you're a bit (.) confused? about why
10		you're coming to see us?
11	**P:**	Yes
12	**C:**	Are you worried? (.)
13	**P:**	Yes? I'm worried?
14	**C:**	because you didn't know why they say, they
15		said go to genetics,
16	**P:**	uh hu
17	**C:**	okay,
18	**P:**	Yes
19	**C:**	So Mary the reason the doctors wanted you to come

In the counsellor's b-event statement (line 1-3), she placed emphasis on what the woman knew about the reason why the doctor wanted her to be referred. The woman's response (line 4) confirmed that she orientated to the statement concerning her uncertainty as to why she was referred being a question which required and answer when she replied with a 'yes'. The counsellor's frame of eliciting what the woman was told about the referral is further evident in lines 9-11. She used a b-event statement and the intonation of the word 'confused' to ascertain how the woman felt about the fact that she did not know why she had been referred. The counsellor attempted to probe further by asking whether this was

causing the woman concern (line 13) and when the woman confirmed that she was worried, the counsellor in her response, linked this to the fact that she was not told why she was referred. This excerpt also showed that the referral was from a doctor when the counsellor explicitly referred to 'the doctors' in lines 2 and 19.

The excerpts showed how the counsellors formulated their questions in specific ways which provided the women with a narrow scope of producing her concerns. This limited the women to provide information relating to what she knows about her referral rather than allowing her to express and share (if any) other concerns. It would seem that the counsellors' aims during this questioning is primarily to gain information regarding the women's knowledge of AMA as increasing her risk of having a child with abnormalities, thereby preparing the ground to provide the women with the relevant information. Evidence for this orientation to the opening question being asked in the service of gathering information rather than exploring the women's concerns, is supported by the way in which the counsellors respond to the women's answers.

Irrespective of the women's answers regarding their reason for the referral, the counsellors informed them that they were referred for a discussion of maternal age. Whether the women knew, did not know or gave another reason (two sessions), the counsellors' responses to the women were uniform. They accepted the women's answers when they referred to maternal age as being the reason for their referral. When a woman did not know, or she gave another reason, the counsellor introduced maternal age as the reason for the session. The counsellors made it clear that the reason for the genetic counselling sessions was advanced maternal age, as shown in excerpt 7.03.

Excerpt 7.03: Couns A Inexp, Session 02 – Referred for age

15	**C:**	Okay ((nods)) did the doctors? explain? to you why you must come
16		and talk to us today? (.) did they say why?
17	**P:**	they say sometimes it happen I have an abnormal baby.
18	**C:**	okay? (.) and did they say why?(0.2)
19	**P:**	>age<
20	**C:**	the >age< okay (.) so that's right (.) so the reason that you come they
21		wanted you to talk to us today is because of your age>you're 36?
22		now<
23	**P:**	Um ((nods))

In excerpt 7.03, the patient in her response, confirmed that she was told that she could have an abnormal baby (line 17) and that this was because of her age (line 20). The counsellor accepted the woman's answer when she repeats 'the age' and followed-up with an explicit statement 'that's right' also placing emphasis on the word 'right', indicating that maternal age was correct. There is an evaluative nature in the counsellor's response which supports the argument that the opening questions are produced as way of gaining information as to what the women's current knowledge are so that the counsellor can then start the discussion about maternal age.

When a woman did not know why she was referred the counsellor informed her that the reason was advanced maternal age. This is shown in excerpt 7.04 below. In response to the woman saying that she did know about this "genetic counsellor", the counsellor started introducing the reason for the referral. The counsellor laid the ground for her discussion, which will follow later by referring to the process of how the woman came to be referred to the clinic. The counsellor first introduced age when she checked in line 26, 28 whether

the woman was over 35 years of age and pregnant before proceeding to explain in lines 32 and 34 that at the genetic clinic all women over 35 years were seen. In lines 39 and 41 the counsellor explicitly stated the reason for the referral as maternal age ('because of your age'). The emphasis on specific words i.e. 'our' and 'pregnant' (line 32), '35 years old or older' (line 34), and 'age' (line 39) highlighted that the reason for the referral was maternal age. The woman's response (in line 36) to the counsellor's explanation when she acknowledged that she was told to 'see the counsel' after 35 years of age, also suggested her orientation that age was the reason for the referral.

Excerpt 7.16: Session 01, Couns C Inexp – Do you know why were referred

		file
8		I just want to ask do you know why they've
9		referred you to us today. (.)
10	**P:**	no. (1.0)
11	**C:**	did they mention anything to you (.)
12	**P:**	no nothing, I don't even know about this
13		genetic counsellor, [I don't know]
14	**C:**	[okay]
15	**P:**	what it is about,
		file
16	**C:**	Okay so the doctors saw you? On, (.) the (.) ((date))
17	**P:**	[yes:]
18	**C:**	and they did a sonar↑
19	**P:**	yes?
20	**C:**	and then (.) they send you must come to genetics but they didn't
21		explain why. (1.0)
22	**P:**	no. [°they didn't°]
23	**C:**	[okay]
26	**C:**	so how? old are you at the moment.

27	**P:**	((age)) [now.]
28	**C:**	[you're] ((age))
29	**P:**	((nods))
30	**C:**	okay and you're pregnant?
31	**P:**	yes?
32	**C:**	>alright< so at our clinic we see all moms who are pregnant↑,
33	**P:**	((nods))
34	**C:**	and they are 35? years old. or older.
35	**P:**	Hmm ((nods))
36	**C:**	oka:y
36	**P:**	Ja they told me after 35 then we have to see the counsel. (.)
37	**C:**	okay so they did? talk to you about it
38	**P:**	[yes that's what]
39	**C:**	[so it's because] of your a:ge.
40	**P:**	yes:
41	**C:**	that they've sent you here,
42	**P:**	Ja.
43	**C:**	so we know that (.) every single person who's pregnant,
44		>has a chance of having a baby with a problem.<(.)

Similarly, Excerpt 7.05 below, shows the counsellor's emphasis on maternal age being the reason for the referral. By using the discourse marker, 'so' (line 19) the counsellor indicated that a new topic would be discussed and stated explicitly that the doctor wanted the woman to be seen because of her age (line 28).

Excerpt 7.05: Session P01, Couns A Inexp – Reason they ask you to come and see us

19	**C:**	So? Mary the reason the doctors↓ wanted you to come
20		see us, is not that (.) they saw any problems on the sonar (.)
21	**P:**	Huhu nods
		file
22	**C:**	okay they did <u>one?</u> I saw your first you had a dating scan on the 20th.
23	**P:**	yes
24	**C:**	okay?
25	**P:**	Yes ((nods))
26	**C:**	So it's not that they saw any problems with that the only? reason
27		they asked you to come see us? (.)
28		is because of your a:ge. (.)
29	**P:**	°Hmm°

The emphasis on the reason for the referral being advanced maternal age is even more evident in the counsellors' responses when the women suggested other reasons for their referral for genetic counselling. This occurred in two sessions. In Excerpt 7.06 (below) the woman responded to the counsellor's question of whether it was explained to her as to why she was referred, by stating that she had explained to the doctor that she had had a number of spontaneous abortions and that she wanted to be sterilized (lines 7-13). The counsellor's response in line 16 was to redirect the conversation to age by asking the woman her age. The women gives her age and the counsellors then proceeds to explains (lines 25-26) that the reason was because of her age and that all woman over 35 years were referred. When the women responded to the counsellor's opening question by stating a concern, the counsellors' redirection to maternal age, suggest that they ask the opening questions as a way of gaining information about the woman's knowledge with regard to AMA rather than being interested in any of her concerns.

Excerpt 7.06 21: Session 12, Couns D Exp – They see the miscarriages

3	**C:**	>did the doctor's< explai:n? to you. (1.0)
		away
4		why? they want you to s- talk to us (2.0)
5	**P:**	no:
6	**C:**	they [didn't-]
		file
7	**P:**	[cause] me I'm explain to the doctor because they
		file
8		see the miscarriage I got how many ((seven))
		file
9		I got it [I say]
		file
10	**C:**	[okay]
		file
11	**P:**	I say I suppose to: sterilize last of last year
12	**C:**	okay
13	**P:**	but they never sterilize I want to sterilize
14	**C:**	okay
15	**P:**	ja they say that I can
		file
16	**C:**	and how old are you now Bethinah↑
17	**P:**	I'm fo:rty now
		file
18	**C:**	you forty oh? you turn forty >this year happy birthday<
		file
19	**P:**	ja [((laugh))]
20	**C:**	[all right] so: what what we ((just want to see year okay)) (.)
21		we: are from the what we call the genetics department↑
22	**P:**	((nods))
23	**C:**	the words don't matter
24	**P:**	uhm
25	**C:**	what we do is we talk to all women who are
26		more than 35 years old
27	**P:**	o::kay: ((nods))

Similarly excerpt 7.07 shows the woman's concern was not taken into account when the agenda was being set as can be seen in lines 16 - 24. The counsellor paraphrases (formulation) (line 13, 14) the woman's response that she was scared about her hypertension. Initially, the woman's confirmation in line 19 was met with an explanation that they will be talking about advanced maternal age, the problems that can happen as well as testing that can be performed (lines 22 to 26), placing emphasis on age being the reason for the referral and the goal of the session.

Excerpt 7. 07: Session 14, Couns E Exp,– All we gonna do now is talking

7	**P:**	Ye:s because I'm litt↑le bit a scared about my
8		pregnancy so I have a high blood pressure↑ (.)
9	**C:**	ri:ght
10	**P:**	so:to do that procedure I think °ja°(1.0)°it's °(1.0)°little bit °(1.0)
11	**C:**	right to do <u>which</u> procedure.
12	**P:**	I: think it's this u:hm genetic (.) tic (.)°ja°
13	**C:**	okay so you're <u>worried</u> that <u>because</u> you've got
14		problems with high? blood pressure?
15	**P:**	yes
16	**C:**	that anything else we might need to do
17	**P:**	uhm
18	**C:**	is gonna cause <u>mo:re</u> [problems]
19	**P:**	[Ja::,] ja:
20	**C:**	okay(.) so Harriet all we gonna do <u>now</u> is talking (.)
21	**P:**	okay
22	**C:**	uhm all I'm gonna talk to you <u>abou::t</u> is uhm (.) the <u>age</u>(1.0)
23		°ja°
24	**C:**	and sometimes the problems that can happen when a woman is <u>older</u>?
25	**P:**	°okay°
26	**C:**	and what the tests <u>are</u> that we can offer you.
27	**P:**	°okay°

Setting an agenda has been investigated extensively in genetic counselling interactions as well as medical interactions. Whether the agenda is doctor or patient led received a lot of attention with different findings from various studies. In genetic counselling studies, findings on the agenda showed great variation. Establishing the agenda was found to involve asking the patients questions, such as 'what important questions or issues did you hope we can go over today?' (Butow & Lobb, 2004). An agenda was discussed in 95% of cancer genetic counselling cases (Pieterse et al., 2005) while no negotiation at the beginning of the session of what the patient's concerns were or what needed to be discussed was found in a study by Smith et al. (2000). Setting the agenda in the interactions in the present study is counsellor-driven as found in other studies (Smith, 2000, Butow & Lobb, 2004). With the exception of two sessions, the women did not state their own reasons for being at the clinic and they did not share their concerns what they would have liked to have known about. Further, the framing of the questions, the techniques used by the counsellors and the uptake of the women's responses allowed for the setting of a narrow agenda. This narrow agenda is evidenced by the question formats, which is directed at gaining information of the women's knowledge of AMA risks. The counsellors use this information to introduce the concepts of AMA and open up an interactional space for providing the women with information regarding their risks, relevant procedures and options.

The counsellor driven agenda also seems to be influenced by the medical system and the genetic counselling agenda. To a degree, the reason for the interaction is determined partly by this medical indication and this seemed to have influenced the interactions due to the counsellors' opening questions being rather to gather information than exploring the women's concerns. The genetic counselling agenda is that: *As a woman's risk of having a*

baby with a chromosome abnormality increases with maternal age (artificial cut off at 35 years), such at risk women should be offered genetic counselling and prenatal genetic diagnosis. Both participants reveal this agenda in the interactions and shows how the genetic counselling session is 'talked into being'.

On several occasions during the interactions, the counselled referred to the referral system. The mention of the referral system in the present study also reveals how the participants are producing 'the institution of genetic counselling'. As the analysis of the opening questions illustrated, the way the questions were framed showed that the counsellors worked within a system where (mostly) doctors (shown in excerpts 7.01 and 7.2) referred woman over the age of 35 years for genetic counselling. Further, as excerpt 7.01 showed (lines 15-20) there is a referral system in place whereby the doctors will see a woman determine her age, perform an ultrasound evaluation and then refer those of advanced age for genetic counselling. The counsellors' emphasis on 'at our clinic this is what we do' is positioning the genetic clinic within the referral and bigger institutional setting. It was also evident that not only the genetic counsellors and the doctors, but also the support staff was familiar with this referral system, as shown in excerpt 7.02 where the counsellor (lines 1-3) stated that the support staff informed her that the woman was not informed about the reason for the referral.

7.3 Agency

The tightly controlled structure of the opening phase and the way in which the agenda was set allowed the counsellors to exert control over the interactions. The counsellors controlled the agenda by the way they framed their questions and their uptake of the

women's responses as they chose whether or not use the given information. The counsellors drove the process, made decisions about what should happen next in the session, and initiated the different phases during the openings. The genetic counsellors had a clear goal going into the session that was evident by the rigid structure they followed, which involved frames to shifts topics and specific questions designs. The excerpts in the previous section illustrated this.

It was also found that the women had less agency in these interactions as seen in the counsellor's uptake of the women's responses. In two sessions, the women introduced another reason or concern for their attendance at the session, the counsellor redirected the talk to maternal age. In the previous section, excerpt 7.06 and 7.07 showed that the counsellor introduced maternal age when the woman was concerned about miscarriages and when the woman was scared about her maternal hypertension. It seems that in the rare instances when the women participated and shared, the counsellors choose to introduce maternal age, negating the women's contribution.

Further evidence that the women appeared to have little choice but to follow the counsellors' agenda, manifested in their failure to respond when they were given interactional space. Explicit attempts from the counsellors to involve the woman were made in eight sessions, in which the women were invited to ask questions or to ask for clarification. However, the women's responses suggest that they did not perceive themselves as having much agency. Excerpt 7.08 shows the woman responding by saying 'no I've got no questions'. The rise in intonation of the 'no' in line 109 and the 'hmm' in line 111 indicated hesitancy. The counsellor gave the woman two opportunities but she did not voice any concerns.

Excerpt 7.08: Session 16, Couns F Exp – I've got no questions

107	**C:**	°okay° (1.0) have you got any
108		questions for me so↑ far.
109	**P:**	No? (I've got no questions)
110	**C:**	°no questions° okay
111	**P:**	hmm?

Similarly in excerpt 7.09, the women did not raise concerns. In addition the excerpt shows that the woman treated the counsellors' invitation as news.

Excerpt 7.09: Session 12, Couns D Exp – I must ask

		File
49	C:	>and you must please<? (1.0)..hh if I'm
50		going too quickly?
51	P:	Uhm
52	C:	Or you're not understanding me?
53	P:	I must ask (you again)
54	C:	you must tell me to >stop<.
		file
55	P:	O:h↑
		file
56	C:	[alright.]
		file
57	P:	[°alright°]
		file
58	C:	so …….

The woman initially responded to the counsellor by saying 'I must ask..'. Her responses further down in lines 55, 57 showed that she treated the invitation from the counsellor as unexpected. The rise in intonation of 'oh' and the softly spoken 'alright' indicated that this process is unfamiliar.

Similarly, in excerpt 7.10, the woman's response to the counsellor inviting her to interrupt if she did not understand demonstrated this request to be unusual. The rise in intonation (line 53) on 'aai' followed by saying 'you can talk' could suggest the woman's unfamiliarity and uncertainty with the situation and resulted in her opting to allow the counsellor to continue her discussion. Penn & Watermeyer (2012) found patients in the South African healthcare setting to have high regard for the doctors as a result the woman might have felt that she had to go along with the counsellor out of respect for her as a professional.

Excerpt 7.10: Session P03, Couns B Inexp – Aai you can talk

		_ _ _

to exercise control over, contributed to the counsellors having more agency than the women do. In excerpt 7.08, the counsellor's questions (line 107) were asked after she had explained to the woman that the doctors wanted the genetic counsellor to discuss the test that is offered to women of AMA. It therefore seems that the invitation to ask a question is limited to the preceding information provided by the counsellor. Restrictions placed on what the women can ask questions about it, was further evident in excerpt 7.09. Here the counsellor did not invite the woman to ask a question as shown in lines 49-52 but rather stated that woman should stop her if she is 'going too quickly' or if she is "not understanding'. It suggests that even though the counsellor opened up interactional space for the woman, the woman was limited to respond to the speed and the content of the information which will be delivered.

7.4 Counselling versus teaching

The genetic counsellors made several attempts during the openings to position themselves as 'counsellors', and building a relationship received much attention. The introductions, greetings, reference to the current research project and attempts to set an agenda, inviting questions and offers of observation were all strategies the counsellors used to build rapport and include the women. The counsellors placed emphasis on the relationship and on putting themselves and the women on an equal footing. There seems to be tension between attempts to build a relationship and controlling the agenda and these are discussed further in the discussion.

The counsellors made an effort to include the woman by the way they introduced themselves informally, by first name only, as shown in excerpt 7.11. By doing this, the

counsellors were indicating their wish to talk on equal terms and may also have been emphasizing that the genetic counselling session was also a 'counselling session', rather than a medical encounter.

Excerpt 7.11: Session 01, Couns C Inexp – Typical introduction sequence

		_ _ _

encounters. The counsellors took care to explain the reason for the referral as seen in excerpts 7.11 and what the woman could expect to happen during the session.

Excerpt 7.11: Session 07, Couns C Inexp – Typical explanation of the reason for referral

20	**C:**	okay so at our clinic here at genetics? (.) we see
21		all moms who are pregnant (.) who are 35? years
22		old or older (1.0)
23	**P:**	okay
24	**C:**	uhm and we talk to them about (.) problems
25		that (.) can? Happen? (.)
26		uhm, just because we (.) get older (.)
27	**P:**	((nods))
28	**C:**	so uhm sometimes there >can be problems with the baby<
29		that are associated with (.) what we call advanced
30		maternal age being? 35 years or older (.) °okay°
31	**P:**	okay ((nods))
32	**C:**	we are just gonna talk about those problems? what
33		they are? what the doctors mean when they say that (.)
34		and then what test can be offered to you if you want
35		to have a test or not (.) okay? (.)

The counsellors attempted to engage the women further by checking whether they agreed with the process, asked them if they had any questions, and made observations. While the counsellors' questions and strategies did not encourage the women to talk about why they were there, it can be said that the counsellors, by merely asking the women whether they knew why they were referred and by guiding them through the session, were attempting to build a relationship. In the medical system in which the counsellors' practice, patients are not usually asked what they know (Penn & Watermeyer, 2012) and therefore the genetic counselling interaction was different from other medical encounters in this setting, as

might be expected, since counselling strategies promote starting where the patient is at, building rapport and relationship and interactional equality.

In eight of the 17 sessions, the counsellor invited the woman to ask questions if there was anything that she did not understand. In excerpt 7.12, the counsellor's question followed her explanation of what was going to happen during the session. The yes/no interrogative resulted in the woman responding by choosing the 'no' option. The counsellor did another check before accepting the woman's answer.

Excerpt 7.12 14: Session 16, Couns F Exp – Any questions for the counsellor

107	**C:**	°okay° have you got any
108		questions for me so? far.
109	**P:**	No? (I've got no questions)
110	**C:**	°no questions° okay
111	**P:**	hmm?

Inviting the women to ask questions seems to be an attempt to encourage them to participate in the session (Byrne & Long, 1976). Invitations for questions occurred after the agenda was set. By their approach the counsellors indicated that they knew that the information was new and complex and that it was understandable, even expected, that the women might not have been able to follow and therefore they had permission to ask for clarification. Simultaneously, they conveyed that they wanted the women to participate in the session.

The one instance where the counsellor addressed the woman's non-verbal behaviour. In excerpt 7.13, after explaining what the reason for the referral was, the counsellor made the remark that the woman looked worried. The counsellor offered the observation after she

had given the woman an explanation of the reason for her referral during which she mentioned that '…. problems can happen in the pregnancy when a woman is older.…'.

Excerpt 7.13: Session 15, Couns E Exp – You look worried

		_____
47	**C:**	Bongumusa you look very worried (1.0)
		_ _ _ _ _ _ _ _ _ _ _ _ _
		away
48	**P:**	.hhh n::o (1.0)
		_____
50	**C:**	you're not (.)
		___
51	**P:**	No
		_____
52	**C:**	you feeling okay?
		_____
53	**P:**	>yes<
		_____
54	**C:**	°okay° Bongumusa if you've got (.)
		_____
55		you must ask me any? questions if you want to
		_____
56		Okay? if you're worried about anything, you must just (.)

The counsellor did not accept the woman's first negative response, as can be seen by her two further attempts (lines 50 and 52) at giving the woman an opportunity to discuss her 'worry'. It can even be said that, although the counsellor finally acknowledged that the woman was not worried, the counsellor did not fully accept this response as she continued to invite questions (lines 54-56). Doctors were shown to offer observations in one study (Byrne & Long, 1976) and such observation seemed to have the same effect as asking a direct question. The effect of this action was to focus the patients' attention on what tensions or fears they might have. Byrne and Long (1976) found this activity, together with silence, was followed by patient participation and that such sessions tended to be longer. Although there were few instances in the present study where the women were invited to ask questions, and only one example of an offer of observation, none of these actions resulted in increased participation.

At the same time, the session was about education regarding the risks and options associated with advanced maternal age. The counsellors ensured that the women understood that the reason for the referral was advanced maternal age, and they took much care in explaining the associated types of abnormalities and risks. The counsellors outlined the reason for the referral and what to expect from the session conveying that the goal of the session was education. The fact that the women were often invited to ask questions, showed the importance of their understanding of what was being explained. Both the content and the strategies (which included the rigid structure of the openings and the uptake of responses) used were in contrast to the counsellors' use of other strategies which were focused on relationship building. In addition, as was seen in the previous sections, the ways in which the counsellors set the agenda and the invitations to the women were rather restrictive and suggested an emphasis on the educational role of the counsellors. The simultaneous inherent emphasis on the educational role and seemingly overt attempts to fulfil a counselling role seems to results in tension between the activities of counselling and teaching in the interactions in the present study. This begs the question as to whether counsellors are attempting to fulfil their counselling role because this is expected of them, or whether this tension between the activities of teaching and counselling reflects the difficulty of achieving both in an interaction.

7.5 Discussion

A more detailed analysis of the opening phase of the genetic counselling sessions revealed some unique features that have not been reported in previous research in genetic counselling encounters. It has been reported that genetic counselling sessions are opened with preliminaries (Armstrong et al., 1998) and determining the reason for the referral

(Butow & Lobb, 2004; Rapp, 1988; Tovell, 2004), but details of the interactions were not examined, unlike in medical encounters where similar activities were reported and analysed in-depth (Byrne & Long, 1976; Heath, 1981, 1986; Robinson, 1998). There were many similarities between the sessions in this study and medical encounters but there were also some unique features. Greetings, introductions, asking the reason for the referral and offering of observations have been reported in medical encounters. Reference to the current research project, explanations of the reason for the referral and what to expect from the session and inviting questions seemed unique to the genetic counselling interactions in this research.

Setting the agenda was found to be a critical activity during the opening phase. In genetic counselling interactions it has been shown that counsellors make attempts to determine the reason for the referral (Butow & Lobb, 2004; Pieterse et al., 2005; Rapp, 1988; Smith et al., 2000; Tovell, 2004) and in medical encounters doctors solicit presenting concerns (Heath, 1981; Robinson, 2006). It was also shown that when the counsellor and the patient's agendas were 'matched' the patients felt more satisfied (Lobb et al., 2002; Shankar et al., 1999). In the genetic counselling encounters in this study the women were referred to the clinic. This played a role in the counsellors' framing of their agenda questions. As shown, the question formats revealed that the counsellors knew that the women were referred by a medical professional and that the women should have received the relevant information. The question formats used allowed the women to state what they understood about the reason for their referral but their concerns, if they had any, did not often emerge. These formats were restrictive in that they were done in the service of obtaining information that was used to prepare the ground for the information that was to be communicated later in the session. Most of the genetic counsellors in their post-session

interviews confirmed that they did not know what the women were concerned about and stated that the reason the women attended the clinic was that they had been referred.

The rigid structure and the order of events were a striking feature of the openings and were also found in Tovell's (2004) study on one genetic counselling session conducted in the same setting. As with the rest of the session, the structure of this phase provided a framework in which to conduct the session. The function seemed to be to guide the woman through the process and give direction to the session. The genetic counsellors in their post-session interviews made reference to having had a 'plan' for the session, thus confirming that genetic counsellors' perceptions supported what the interactions revealed. It seemed that the structure in the openings, coupled with the counsellors' agenda questions and the counsellor's uptake of the women's responses, allowed the counsellors more agency and power in the interactions. Agency of medical professionals over patients (the voice of medicine) is well known (Heath, 1981; Mishler, 1981; Roberts, 2000; Robinson, 2006). Similarly, it was shown that genetic counsellors have control in genetic counselling interactions (Armstrong et al., 1998; Babul-Hirji et al., 2010; Hodgson et al., 2009). In this respect, the genetic counselling interactions in this study were not very different from the previous research as a counsellor led agenda was evident, the agenda was tightly controlled and the voices of the women were not often heard.

The observation that the counsellors had agency in the openings and the women seemed to be relatively passive participants may be linked to the country's socio-political and healthcare history. Research has suggested that patients in this health care setting seemed less assertive, lacked knowledge about patient's rights and had high regard for doctors (Penn & Watermeyer, 2012). It is suggested that the lack of agency in these interactions

was reflected in the counsellors' agenda question formats and the structures the counsellors put in place rather than clear orientations by the participants. The women being part of a 'referral system' is further thought to be linked to a medical setting in which traditionally patients do not make their own health care decisions. In addition to these aspects, it was found that the women in this study were reluctant to take up interactional space when given the opportunity. The women's lack of active participation was evident as the women seemed unfamiliar with the idea of being invited to ask questions and they seldom initiated discussions.

The counsellors agenda were based on medical policy and the medical indication for the referral (Centini et al., 2005), which is that a pregnant woman at an increased risk of having an infant with a chromosome abnormality should be advised of her risks and options. The genetic counselling agenda influenced the interactions, as shown by the counsellors ensuring that the women understood that their advanced age was the reason for the referral. The counsellors had a set plan of what they needed to discuss with these women during the sessions. They ensured that the women understood the reason for referral and by providing the plan for the rest of the session. This was confirmed in the counsellor post-session interviews, as the counsellors emphasised that the women attended the clinic so that they could be given information on maternal age and the associated risks, with comments in the interviews such as 'the patient was well informed', 'she knew why' and 'she went off topic'. The counsellors claimed the right to decide what the right topic was.

With this goal in mind the counsellors had to ensure that the woman received the necessary education. However, simultaneously the counsellors made deliberate efforts to

establish a relationship with the women and to encourage them to participate in the sessions. The counsellors' role, therefore, simultaneously seemed to be as educator, on the risks and options associated with advanced maternal age, and as a counsellor, who attempted to build a relationship and connect with the women. This is in keeping with the definition of genetic counselling (ASHG Ad Hoc Committee on Genetic counselling, 1975; Resta et al., 2006). The counsellors referred to their relationship with the women during their post- session interviews. Whether the emphasis on relationship building in these interactions is as a result of the counsellors' perceived responsibilities or not is unsure.

The sessions in the present study seemed to reveal tension between the activities required by the genetic counsellors. The tension is evident in the counsellors' responsibility to educate on maternal age and their attempts to "counsel" by attempting an informal approach with attempts to connect with the women. The interactions are therefore thought to be shaped not only by the genetic counselling agenda, but also by the context of the local health care setting and its historical and socio-political background, by the socioeconomic and educational levels of the patient, as well as by the training of the counsellors.

7.6 Summary

This chapter covered the description of the content and structure of the genetic counselling session openings. These were found to consist of: the preliminaries (introductions, greetings, reference to the current research project); the setting of an agenda (reason for referral, explanation of the reasons for the referral and the plan for the session); and the

encouraging of participation (inviting questions, offering observations). The analysis further revealed that the setting of the agenda was a process tightly controlled by the counsellors. The framing of the questions allowed the women to respond with regard to what they knew about their referral. In establishing the agenda, the counsellors aimed to educate about the risks and options associated with advanced maternal age. At the same time, they attempted to build a relationship and be counsellors, which resulted in some tension between their counselling and teaching role. Finally, the chapter concluded with a discussion about the institutional forces which impact on these interactions and that these forces may be unique to this setting.

Chapter 8 Results III – Analysis of the Decision-Making Sequences

8.1 Introduction

Coming to a decision regarding whether to have an amniocentesis performed or not was a pivotal activity in the sessions. During the preliminary analysis, it became evident that this process contained several features that required further analysis to reveal the elements involved. The focus of this chapter is an in-depth analysis of how the counsellor and the women engaged in a discussion about whether or not an amniocentesis should be performed.

This chapter begins by providing a description of the decision-making process. A discussion on other emerging issues that include various counsellor strategies as well as directiveness and non-directiveness follows.

8.2 A description of the process

The central reason for the genetic counselling interaction was for the women to make a decision regarding amniocentesis and prenatal diagnosis. This was made clear by the counsellors, during the opening phase, when they informed the women of the need to make a decision about a test that would be discussed. The actual discussions however, only occurred later in the session after some or all of the relevant information had been communicated. The decision regarding amniocentesis was not made instantly but rather

developed during the course of the discussions. The counsellors guided the women through the process by engaging them in several aspects of the decision. The analysis is based on 14 of the 17 sessions as the women in three sessions were too far advanced in the pregnancy for the amniocentesis to be performed.

The counsellors initiated the decision-making sequence mostly with a question. The counsellors made use of open wh-type interrogatives to engage the women in a discussion. The questions included asking the women what they thought about the risk of having an infant with Down syndrome, what they thought about having the test done, what they would do if the results showed that their infant had a chromosome problem and how it would be for them if they had a baby with abnormalities. Although the discussion was mostly initiated by the counsellors, in one session the woman volunteered that 'she could not take the chance' in response to the counsellor's discussion on abnormalities.

After initiating decision-making, the counsellors used several strategies to guide the women through the process. The counsellors directed the interaction so that the women could consider different consequences relating to the decision. These identifiable components seem to emerge in a recurring order and the counsellors generally used questions to initiate a discussion on the new topic. The counsellors' engaged with the women about their risk, fetal abnormalities, and/or what they thought about having the test and/or their reaction to a positive test result and/or how they imagined it would be for them if their baby was born with abnormalities.

The sequences were concluded when the counsellors and the women came to an agreement regarding what the women wanted to do. This was either not wanting the amniocentesis performed (in nine sessions), choosing to have the procedure (in four

sessions), and in one session the couple was undecided and was given more time to consider their decision. Of the four sessions in which the women chose amniocentesis, one wanted to have an ultrasound first, one had to undergo an HIV test first and one wanted to discuss the option with her husband. The conclusion of the sequences were signalled in different ways and included having a discussion about the decision and what it meant for the women, checking whether they were sure about what they wanted, providing a summary and making arrangements.

The overview of the decision-making phase as discussed above revealed several interesting features. In keeping with the rest of the session, the counsellor's control over the interaction (Mishler, 1984; Pilnick & Dingwall, 2011; Ten Have, 1991) was evident in the way in which the counsellor directed the conversation, as well as the strategies used to engage the women in discussions regarding amniocentesis. The strategies the counsellors used seemed to provide some evidence of how counsellors assisted women with decision-making and they are in keeping with Veach et al. (2003) and Weil's (2000) advocated strategies. Upon closer examination, several other features were revealed as will be discussed below. The counsellors' strategies, how the need for a decision was introduced and how the counsellors and women dealt with this, as well as directive and non-directiveness will be discussed below.

8.3 Different strategies

The counsellors used a number of strategies to assist the women to come to a decision. The counsellors directed the interaction so that the women could consider different consequences relating to the decision of having an amniocentesis. These identifiable

components seem to emerge in a recurring order. In excerpt 8.01, the counsellor engaged the woman in a discussion on the test, having a baby with abnormalities, termination of pregnancy and outcome if no testing is performed.

Excerpt 8.01: Session 05, Couns B Inexp – Identifiable components in a recurring order

file

1005 **C:** how does this test sound to you Thembi (5.0)

1006 **P:** (give me a thoughts) (.) I thought will they don't have

1007 problem to (.) use this needle but (.) when they say (.) its

1008 going to be a problem when (.)I maybe the baby's too

1009 much growing can give me a problem you see

Lines 1010 to 1033 omitted

1034 **C:** and Thembi? if we did the test (.) and we find that there

1035 was a problem for the baby↓ what would that (.) mean for

1036 you (3.0)

1037 **P:** °hh eish I dohhn't knhhow°

Lines 1038 to 1043 omitted

1044 **C:** [not all right] okay Thembi if we could do the test and

1045 we find that the baby did have a problem (.)with the

1046 amount of information (.) the doctors could take the baby

1047 out (.) could stop the pregnancy (3.0)

1048 what do you think about that (3.0)

1049 **P:** ((sigh)) (3.0) °it will be the hard (.) way°

Lines 1050 to 1078 omitted

1079 **C:** Thembi if we didn't if we can't do the test (.) and we

1080 found that and the baby is born (.)if the baby did

1081 have a problem (.) how do you think that would be for

1082 you (3.0)

1083 **P:** No its going to be hard to know but eish? (1.0) I must accept

1084 **C:** okay so you feel like you would have to accept? if the

1085 baby? was born with a problem.

Lines 1084 to 1099 omitted

1100 so what do you thinking about (.) what (.) you don't

1101		have to decide right now you can go and sit for half
1102		a hour? think ?about it okay you don't have to decide
		file
1103		right now but because we know that you are quite far
1104		if you want to have the test. probably need to do it
1105		today. (.) okay
1106	**P:**	uhm
1107	**C:**	so I don't know if you want to maybe go and think? for
1108		a little? bit? and then came back and we can talk some
1109		more (2.0)
1110	**P:**	with sonar I don't have a problem but with needle °eish°

The counsellor started the interaction with a question about the test in line 1005. This was followed by a discussion in which the counsellor engaged with the woman. The second cycle started in line 1034 and the counsellor asked the woman what it would mean for her if she did the test and the result was positive. In the third cycle, line 1044, the counsellor asked the woman whether she would terminate a pregnancy. In the fourth cycle starting in line 1079, the counsellor asked what if testing is not done and the baby is affected. Then, in the fifth and sixth cycles (lines 1101, 1107), the counsellor asked whether the patient wanted more time to think.

Other than splitting the decision into smaller parts, the counsellors also made use of questioning (PDS), scenarios, weighing up the options, and 'what if' questions, to further assist the women to come to a decision, without advising them on a course of action. Excerpt 8.02 shows a PDS.

Excerpt 8.02: Session 01, Couns C Inexp – PDS question

1242	**C:**	(.) how? would you feel if if we did this test and we
1243		picked up your baby had a problem. (.) how would you
1244		Feel? what would be(.) <the right thing (.) for <u>you</u>>
1245		(0.3)
1246	**P:**	no? I'd rather stay with my child it's [fi:ne]

The excerpt starts with the counsellor asking three wh-type interrogatives l242-1245 'how would you feel' twice and once 'what would be the right thing for you?'. The counsellor's questions (PDS) were designed in such a way that they invited the woman to adopt introspection so that she could share her feelings and thoughts (Maynard (1991) and they initiated a reflective frame (Sarangi, Bennert et al. (2004)). The woman took time (3 sec pause) to think over the questions before she gave a response saying in line 1246 that she would keep her baby. The counsellor not only used a PDS question format to engage the woman but her emphasis on 'you' in line 1244 further indicated the counsellor's orientation that this is about what the woman wanted.

Excerpt 8.03 show the counsellors use of another strategy, sketching a scenario, for the couple (woman (P1) and her partner (P2)). Sketching a scenario means that the counsellor refers to a story of how another individual have dealt with a similar situation.

Excerpt 8.03: Session 15, Couns E Exp – Sketching a scenario

1121	**C:**	so(.)you must think(.)about(.)how you feel(.)because(.) some
1122		people as I say to you they say >we are not going to do the
1123		abortion< but we want to know so we are >gonna do the test.<
1124	**P1:**	yes
1125	**C:**	other people say to me(.) we are not gonna do the
		file
1126		abortion. and we don't want this test because of this
		file
1127		chance to make a miscarriage [we don't want]
1128	**P1:**	[(miscarriage)]
1129	**C:**	to take that chance
1130	**P:**	ja
1131	**C:**	s:o? different people they feeling? different things.
1132	**P1:**	uhm
1133	**C:**	so you must decide for you what is the right thing
1134	**P1:**	okay
1135		(0.10)
1136	**C:**	it's difficult ((laugh))
		looks down
1137	**P1:**	It's to difficult now (.) at this present moment >I don't want to
		looks down
1138		loose the child< (it's time to come gonna lose because of this)

The Excerpt shows how the counsellor gave the couple a scenario of how 'some people' in line 1121, 1122, and how 'other people' in line 1125, have dealt with the situation, emphasising how people treat the situation differently, giving the couple an example of options they can choose from. In line 1133, the counsellor explicitly stated that the couple needed to decide what was right for them. After a long pause of 10 seconds the counsellor remarked that it was difficult for the couple to decide, at which point the husband shared his thoughts on the situation.

Another strategy used was to *weigh up* the different options as shown in excerpt 8.04. Weighing up options is different to sketching a scenario as it compares two options with each other.

Excerpt 8.04: Session 11, Couns A Inexp – Weighing up options

1727	**C:**	It's really worrying you hey? [the miscarriage risk]
		file
1728	**P:**	[That it's only]
1729		that miscarriages risk [and <u>that</u> needle]
1730	**C:**	[It's only that]
1731		And I <u>suppo:se</u> its saying my chance of having a baby
1732		with a problem?
1733	**P:**	uhm
1734	**C:**	is about hun <u>ONE</u> in a hun in two hundred and forty
1735	**P:**	uhm
		file
1736	**C:**	and the chance to have a <u>miscarriage</u> it is? higher then
		file
1737		the chance to have a baby with problems
		file
1737	**P:**	But but this this needle in
		file
1738		(0.2)
		file
1739	**P:**	is a if she put it in <u>my</u> it doesn't going to damage me?

Here the counsellor was 'weighing up' the numerical risks of having a procedure related spontaneous abortion (lines 1736-1737) to the risk of having a baby with a chromosome abnormality in lines 1731-1732. The weighing-up was in response to the woman's concern about the risk of aborting, which she stated earlier (lines not shown), and in line 1730 above. The counsellor drew the woman's attention to the two risks thereby inviting

her to think about these individually and in relation to each other. The woman was still concerned about the needle and a further discussion ensued around the risks associated with the test. The woman kept her gaze on the picture of the amniocentesis test on the desk.

The counsellors further used what if/when + present/past tense questions as can be seen in excerpt 8.05. What if questions are defined as questions that require the woman to think about a hypothetical future.

Excerpt 8.05: Session 5, Couns B Inexp – If/when questions

1077	**P:**	_____ ((sigh)) _____ (2.0) _____ eisch
1079	**C:**	_____ Thembi if we didn't if we can't do the test (.) and we
1080		_____ found that and the baby is born (.)if the baby did
1081		_____ have a problem (.) how do you think that would be for
1082		_____ you (3.0)
1083	**P:**	_____ No its going to be hard to know but eish? (1.0) I must accept
1084	**C:**	_____ okay so you feel like you would have to accept? if the
1085		_____ baby? was born with a problem.

The counsellor used a 'what if + present tense' (line 1080) as she referred to undergoing the test. Then she used an 'if + a future tense' line 1081 when she referred to the baby being born with a chromosome abnormally. The woman took three seconds before she responded to the question by stating that it would be 'hard' for her (line 1083) and she would have to 'accept' (line 1083).

In the process of helping the women decide the counsellors as shown in excerpt 8.06 provided the women with more information.

Excerpt 8.06 Session 1 Couns C Inexp - More information

1214	**C:**	So it >doesn't go anywhere near< baby, it just goes into
1215		the water
1216		(3.0)
		picture
1216	**P:**	I am scared of this I really scared I rather, (.) be a
		picture
1217		Surpri::se I don't want to know because it's going to worry me
1218	**C:**	It's gonna worry you
1219	**P:**	A::hh
1220	**C:**	Okay
1221	**P:**	Ja
1222	**C:**	You see when we if we did this test on a women, and we picked up
		picture *picture* *picture*
1223		the baby did have a problem, like Down syndrome? or trisomy 18? or
1224		trisomy 13? the doctors would offer the women an abortion. If
1225		she wanted to end? the pregnancy (.) she would be able to(.)°Okay°
1226	**P:**	°uhm°
		picture
1227	**C:**	cause they do consider these chromosome? problems to be serious
1228		problems
1229	**P:**	Ja

The excerpt shows the conversation which followed a discussion about the needle and whether it would touch the baby. The woman responded to the counsellor after a three second pause and stated that she was 'scared' and 'worried'. The counsellor formulated (line 1219) the woman's statement that if she underwent the amniocentesis she would be concerned about her baby throughout her pregnancy. The counsellor's response to the

woman's concerns was to provide her with more information regarding the abnormalities and options available.

Finally, the counsellors, when it seemed a decision could not be reached, granted more time to make a decision. The counsellor in excerpt 8.07, after having made several other attempts to help the couple come to a decision, made a suggestion that they should take more time to think about it.

Excerpt 8.07: Session 15, Couns E Exp – Granting more time

		_____ _ _ _ _ _ *handbag*
1157	**P:**	yes (too scared) for taking
		_____
1158	**C:**	this chance
		_____
1159	**P:**	mmm
		_____
1160	**C:**	okay(.)uhm if you tell me n:o now, that's absolutely fine? but
		_____
1161		if you want some time to think about it, you can maybe (.)uhm (.)
		_____
1162		I can give you a call on Monda:y and you can tell me.
		_____
1163	**P:**	okay
		_____
1164	**C:**	I don't know
		___
1165	**P:**	Eh
		___
1166	**P1:**	[ja]
		_____
1167	**C:**	[do] you want to think about it or you know that
		_ _ _ _ _ _ *down*
1168	**P1:**	Ja but
		_ _ _ _ _ *down*
1169		(0.2)
		_ *down*
1170		To think about it (.) it's a <u>good</u> thing
		_____
1171	**C:**	Okay

The excerpt followed a discussion regarding the couple's fear of losing the baby due to a spontaneous abortion, but they also wanted to know whether the baby had abnormalities.

The woman's (P) response in line 1157 was to a question from the counsellor 'what do you think?' as there was a discussion mostly with the partner (P1) up to that point. It is in lines 1160-1162 that the counsellor offered the couple more time to think about whether or not they wanted to have an amniocentesis. The woman replied 'okay' to which the counsellor restated her offer twice more (line 1164 and 1167). The partner (line 1168-1170) stated that they would take up the offer of delaying making a decision. The partner's two second pause and insertion of the 'but' indicated that he treated the counsellor's comment to take more time as a suggestion.

By engaging with the women on all the different aspects involved in deciding whether or not to have an amniocentesis, the counsellors used active counselling techniques. Such anticipatory activities are advocated by Veach (2003) and are taught as counselling skills. These techniques have been discussed in the debate about non-directiveness and how it can be achieved in practice (Kessler 1992; Wolff and Jung 1995; Shiloh 1996; Kessler 1997b; Elwyn, Gray et al. 2000). Reflective elements, such as the PDS questions used by the counsellors, were shown to be markers for non-directive genetic counselling (Sarangi et al., 2004), as are explicit references, such as emphasizing that the patient's make the choice and withholding advice (Pilnick, 2008). The counsellors made use of both reflective strategies and recurring questions in this prenatal context in order to adhere to the ethos of non-directiveness. However, some of the strategies the counsellors used could be seen as more directive such as providing more information and granting more time. By granting more time the counsellors suggest a course of action. This is in line with Kessler's argument that a counsellor's course of action can suggest preferred actions (Kessler, 1992, 1997b). By providing more information on the seriousness of the conditions and that termination is an option, the counsellor can appear to be directing the

woman towards having an amniocentesis. Statements emphasising negative outcomes (contra-indicative statements) can be heard by patients to be advice and can indicate directiveness (Chandlin & Lucas, 1986). Pilnick (2008) argued that although there are explicit attempts to be non-directive, the professionals' actions are not 'neutralistic'.

8.4 Orientation to decision-making

The fact that the women were required to make a decision regarding having an amniocentesis test, was first discussed during the opening sequences of the sessions. The counsellors described what was going to happen during the session, what the test involved and explained that the women would be making a decision. The counsellors made it clear that they would be giving information but the women needed to decide about the test. An example is seen in excerpt 8.08

Excerpt 8.08: Session 13, Couns E Exp – You decide about the test

		—————————————————— *file*
74	**C:**	so I'm gonna tell you >all about< those thhests
		____
75	**P:**	yes
		_____
76	**C:**	and then you can dhhecide.
		_____
77	**P:**	°uhm°

The counsellor in line 74 stated that she would talk to the woman about tests, but also said 'you can decide'. The woman's response 'yes' (line 75) and 'uhm' (line 77) illustrated that she agreed to this and accepted the counsellor's role being to provide information and her role being to make the decision.

Later in the sessions how the counsellors distinguished between information delivery and the invitation to make a decision can be observed, as shown in Excerpt 8.09. It shows how the woman orientated to the counsellor's information as a need to make a decision.

Excerpt 8.09: Session 11, Couns A Inexp – Information delivery as an invitation to make a decision

1191	**C:**	OR she d (.) we offer that to her
1192		so she cou:ld say (.) she wants? the abortion or no.
1193	**P:**	[uhm]
1194	**C:**	[she] wants to carry on with the pregnancy
1195	**P:**	hmff?
1196	**C:**	but she wants to know.
1197	**P:**	uhm
1198	**C:**	oka:y?
1199		(1.0)
1200	**P:**	uhm
		picture
1201	**C:**	how do you how do you feel about all of this (.)
1202		about ha:ving? the te:st?
1203		(2.0)
		picture
1204	**P:**	I want to have a thhest.

The counsellor used different pronouns to distinguish information delivery on genetics from the invitation to decide. Lines 1191-1196 demonstrate that the information was not designed as information about the patient but about a generic pregnant woman. The counsellor used the third person pronouns 'her'(1191) and 'she' (1192, 1194, 1196) to refer to this generic woman. In line 1201 the counsellor turned to the use of the second person pronoun 'you' to invite the woman's decision. The excerpt shows that the counsellor distinguished information delivery from an invitation to make a decision. The

invitation was explicitly made by the counsellor towards the end of the excerpt. The woman's response in line 1204 shows her orientation to the invitation to make a decision when she says I want to have a test.

In the excerpt below (8.10), the woman treated the counsellors' information delivery as an invitation to make a decision without the counsellor actually inviting the decision.

Excerpt 8.10: Session 13, Couns E Exp – No invitation to make a decision

		– – –

counsellors' prior information as relevant for her situation and an invitation to make a decision.

When and how the need for decision-making is introduced in a session was examined when antenatal screening tests were offered in the UK (Pilnick 2004; Pilnick, 2008). The findings of the present study were similar to those of Pilnick et al. (2004; 2008) in that the genetic counsellors introduced and 'topicalized' the need for choice concerning an amniocentesis. However, how the participants deal with making these choices was found to be dependent on several factors. In this present study particularly, it was found that the counsellors made great efforts to avoid persuading the woman to take a particular course of action. These efforts seem to be in keeping with the genetic counselling profession's central ethos of non-directiveness (Kessler, 1992; Weil, 2000). However, in other studies it was found that despite the counsellors' efforts the interactions were somewhat directive (Weil, 2003; Weil et al., 2006).

8.5 Directiveness and non-directiveness

In spite of attempts to be non-directive and to withhold advice as illustrated, the counsellors' contributions to the interaction influenced the interaction. It was found that the counsellors overtly orientated to non-directiveness when the women indicated that they did not want an amniocentesis but not when they indicated they wanted the test. The overt orientation to non-directiveness was only seen in response to a woman's indication that she is not interested in having an amniocentesis. Excerpt 8.11 below illustrates this. The interaction starts with the counsellor asking the woman how she would feel if the amniocentesis was performed and her baby was found to have an abnormality.

Excerpt 8.11: Session 01, Couns C Inexp – Overt orientation towards non-directiveness

1242	**C:**	(.) how? would you feel if if we did this test and we
1243		picked up your baby had a problem. (.) how would you
1244		Feel? what would be(.) <the right thing (.) for you>
1245		(0.3)
1246	**P:**	no? I'd rather stay with my child it's [fi:ne]
1247	**C:**	[stay] with your [child]
1248	**P:**	[ºJaº]
1249	**C:**	ºOkayº
1250	**P:**	ºuhmº
1251	**C:**	So for [you-]
1252	**P:**	[I'll just] accept
		file
1253	**C:**	ºokayº So for <u>you</u> if your baby has a problem, like this
1254		it would be okay.
1255	**P:**	ja:
1256	**C:**	you would accept it.
1257	**P:**	ºuhmº
1258	**C:**	and I know you said earlier it's a gift from [<u>Go:d</u>]
1259	**P:**	[uh:m]
1260	**C:**	so for <u>you</u> you'd feel it's a gift
1261	**P:**	uhm
1262	**C:**	from God (.) and it ? is <u>your</u> choice.
1263	**P:**	ja, I
1264	**C:**	we're just >here to provide you with the information<
1265	**P:**	okay
		picture
1266	**C:**	But it's <u>complete↑ly</u> up to you as to
1267	**P:**	uhm
		picture
1268	**C:**	>whether or not you <u>want?</u> this test<
1269	**P:**	Yes
1279	**C:**	or not,

In lines 1246 and 1247 the woman stated that she would accept a baby with an abnormality thus indicating that she would not choose to have an amniocentesis performed. It is in lines 1251, 1253, 1256, 1260 that the counsellor responded with 'you', indicating that it is up to the woman to decide. In line 1262 the counsellor overtly showed her non-directive stance when she explicitly stated 'it's your choice' again in line 1264 'we are just here to provide you with the information', in line 1266 'but it's completely up to you', and in line 1268 'whether or not you want to have the test'. The counsellor accentuated the words 'completely' (line 1266) and 'want' (line 1268), further emphasizing that it is the woman's choice.

The counsellors responded differently to the women when they indicated that they are interested in having an amniocentesis performed. In such instances, the counsellors 'checked' whether the women understood what they chose as shown in Excerpt 8.12.

Excerpt 8.12: Session 11, Couns A Inexp – Check understanding

1199	**C:**	HOW DO (.) how do you feel about all of this (.)
1200		about having? this te::st? (1.0)
		file
1201	**P:**	I want to have a thhest?
		file
1202		(0.1)
1203	**C:**	[You want to have it]
		file
1204	**P:**	[So that I must] know [very early what is]
1205	**C:**	[(want to see better)]
		file
1206	**P:**	going on
1207	**C:**	Ohhkay
		file
1208	**P:**	>uhm<
1209	**C:**	you want to know.
		file
1210	**P:**	uhm

The counsellor started the interaction with a wh-type interrogative that served to initiate a reflective frame (Sarangi et al., 2004). The woman answered the counsellor's question 'how do' by indicating her decision that she wanted to have an amniocentesis. The counsellor checked in line 1203, when she said 'you want to have it' to which the woman elaborated why she wanted the procedure. The counsellor did a further two checks in lines 1205 and 1209. The reflective frame was successful in that the woman shared what she wanted to do as well as elaborated on her reason why she wanted the test.

The asymmetry in the counsellors' responses to the women's indications of having or not having an amniocentesis suggests that there was a preference for the woman to have the amniocentesis, suggesting directiveness. When the woman indicated that she wanted to have the procedure, the counsellors accepted the decision, but when the women indicated that they did not want to have the procedure, the counsellors overtly orientated towards non-directiveness thus suggesting that this was not the preferred action. This behaviour may partly reflect 'institutional directiveness' (Clarke, 1991; Weil, 2003) as the women were referred to the clinic for a discussion about maternal age and testing options with the premise that this offer should be accepted. In spite of the counsellors' attempts to maintain neutrality, they influenced the interactions. They made use of several strategies and made explicit reference to non-directiveness as was shown in the previous section. Further evidence for directiveness in the interaction can be seen in the actions the counsellors performed. Whatever the counsellor did or omitted to do had an effect on the interactions. Excerpt 8.13 is an illustration of how the counsellor had a choice with regard to how and when to respond to the woman.

Excerpt 8.13: Session P01, Couns A Inexp – Counsellor Contribution

999	**P:**	No? °I just want to be eh eh eh (.) positive°
1000	**C:**	°you want to be positive,°
1001	**P:**	I don't want to think (.)
1002	**C:**	>you don't want to think< about all these worrying things
1003		it makes you feel anxious? hey?
1004	**P:**	Jhha? ja and then you you becoming depressed
1005		you sometimes, you you do
1006		something you know, something happen to you
1007		when you're always eh eh depressed,
1008	**C:**	uh:m,
1009	**P:**	thinking those things,

In line 1000, the counsellor 'formulates' (Heritage & Watson 1980) the woman's prior statement in a way that the woman did not subsequently (in line 1001) confirm. Further, the counsellor's formulation in lines 1002-1003 of what the woman said before, did get a confirmation (1004: 'ja ja'). However, the woman extended her comments, suggesting that the way the counsellor formulated, was incomplete, or possibly indicating that the woman had not yet completed what she wanted to say or that she was encouraged to elaborate. In line 1008, the counsellor produced a continuer ('uhm') that encouraged the woman to continue her turn, which she did in line 1009.

The directiveness of the interaction was suggested by the fact that the counsellor could have chosen to say nothing in line 1000, to produce an 'uhm', or to have phrased the formulation differently. Moreover, this argument – that something else could have been done or said - could be repeated for each utterance the counsellor produced or, did not produce. Whatever the counsellors chose to do or not to do, their delivery and design of

the discourse involved choices that did not leave the interaction untouched. While this does not imply directing the interaction towards a particular outcome, the interaction is not neural.

Directiveness was also evident in the way the women treated the counsellor's questions or invitations. For example in excerpt 8.14, the woman treated the counsellor's invitation to make a decision as if she was expected to accept the amniocentesis.

Excerpt 8.14 Session 01 Couns C Inexp – Decision as an expectation

1242	**C:**	(.) how? would you feel if if we did this test and we
1243		picked up your baby had a problem. (.) how would you
1244		feel? what would be(.) <the right thing (.) for you>
1245		(3.0)
1246	**P:**	no? I'd rather stay with my child it's [fi:ne]

The counsellor asked three consecutive open-ended questions (1242-1244) to invite the woman's decision in the form of PDS. The woman treated the questions as 'closed' yes/no questions with a preference for a yes-answer. She answered 'no' (1246), and she paused 3 seconds before producing the 'no'. Preference organisation in interaction is a practice in which an initiated action - such as a question - has two alternative responses, 'yes' and 'no', that are treated asymmetrically (Schegloff, 2007). The preferred alternative is produced in immediate response to the initiated action, while the dispreferred alternative is produced while distancing the response from the initiative by inserting items between the initiative and the response. These can be particles such as 'well', phrases such as 'I would have liked to but....', or as in the excerpt above, a pause (line 1245). The woman's response thus suggested that she treated the counsellor's invitation as an 'offer' rather than

as a question and that this offer should be accepted. The woman also added 'it's fine' (line 1246) and produced and account for her answer which further showed her orientation that there was possibly a preference to agree with having the test done. Even though the counsellor did not intend her wh-interrogative to imply a preference for agreeing to the test, the woman treated it as such.

It was evident that despite the counsellors' efforts to maintain non-directiveness, the interaction is affected by the counsellors. However subtle, the choice of responses, the asymmetrical uptake of the women's yes and no responses, the questions asked, formulations, the order of providing information and some of the counsellors' strategies, contributed to influencing the interactions.

8.6 Discussion

The decision-making sequence was a critical aspect of the genetic counselling sessions. As shown, the genetic counsellors informed the woman from the outset of the session that they would be receiving information regarding a test and that they needed to make a decision regarding whether or not to request it. Later in the session, after all, or some, of the information had been communicated, the counsellors engaged the women in a discussion about this decision thereby assisting them to make it.

What was apparent throughout the decision-making sequences was that the counsellors took care not to influence or advise the women one way or the other. The counsellors' actions pointed to attempts to adhere to the ethos of non-directiveness as advocated since the inception of the profession (Kessler, 1992; Marks & Richter, 1976; Weil, 2000; Wolff

& Jung, 1995). In their attempts, many were found to have explicitly referred to the women's responsibility and right to make their own decisions, thereby emphasising patient autonomy (Kessler, 1997c; Weil, 2000, 2003) and informed choice (Marteau et al., 2001). To promote autonomy and assist patients with decision-making several counselling approaches and techniques have been advocated (Veach et al., 2003; Weil, 2003). Research has shown that health care professionals have developed several strategies to achieve non-directiveness in their interactions, such as using indirect speech (Benkendorf et al., 2001), initiating reflective frames (Sarangi et al., 2004), presenting screening options (Pilnick et al., 2004; Pilnick, 2008; Schwennesen & Koch, 2012) and contrasting outcomes (Sarangi & Clarke, 2002). The counsellors in the present study were also found to have developed similar strategies to assist their patients to decide whether they wanted to have an amniocentesis performed. However, on closer examination, their strategies were not all equally non-directive.

Although the genetic counsellors orientate towards non-directiveness, some of their actions suggested a preferred course of action. It was demonstrated by others how professionals, despite their efforts to maintain non-directiveness, influenced the interaction by their contributions (Kessler, 1997b; Kirklin, 2007; Pilnick, 2008; Weil, 2003; Weil et al., 2006). These findings support the notion that, in interaction, complete non-directiveness is not possible. These seemingly contradicting findings of the counsellors making use of active strategies to be non-directive but at the same not achieving it, may point to how non-directiveness is defined rather than failing in the endeavour. Studies that found that counsellors were unable to maintain non-directiveness (Hallowell et al., 1997; Michie, McDonald, et al., 1997) may reflect the nature of an interaction rather than the counsellors' approach. However, non-directiveness is a complex concept and it is difficult

to evaluate (Weil, 2003; Weil et al., 2006). In this study counsellor strategies were identified and a distinction can be made between 'counsellor strategies' (choice of action) and the counselling interaction (unconscious actions). It is argued that this may be one way of defining non-directiveness. Figure 8.1 shows how this distinction between counsellor strategies and genetic counselling interactions might be conceptualised although the two are inextricably intertwined.

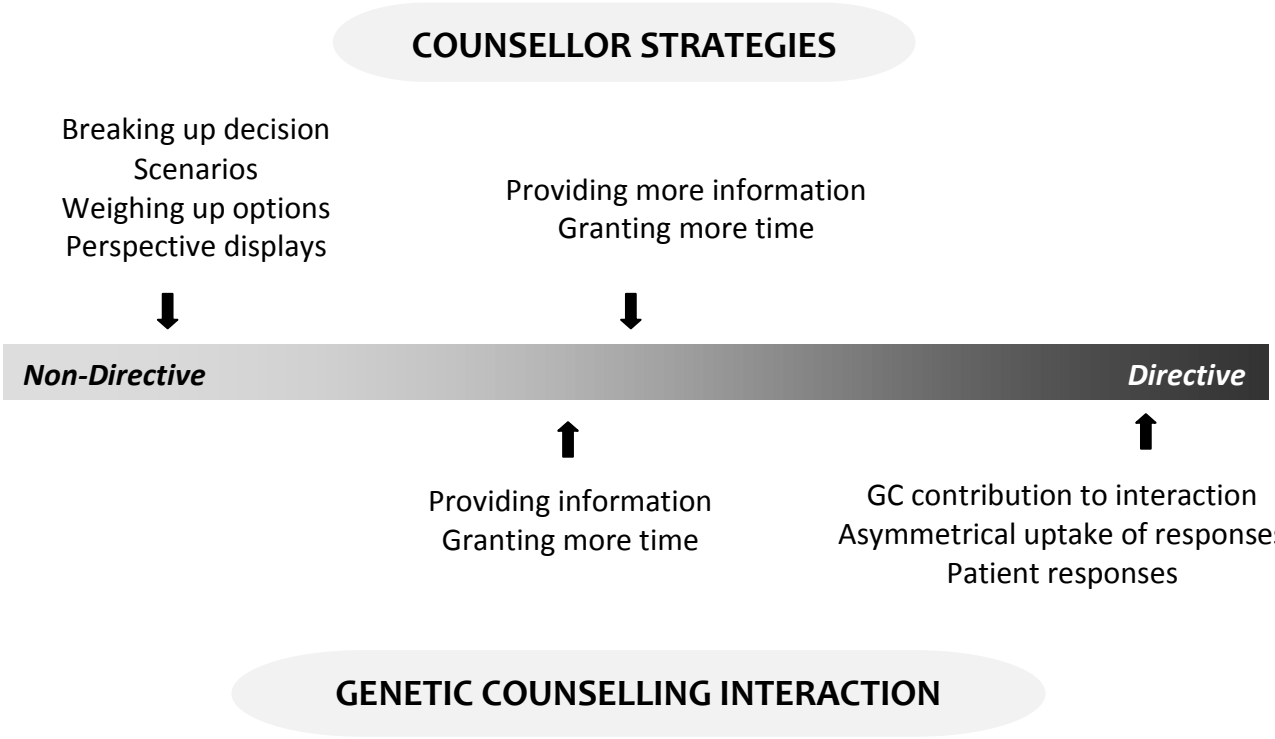


Figure 8.1. *A continuum distinguishing non-directiveness in terms of genetic counsellor strategies and genetic counsellor interactions*

While the findings of this study are, to some degree, in agreement with Wolff et al.' (1995) proposal that the term non-directive should be removed from the profession, it is apparent that non-directive strategies are used and it might be valuable to define these in terms of counsellor strategies, but also accept that no interaction can ever be completely non-directive.

The counsellors' orientations to non-directiveness by the use of active counselling techniques were striking in these interactions. It illustrated the effort and care put in to help and guide the woman through the decision-making process. As seen in the previous result chapters, the counsellors' active role was a feature of the interactions as a whole while the women remained relatively passive. In the decision-making sequences, the counsellors' active role was in their introduction of different topics and strategies. While the power asymmetry in the genetic counselling interactions in this setting is not a unique phenomenon, (Mishler, 1984; Pilnick & Dingwall, 2011), they asymmetry in the session in the present study could also have been influenced by local contextual factors.

It has been demonstrated that many of the patients in the health care system in South Africa endure several barriers and inequalities in obtaining healthcare (Harris et al., 2011) and that many lack assertiveness (Penn & Watermeyer, 2012) due to a number of reasons some of which are related to the country's socio-political history. In other medical encounters in the state system, the consultations are usually shorter and are directive in terms of treatment outcomes and management decisions and thus the women do not have much say in their health care decisions. Further in the case of many patients (80 %) (Kale, 1995) who seek encounters with traditional healers these interactions tend to be organized as much more directive and not involving patient decisions (Munk, 1998). This passiveness was echoed in the genetic counselling interactions by the fact that the women were referred and most of them did not choose or request to attend the clinic. This arrangement placed an additional burden on the genetic counsellors, which was possibly the reason that they developed the deliberate strategies observed in the interactions. While the initiation of reflective frames was found to be a feature of non-directive counselling, a high number of such initiations were thought to signal the counsellors' failure in attempts

to engage the patients in reflection (Sarangi et al., 2004). As a result, it was possible that the counsellor's repeated introductions of different aspects regarding the decision, reflected their difficulty in engaging with the women. This suggests that non-directiveness in these interactions was less successful in achieving its goal of helping the patients make their own autonomous decisions.

8.7 Summary

A decision about having an amniocentesis performed is a pivotal activity in AMA genetic counselling sessions. In this chapter the orientation towards the women's responsibility for making a decision as well as the genetic counsellors' strategies in assisting the woman to come to a decision were discussed. However, despite the counsellors' deliberate efforts to maintain non-directiveness, directive interactions were observed. These were generally due to the counsellors' choice of actions and the asymmetry in the uptake of the responses of the women. Efforts at maintaining non-directiveness, and adhering to this central ethos of genetic counselling, were shown to be mixed with more directive activities of the counsellors and thus question the effectiveness of using non-directive strategies in enhancing autonomy in this setting.

Chapter 9 Results IV – Analysis of the Counselling Segments

9.1 Introduction

As was demonstrated in the preceding results chapters, the overwhelming feature of the sessions was that the counsellors dominated the discussions by taking up more interactional space than the women and generally lead the discussions. However, there were other sections in which this was not the case. Such sections occurred during any stage of the genetic counselling session. They were characterized by the women doing most of the talking, while the counsellors were in the 'responders' position, using encouragers and other responses. Overall, the genetic counselling sessions were mostly characteristic of the 'voice of medicine', whereas in these segments the women were allowed and encouraged to share their experiences of their everyday lives, allowing the 'voice of the life world' to emerge.

The sections were termed counselling segments. The term was used as it aligns with Kessler's terminology, "counselling" and "teaching". The sections were selected because the women took up more interactional space. As explained in chapter 8, the demarcation is not absolute and some the sections which were identified as decision-making could have been called a counselling segment and vice versa. This definition "counselling segment" is not clearly effective in describing these segments as they were found to provide the counsellors with more information, discussed a concern and be a way of connecting in addition to showing empathy. While this limitation is acknowledged, the analyses as

presented here do provide some insight into the counselling aspects of the genetic counselling profession. This chapter explores these counselling segments, which refer to an identifiable segment where the woman spoke a considerable amount. It contains a description of the function of the segments and of the counsellor strategies which influenced the development of these segments.

9.2 Characteristics of the counselling segments

The features of the counselling segments that made them unique were the extended turns taken by the women. This phenomenon was briefly discussed in chapter six and below is another example (excerpt 9.01) which illustrates that the woman's talk predominated and that the counsellor took up minimal interactional space. This sequence organization mirrors the information delivery formats in HIV counselling, as the women provided the information and the counsellor acknowledged (Silverman, 1997).

Excerpt 9.01: Session 10, Couns C Inexp – Woman's talk predominates

264	**P:**	ja the pain was there so and somebody has to come
265		and help me to (.)get up from? that time I had the pain TILL (.)
266		I started bleeding. and all that [it was]
267	**C:**	[so]
268	**P:**	>very, very difficult [for me]<
269	**C:**	[it was a hard] <time for you.>
270	**P:**	it was a ha:rd time.

Lines 264-268 show that the woman took an extended turn in which she talked about how painful the ectopic pregnancy was, that she needed help and that she started bleeding. She also shared how she felt as she stated it was 'very difficult for me'. The counsellor's turn

(in line 267) is minimal in that she interjects, by repeating some of the woman's responses (completed in line 269).

Other researchers examining genetic counselling interactions have found that counselling segments occur in sessions: for example Babul-Hirji et al. (2010) described similar sections in their research during what they termed the counsellors' 'humanistic voice'. Still others found that psychosocial styles were evident in cancer genetic counselling sessions (Butow & Lobb, 2004; Duric et al., 2003; Ellington et al., 2005; Ellington et al., 2006; Roter et al., 2006b).

The number of counselling segments varied considerably, not only between sessions but also between the different sessions of a particular counsellor, and between experienced and inexperienced counsellors. In an attempt to provide an overview, table 9.1 was constructed. It shows that Counsellor D, who is an experienced counsellor, had a number of counselling segments during her sessions, but none were related to showing empathy. Counsellor B who is inexperienced had overall fewer segments but had segments that showed empathy. Counsellor E who is experienced, had a number of counselling segments in two of her three sessions but only had one short segment in her third session. The summary shows the great variation but it was observed that the emphatic segments were the most predominant type and by simply averaging the overall number of segment of each of the sessions, the experienced genetic counsellors had more counselling segments than the inexperienced counsellors.

Table 9.1. *Summary of the number of counselling segment (No) in each session*

Couns	Sessions	No	Characteristics			
			Empathy	***Connect***	***Information***	***Concern***
Couns A	P01	4	4	-	-	-
Inexp	02	1	1	-	-	-
	06	5	2	3	-	-
	11	1	-	1	-	-
	Ave	***3***				
Couns B	P02	2	2	-	-	-
Inexp	P03	2	2	-	-	-
	05	1	-	-	1	-
	Ave	***2***				
Couns C	01	7	5	-	2	-
Inexp	07	4	2	1	1	-
	10	5	4	1	-	-
	Ave	***5***				
Couns D	09	5	-	1	2	2
Exp	12	7	-	2	5	-
	Ave	***6***				
Couns E	13	6	5	-	1	-
Exp	14	4	2	1	1	-
	15	1	1	-	-	-
	Ave	***4***				
Couns F	08	8	1	5	2	-
Exp	16	3	-	2	1	-
	Ave	***6***				

Further examination of the segments in the present study were able to identify why and when they occurred, providing more information than just showing that the counsellors do sometimes take on a humanistic voice (Babul-Hirji et.al., 2012) or a psychosocial style of interaction (Ellington et.al., 2006a).

9.3 Functions of the counselling segments

The counselling segments appeared to serve different purposes in the genetic counselling sessions. In some instances, they were found to provide the counsellors with more

information, in other instance, the women discussed a concern, in others they appeared to be a way of connecting, and in others they demonstrated empathy.

9.3.1 More information

The excerpt below (9.02) shows how a counselling segment functioned as a way of obtaining more information. This segment occurred during the information-gathering phase of the session when the counsellor was obtaining information on the pregnancy history.

In excerpt 9.02, the counselling segment occurred after the woman informed the counsellor that she had an ectopic pregnancy (line 235). The counsellor initially asked the woman more questions (lines 236, 238, 240) but then in line 242 the counsellor's responses changed to continuers 'okay' (line 242), 'right' (line 244), and 'yes' (line 249). The excerpt shows how the interaction was more than the typical question-answer sequence, observed during the information-gathering stage, and the woman shared details about her pregnancy loss. As seen during the other phases the counsellor held the woman's gaze except when she recorded information in the patient file. It might be that a combination of gaze and the use of continuers facilitated the development of the counselling segment.

Excerpt 9.02: Session 10, Couns C Inexp – More information

		_____
234	**C:**	did you have any mi:scarriages?
		_____
235	**P:**	only? the ectopic last year
		_____ _ _ _ _ _ _ _ _ _ _ _ _ _
		file
236	**C:**	okay that was last year.
		____
237	**P:**	ja?
		_ _
		file
238	**C:**	when? in (.) when [last year?]
		_____
239	**P:**	[In August] °I had a operation° (0.2)
		_____
240	**C:**	and how far pregnant were. you. did you know?
		_____
241	**P:**	uhmmm (.) I THINK I (.) was even? less than three? months
		_ _ _ _ _
		file
242	**C:**	okay
		_____
243	**P:**	because I (.) didn't get my period in Ju:ne
		_____
244	**C:**	right?
		_____
245	**P:**	and on the: (0.3)
		_____
246		((DA:TE)) (2.0))
		_____
247		then I I had a (.) problem that I started bleeding and all that and (.)
		_____
248		when I come here they found that the: fallopian tube fractured?
		____
249	**C:**	yes
		_____
250	**P:**	and then they operated to take the: fetal remai:ns (.)out

9.3.2 Discussing a concern

The next excerpt (9.03) shows how the woman when asked whether she had any problems in her pregnancy shared her concern about having experienced pain during the pregnancy and that she was anxious that this might indicate a threatened abortion.

Excerpt 9.03: Session 9, Couns D Exp – Discussing a concern

657	**P:**	lots of problems
658	**C:**	what's the problem
659	**P:**	no? no? I'm <u>not</u> healthy because it's I'm <u>on</u>? and <u>of</u> ? (1.0)
		file
660	**C:**	okay so tell me a little bit about what's what's wor↑rying (1.0)
661		you
662	**P:**	me
663	**C:**	ja [( )]
664	**P:**	[about] my pregnancy
665	**C:**	ja
666	**P:**	no always? they stay? here. (1.0)
667	**C:**	°uhm°
668	**P:**	and I feels pains like (.)
669	**C:**	Okay
670	**P:**	I do having miscarriage you see(.)
671	**C:**	okay but you haven't had any bleeding↓ (.)
672	**P:**	No:
673	**C:**	all right <does> that pain happen mostly when you <u>walk</u>ing? (1.0)
674		or when you're [standing for long]
675	**P:**	[am <u>standing</u> or <u>whatever</u>]
676	**C:**	okay
677	**P:**	(at night too I feel pain) I don't know? what's going on
678		(inside)
679	**C:**	°but you are you worried about it°
680	**P:**	JA I'm <u>worried</u> because a I'm worried because I I say
681		maybe it's a mis<u>car</u>riage.
682	**C:**	°okay°, I'm going to explain to you why? (.) you can sometimes
683		<u>feel</u> that pain
684	**P:**	°>uhm<°

The excerpt shows the interaction from the point where the counsellor asked the woman to tell her about her 'problem'. The woman responded by sharing some of her concerns. After a pause of 1 second, the counsellor used her turn to ask a question (line 660). The woman was somewhat confused regarding the counsellors' question. The counsellor clarified that she meant the woman's concerns for her current pregnancy. After this initial misunderstanding, the woman stated her concern (line 666) and the counsellor responded with minimal response tokens (lines 667 and 669) which encouraged the woman to continue. The counsellor then asked further questions; in lines 673, 674 the question was specifically aimed at getting more information about when she experienced the pain and in line 679 the question (b-event statement) enquired whether the woman was concerned about it. The woman responded to the b-event statement by describing her concern and fear of having a spontaneous abortion. The segment ended in line 682 when the counsellor stated that she would explain what the cause of the pain was.

9.3.3 Connecting

There were several examples where the counsellors and the women engaged in 'chatting'. These discussions seemed to be a way of connecting or building a relationship. The women told stories and spoke about different aspects of their lives and the counsellors and woman engaged in topics regarding everyday issues.

Excerpt 9.04 shows the counsellor and the woman talking about her desire for a girl. The interaction starts with the counsellor asking the woman what she was hoping the sex of her baby would be and she replied (lines 345-348) by expressing that she wanted a girl.

Excerpt 9.04: Session 8, Couns F Exp – Wish for a girl

344	**C:**	so now you hoping this is gonna be a? (.)
345	**P:**	Oh(.) I wish (.) I wish I didn't plan for this one because I were I'm old
346		but okay?
347		I wish (.) cause(.) it's on the way now wish it
348		could be a girl
349	**C:**	girl
350		((laugh))
351		Ja
352	**P:**	Have had boys
353		That will be nice
354	**C:**	that will be nice, how are you feel↑ing about the pregnancy now.

The counsellor's response was to repeat 'girl' (line 349). In her turn, she further elaborated and stated that she had had boys and again expressed her desire for a girl. In line 354, the counsellor simultaneously ended the discussion regarding the sex of the baby and introduced a new topic.

9.3.4 Empathy

The majority of the counselling segments functioned as a way of showing empathy. Excerpt 9.05 provides an illustration.

The excerpt starts with the counsellor's formulation of the woman's previous statement. The woman treated the counsellors' response as an invitation to share, which she did over five lines (line 289-293).

Excerpt 9.05: Session 10, Couns C Inexp – Show empathy

288	**C:**	you have to [lo:se the baby]
289	**P:**	[it was very] very very difficult for me to:
290		accept it like (.) even >after like I (get birth) it was ectopic
291		and operation< (.) it was hurt↑ing inside like I (.) did it purposely
		patient cries
292		you see (.) but I know? that I didn't do it (.) maybe (.) God (.)
		patient cries
293		saw that (.) I couldn't (.) go through with that pain you see
294	**C:**	uhm (.) so it was for you it was a really ha:rd emotional ti:me
295	**P:**	°it was emotional time°
296	**C:**	and I can see it still upsets you?
297	**P:**	it's still(.) it's °still upsets me a lot°
298	**C:**	what was the ha:rdest part of that time for you?
299	**P:**	to lose the baby.
300	**C:**	° to lose the baby°
301	**P:**	because (.) after? I found out that I was (.) pregnant >I learned to as< (.)
302		accept it because I didn't want a baby< (.) you see (.)
303	**C:**	right
304	**P:**	so I learned to a accept it when I learned? to accept it then
305		that's happened it was very (.) hurtful for me

The excerpt shows how the counsellor and the woman both contributed to the woman sharing her feelings about the loss of her pregnancy. As also seen in the previous segment in excerpt 9.04, the counsellor held the woman's gaze throughout the interaction.

The findings of other studies, using the ROTER scoring system have shown that counsellors engaged in facilitatory behaviours. In cancer genetic counselling sessions conducted by consultants, Butow and Lobb (2004), found that there were attempts at partnership building and eliciting emotional concerns. Similarly, genetic counsellors were

shown to use a psychosocial communication pattern that functioned to show empathy and partnership building (Roter et al., 2006b). In the study during which the counsellors' 'humanistic voice' were evident, the counsellors were also found to show empathy and encourage emotional participation (Babul-Hirji et al., 2010).

Thus far, the findings of the present study showed that counselling segments occurred and what their functions seemed to be in the session. Upon closer examination, the counsellors used several strategies that allowed the woman more interactional space and thus allowed them to share life world related issues.

9.4 Development of the counselling segments

As the previous excerpts have shown, although the women took up some interactional space and shared information, the counsellors generally controlled the development of the segments in the interactions as they initiated and facilitated their development. In almost all of the cases, the counselling sequences were initiated by the counsellors in the form of questions or statements.

The development of counselling segments was usually dependent on how the counsellors responded to the women. When the segments developed further it was because the counsellors facilitated this process. Excerpts 9.06 and 9.07 show the techniques the counsellors used that allowed further development of the counselling segments.

Excerpt 9.06: Session 10, Couns C Inexp – Further development of the counselling segment

240	C:	and how far pregnant were. you. did you know?
241	P:	uhmmm (.) I THINK I (.) was even? less than three? months
		file
242	C:	okay
243	P:	because I (.) didn't get my period in Ju:ne
244	C:	right?
245	P:	and on the: (0.3)
246		((DA:TE)) (2.0))
247		then I I had a (.) problem that I started bleeding and all that and (.)
248		when I come here they found that the: fallopian tube fractured?
249	C:	yes
250	P:	and then they operated to take the: fetal remai:ns (.)out
251	C:	°okay:°
252	P:	hmmn
253	C:	and how? was? that time for you.
254	P:	Oit was very difficult you KNOW I didn't know that I was
255		pregnant↑ (.) I knew when the pain started then I went to the
256		doctor to go find out why do I have a pain on one side and
257		like (.) it used >to come every morning when I go toilet<
258	C:	uhm
259	P:	>once I have sit? I (feel like) I can't get up (.) from there's a [pain]
260	C:	[the pain]
261	P:	ja the pain was there so and somebody has to come
262		and help me to (.)get up from? that time I had the pain TILL (.)
263		I started bleeding. and all that [it was]
264	C:	[so]
265	P:	>very, very difficult [for me]<
266	C:	[it was a hard] <time for you.>
267	P:	it was a ha:rd time.
268	C:	it was a shock to find out you were pregnant?

269	P:	it was a shock when I went? for the pain and the doctor is not?
270		telling me about the pain is telling me about the °pregnant° a
271		pregnancy I was sho:cked I >[couldn't couldn't believe]<
272	C:	[couldn't believe that]
lines 273 – 287 omitted		
288	**C:**	you have to [lo:se the baby]
289	**P:**	[it was very] very very difficult for me to:
290		accept it like (.) even >after like I (get birth) it was ectopic
291		and operation< (.) it was hurt↑ing inside like I (.) did it purposely
		patient cries
292		you see (.) but I know? that I didn't do it (.) maybe (.) God (.)
		patient cries
293		saw that (.) I couldn't (.) go through with that pain you see
294	C:	uhm (.) so it was for you it was a really ha:rd emotional ti:me
295	P:	°it was emotional time°
296	C:	and I can see it still upsets you?
297	P:	it's still(.) it's °still upsets me a lot°
298	C:	what was the ha:rdest part of that time for you?
299	P:	to lose the baby.
300	C:	° to lose the baby°
301	P:	because (.) after? I found out that I was (.) pregnant >I learned to as< (.)
302		accept it because I didn't want a baby< (.) you see (.)
303	C:	right
304	P:	so I learned to a accept it when I learned? to accept it then
305		that's happened it was very (.) hurtful for me

In excerpt 9.06 above, the counsellor used continuation markers such as 'okay' (line 242) and further down (line 244) she used 'right' and later (line 249) she use 'yes', 'okay' in (line 251), 'uhm' (line 258) and 'right' (line 303). Each time the woman continued her account of the events that seemed to flow from one turn to the next. The woman's responses showed that she treated the counsellors' continuers as encouraging her to tell her story. In line 253 the counsellor changed her response from continuers, which she

used up to this point, and asked the woman a PDS question. The woman regarded this as an invitation when she elaborated on her emotional reactions and then she shared more than just an account of events. The counsellor's next response in line 258 was a continuer 'uhm' which further encouraged the woman's talk as did the counsellor's repeat of the words 'the pain' (line 260), 'so' (line 264) and ' it was a hard time for you' (line 266). Repeating in counselling skills terminology is 'mirroring' (Egan, 2001). The counsellor then in line 271 repeated the gist of the woman's previous exchanges by paraphrasing (a formulation). The woman responded by agreeing but also further elaborated her disbelief in the doctor's news. The counsellor then summarized the events as they occurred (lines omitted) and ended with stating that the pregnancy could not be continued (line 272). The woman in her extended turn started crying as she spoke about having gone through this experience. The counsellor responded to the woman by paraphrasing (line 294) which the women then stated that she was still affected by the incident (line 296). The counsellor then in line 298 asked a question about the hardest part of the experience. The woman took up this invitation and the counsellor then repeatedly mirrored the woman's remarks, which she took up as an invitation to elaborate on her story. The woman also took up the counsellor's continuer, further in line 303, as an invitation.

The next excerpt shows the counsellor's use of specific questions and how this allowed the counselling segment to develop.

Excerpt 9.07: Session 13, Couns E Exp

1207	**C:**	Are you worried?
1208	**P:**	I'm worried but I want to do it (.) I was worried before as well?
1209		But uhm

1210	**C:**	Why: are you worried?
1211	**P:**	Uhm you know (.) as a but I'm feeling strong and my husband
1212		is strong he's not sick? I'm not sick? but there is? The
1213		chances to have an °HIV°
1214	**C:**	°ja°
1215	**P:**	°ja positive°
1216	**C:**	°okay°
1217	**P:**	there is the chances to be have uhm eh (.) an (.) HIV negative (.)
1218		you know. we don't know.
1219	**C:**	Ye:s
1220	**P:**	Ja
1221	**C:**	yes uhm and where do you think the HIV would
1222		have come from Cynthia?
1223	**P:**	You know my as I told you that my husband have another
1224		woman (.) I don't know where she's going. I'm sitting at home
1225		waiting for my husband to come back always (.) by doing the
1226		funny things (1.0) there to tell you the truth I don't like the ma:le
1227		if (.) ah I were the other woman maybe I protect is is like
1228		now (.) I don't ca:re I don't care maybe even if my husband's
1229		gone I don't care whether he will be back but he's not ah
1230		ah a (.) bad person (.) but (.) as I told you that (.) he had another woman (.)
1231		I don't trust myself (.) sometimes (.) I always said (.) this (.) since I was
1232		born I (slept) (.) he's the one who's (.) (been found with
1233		the infection) but what is the other ones because this man is
1234		staying with me every time (.) > sometimes< he's stays six months
1235		with me and then (.) he I don't' know when he's going there (.) I
1236		don't know when I (they having a baby) so (.) he always (.) tell
1237		me if that woman's pregnant

The excerpt is taken from line 1207, where the counsellor used a yes/no interrogative to ask about the woman's emotional concerns regarding having an HIV test. This interaction came after a discussion that the woman would have to undergo an HIV test first before she could have an amniocentesis performed. The counsellor, in line 1210, then asked the woman using an open-ended question, why she was worried. The woman treated this as an invitation and responded by stating her concerns. The counsellor used continuers (line 1214), and 'okay' line 1216, which the woman treated as an invitation to expand on her story. In line 1221 the counsellor asked the woman another question, by linking to the woman's earlier response (line 1212-1213), as to where she thought the 'HIV could have come from'. The woman treated this as an invitation and took an extended turn (15 lines) where she talked about her relationship with her husband and her fears.

Counselling segments do not always develop further, as seen in excerpts 9.08 and 9.09 where the counsellor shifted the topics. Some techniques used by the counsellors disrupted the development of the counselling segments. Excerpt 9.08 shows how the counselling segment was initiated by the woman, but the counsellor did not allow the segment to develop further as she said 'so let me explain' (line 1129), indicating that she wanted to give the woman more information, before she could make the decision. The counsellor could have asked another question or responded with a continuation marker or formulation as seen in the previous excerpts. Instead, she used her turn to return to the explanation of Down syndrome.

Excerpt 9.08: Session 09, Couns D Exp – New topic

1125	**C:**	but they will always be <slower> than other children (0.1)
		file
1126	**P:**	uhm, its >fine< it's okay (.) its >mine< (.)
1127	**C:**	okay.
		file
1128	**P:**	°>uhm<°
		file
1129	**C:**	>so let me explain<
		file
1130	**P:**	((laughs))

Similarly, in excerpt 9.09 the counsellor ended the segment by introducing a new topic, and closing the session.

Excerpt 9.09: Session 09, Couns D Exp - Okay

1769	**P:**	and then in last (.) this month
1770		(0.1)
1771		they were here. because the school was closed
1772		so Simphiwe he took mo:ney go and buy clothes for the Children?
1773		and when they go back you must be nice (.) to show is
1774		you come to (.) your father and mother's you see
1775	**C:**	o↑kay.
1776	**P:**	°uhm uhm°
1777	**C:**	Good? so it sounds? like you very? Happy? Hey
1778	**P:**	°ja ja ja I'm? happy? ((laughs))°
1779	**C:**	((laughs)) okay? Lerato I think (.) we gonna stop there what I'm
1780		going to do is I'm going to come with you no:w (.)
1781	**P:**	uhm

The same argument applies to both excerpts 9.08 and 9.09, as the counsellor could have used any of the strategies seen in excerpts 9.06 and 9.07 but she chose not to do so.

Excerpt 9.09 follows a discussion about the woman and her partners' relationship and the fact that he supported her children (from a previous relationship). The counsellor's continuation marker 'okay' (line 1779, 1780) followed by the statement that the session had come to an end, resulted in the woman responding with a continuer, which was in contrast to her earlier responses (lines 1773-1774, 1778). The reasons for terminating the counselling segments is not sure, but as in the case of excerpt 9.09, it might be due to the women's response that she was happy, thus indicating that further discussion is not required.

The counsellor strategies identified in the present study were similar to those observed in other counselling and therapeutic discourses. As shown above, the counsellor used several types of questions that allowed the women to share how they perceived or felt about an issue. In HIV counselling, such questions were termed circular questions (Miller & Silverman, 1995). As seen in excerpt 9.06, line 298, the counsellor's question about the hardest part of the experience allowed the woman to focus on her fear and feelings about her situation. In HIV counselling this has been referred to as eliciting a dreaded issue (Miller & Silverman, 1995). The counsellors were also found to repeat the woman's talk by mirroring (repeating a 'mirror' of the woman's statement) and paraphrasing (giving a 'formulation' of the most salient aspect of the woman's response). Paraphrasing (Egan, 2001), or formulations (Heritage & Watson, 1979) has been shown in previous studies to encourage participation (Babul-Hirji et al., 2010; Miller & Silverman, 1995; Roter et al., 2006a).

Comparing the counsellor strategies with the functions of the counselling sequences, there seems to be a suggestion of a link between the type of strategy used and what the function of the segment was. Continuers were found in all types of segments, while questions and

repeating the woman's previous talk were more related to certain functions. In excerpt 9.03, when the counselling segment lead to a discussion of a concern, the counsellor's questions had focused on that concern, for example in line 673 the counsellor asked 'tell me what's worrying you' and line 679 when the counsellor's b-event statement 'you haven't had any bleeding". These questions formats were different from those seen in the empathy segments where the counsellor's questions elicited dreaded issues and circular discussion as seen in excerpt 9.06 and 9.07.

Further, as seen in the connecting segments, the counsellor questions' and repetitions of the women's talk did not seem to address deeper emotional aspects but focused on the content of the discussion. Similar differences in levels of empathy of responses were found in cancer genetic counselling sessions (Duric et al., 2003, p. 248). The authors coded the levels of responses according to whether the counsellor delayed or ignored a response (level1), or responded to content only (level 2), or responded to feelings level 3 or responded to feeling and invited elaboration (level 4). The authors provided examples: " …. if a patient said: "My mother died last year of breast cancer and it was terrible," the responses: "Yes, and have any other members of the family had breast cancer?" would be coded as Level 1; "So your mother died quite recently" would be coded as Level 2; "It sounds like your mother dying was a difficult time for you" as Level 3; and "It sounds like it was a hard time. What made it particularly awful for you?" as Level 4. The results from the present study seem to point to similar levels of responses to those reported by Duric et al. (2003). What the analysis showed, in addition, was a possible correlation between the type of response and the outcome of the segment i.e. empathy or discussion of a concern, suggesting that counsellors could select a strategy depending on what they wanted the discussion to achieve.

The observed non-verbal behaviours also appear to differ according to the functions of the segments. The counsellors and women's gaze were directed at each other during most of the discussion, particularly during empathy and connecting segments. It was only in the segments where the function was to obtain more information or to discuss a concern that the counsellors occasionally directed their gaze at the patient files to record or check information.

9.5 Discussion

The counselling segments were defined as such, since they differed from the rest of the session as the women took up more interactional space. In addition, the content of the discussions related to the issues of everyday life, beliefs and emotions. An analysis of these counselling segments provided some insight into how genetic counsellors addressed the emotional aspects in the sessions. The counselling segments showed that the counsellors were 'being counsellors' as they allowed the women to share. This is in contrast with the other phases where they had to obtain family, medical and pregnancy history and explain complex scientific and medical concepts.

As discussed in Chapter 2, the extent to which genetic counsellors practise according to 'the prevention goal' and the goal of 'psychological well-being' (Biesecker, 2001) has not yet been answered (Biesecker & Peters, 2001) and the profession still needs to develop an empirical comprehensive model of practice (Fox et al., 2007; Veach et al., 2007). Although the emotional aspects have been regarded as important and it is advocated that these are addressed (Djurdjinovic, 1998; Weil, 2000), and if they are addressed the patients show more satisfaction with the session (Bernhardt et al., 2000; Davey et al.,

2005) evaluating whether counsellors do this in sessions has been difficult. Research in genetic counselling interactions has provided evidence that different styles, such as counsellor-driven psychosocial and biomedical question and answer styles, exist (Ellington et al., 2006; Roter et al., 2006a), that there are different 'voices' in sessions such as the 'humanistic voice' (Babul-Hirji et al., 2010), and that different levels of responses occur (Duric et al., 2003). Nevertheless, little is known about how these styles or voices relate to each other.

In the present study, an examination of the counselling segments of the interactions showed they had different functions in the sessions: they sometimes provided the counsellors with more patient information, while at other times patient concerns were addressed, allowing for building a relationship, for the counsellors to show empathy and for the women to speak about their emotions. During these segments, the counsellors were found to make use of several strategies, some facilitatory and others inhibiting. When counsellors used minimal encouragers, the discussion was facilitated and the woman shared more, as was also shown by Babul-Hirji et al. (2010). Similarly, asking certain questions (Miller & Silverman, 1995) and using counselling skills (Egan, 2001) seemed facilitatory and encouraged the women to share and participate in the sessions. In counselling and psychotherapy encounters, these techniques have been used and have illustrated how the theories of counselling are put into practice and how clients are assisted to talk through and understand their experiences (Miller & Silverman, 1995; Peräkylä, 2004; Silverman, 1997). In the present study, in addition to identifying counsellor strategies, some strategies were found to be linked to achieving the different functions. While continuers were found to encourage the woman's participation, irrespective of whether the counsellor was obtaining more information or whether the

counsellor was showing empathy, only circular and future orientated questions allowed for empathy segments. In HIV counselling sessions, the clients only experienced empathy if they interpreted the counsellors' responses as 'I hear and understand you' (Silverman, 1997). This might be one of the reasons for there being different functions of the strategies used in the present study as the women could have interpreted the counsellors' statements differently, thereby affecting their own responses.

Although counsellor strategies were found to affect the outcome of the counselling segments, it is difficult to regard some strategies as better or linked to different outcomes. Also, it was not possible to link the use of strategies to counsellor experience. There was so much variation between and within counsellors and sessions that counsellor experience alone could not account for it. Though the counsellors had control over the counselling segments as they could allow or disallow their development, this does not entirely explain the outcome. Not all the counsellor strategies worked with all the women. The use and functions of these strategies is more complex as to how they determine the responses of the women and the counsellors. In one session in particular, the counsellor who was inexperienced, was unsuccessful in engaging the woman even after several attempts and using different strategies (session P03), while in session 10, also with an inexperienced counsellor, she was able to successfully engage with the woman. What accounts for differences and success is complex and multidimensional and is related to counsellor sensitivity, skills and experience as well as patient attributes and qualities.

What the analysis seemed to illustrate was that the counsellors and the women could connect and the women's voices could be heard. However, the fact that the counsellors had to use a number of strategies to engage the women, that the counsellors mostly

initiated the segments, that the topics were mostly unrelated to the medical indication for the session, and that there were some unsuccessful attempts, could point to the counsellors having had to work hard at building a relationship with these women. The relative passiveness of the women observed in the session as a whole is echoed in these counselling segments even though there was more actual participation.

Although the analysis revealed that counselling segments did occur and that counsellors facilitated or inhibited the discussion, this does not mean that all the emotional aspects were addressed. In some sessions there were difficulties and there were several misunderstandings, for example in session P03 as seen below (only content is shown with relevant points highlighted in bold) where the woman's use of 'afford' referred to not wanting the test while the counsellor took it to mean affordability of the test. This could be as a result of language difficulties but also due to the counsellor orienting to the patient as having limited financial resources as she interpreted "afford" in financial terms.

1240	**P:**	I can't **afford** to make this
1241	**C:**	You don't **pay anything** for the test because
1242		it comes the hospital pays
1243	**P:**	**No I I can't [afford]**
1244	**C:**	[You]You don't want to
1245	**P:**	To make this thing

These aspects are difficult to measure in any session, and especially in these genetic counselling interactions, where language, general and health education and other factors, such as the reason for the interaction and the hospital setting, make the situation very complex.

The challenge for the profession in this setting is therefore how to integrate the information-giving with the patient's socioeconomic and educational status, views, needs and expectations. This lack of integration was observed in the sessions in the present

study, suggesting that there are some difficulties in putting the proposed theories into practice and that by trying to adhere to principles advocated by the profession, might lead to tension in the sessions in this context.

There appeared to be tension between counselling and information giving roles as was also shown in chapter 7. Mishler (1984) and others have drawn on the concept of the life world and the philosophical theories which led to its conceptualisation, when examining medical encounters. The voice of the life world is heard when patients address the personal and social contexts of their problems. Mishler (1984) concluded that there is tension between the voice of medicine and the voice of the life world in medical interviews, as the two voices represent different domains of meaning. This seems to be evident in the sessions in the present research, because the counsellors attempted to either educate or counsel. This dichotomy between the two roles has also been highlighted in outcomes based studies (Davey et al., 2005). The challenge therefore is how to integrate education and counselling during an interaction. It was shown that by removing some of the medical questions from HIV interactions, the emotional aspects were considered to a greater extend (Sheon et al., 2010). This, however, does not address the matter entirely as in this context medical information cannot be taken out of sessions, as it would defeat the purpose of the consultation.

9.6 Summary

Counselling segments were different from the rest of the session as the women were found to participate more in these than in other segments of the interaction. The women took up more interactional space and responded by discussing issues rather than just providing

answers. The segments were found to have different functions and these included: showing empathy, relationship building, providing information and discussing a concern. Even though the women participated in the interaction and were less passive, the counsellors were in control of the initiation and development of the counselling segments. The analysis of these segments provided more information on how the counselling activity occurred in the genetic counselling sessions and that the patient's emotional and life world could be included in the interaction.

Chapter 10 General Discussion and Conclusion

10.1 General discussion

The researcher entered the present study with many assumptions about the role of genetic counsellors and their interactions with patients and had fixed ideas about the principles on which these are based and how and what should be achieved in a session. Simultaneously, the researcher also questioned these principles and practices and the low uptake of services in the clinics. In performing the research, it was hoped that insights would be gained into the practices in the setting and as the aim of the study was to investigate the discourse in multicultural genetic counselling interactions, there was an expectation that cultural aspects would emerge in the sessions. However, cultural aspects were not apparent or explicitly discussed. What the study revealed instead was that the genetic counselling sessions were a complex interplay of many factors.

It was evident that the overall structure of the sessions aligned with the definition of genetic counselling. The data showed how the counsellors set an agenda, and revealed how they framed their questions and how they responded to the women's answers during this process. It showed how the counsellors obtained medical and family history information by making use of a number of different question formats. The manner in which they explained the complex medical concepts consisted mostly of long but also shorter monologues. The counsellors assisted the women in making decisions and a number of non-directive strategies were identified. An analysis of the counselling segments revealed counsellor strategies and how these were linked to specific functions. The mapping of the sessions into different phases and an examination of the sequence

organisation of the different phases, revealed the interactional hybridity. It showed associations between the specific phases with regard to their functions, their unique interactional sequences and variation in non-verbal behaviours.

In addition to showing how the principles of the profession were put into practice, the results revealed some unique features. The most striking of these were how the genetic counsellors guided the women through the genetic counselling session. The counsellors' control was apparent in all six of the identified phases and was evident from the clearly discernable and rigid overall structure: how the counsellors set the agenda, how they introduced the different phases and topics as well as how they chose the strategies they used. Further, the decision-making sequences illustrated how the counsellors had tried to engage the woman, by using active strategies and introductions of various relevant scenarios, to assist them to make their own informed decisions. Even during the counselling segments, the counsellors directed and promoted or prevented the development of the segment. Generally, the genetic counsellors' active and explicit role in directing the interactions resulted in a counsellor led agenda.

The counsellors' active role and control in the interactions, linked to the interactional asymmetry observed during these sessions. The structures and active strategies the counsellors used, and being the first and last speaker allowed the counsellors to be in control. The women went along with the counsellors' agenda. This combined with the woman's lack of taking up interactional space when given an opportunity and not asking questions, contributed for the most part of the session, to the interactional asymmetry. The asymmetry in the interactions allowed the counsellors agency and power, while the women remained relatively passive. Power asymmetry is a well described phenomenon in

institutional discourses and particularly medical encounters (Mishler, 1984; Roberts, 2000). In some genetic counselling encounters others have also found that the genetic professionals generally control the interactions and that patients' voices are were not always heard (Armstrong et al., 1998; Babul-Hirji et al., 2010; Hodgson et al., 2009). The finding that the women in this study appear disempowered is, therefore, in itself not unique as the asymmetry is partly due to the medical agenda. However, the observed asymmetry in these genetic counselling sessions appeared also to be linked to the setting in which this service was provided.

The role of the setting in establishing the reason for the women's attendance at the clinic manifested in the transcripts. The counsellors' opening questions were structured around an implicit understanding that the women were referred for genetic counselling and there was explicit reference made to the referral system in some of the transcripts. The women who attended the clinic did not elect or seek out the service, instead they were integrated into the medical referral system practiced in the state hospitals in which a pregnant woman over the age of 35 years is routinely referred (depending on gestation) for an ultrasound examination and/or a genetic counselling session, to discuss the risks and options associated with advanced maternal age. The context, therefore, affected how the counsellors structured their opening questions, which ensured that the women responded with what they knew about their referral. The counsellors' question functioned as a way of checking the women's knowledge regarding their referral, rather than allowing them an opportunity to share concerns. As a result, the counsellors opening strategies and uptake of the women's responses allowed the setting of a narrow counsellor driven agenda.

The women's apparent disempowerment is also thought to be influenced by the historical and socio-political history of the country in which women did not have the power (and still do not have) to make their own healthcare and many other decisions (Harris et al., 2011; Penn & Watermeyer, 2012). The counsellor's agenda was based on the predetermined genetic counselling agenda and the women had no choice of whether they wanted to receive this service. Both the counsellors and the women seemed go along with the agenda and their roles. The counsellors' role was to provide direction while the women's role was to follow. The counsellors' attempts at changing this role by including, empowering and giving the women interactional space, mostly failed as was evident by the women's lack of taking up these opportunities. However, the counsellors' strategies were restrictive as it provided a narrow scope of what the women was allowed to participate in.

Both, the western and traditional healthcare interactions the patients are use to in this setting are more commonly directive and they generally receive advice and not options (Penn & Watermeyer, 2012). As a result, patients are not expected to make their own decisions. The decision-making in these sessions was therefore critical. The counsellors played an active role in assisting the women in the decision-making process and took great care and effort to be non-directive as recommended in the practice of genetic counselling. Although their non-directive stance was evident, the strategies they developed were directive. Inviting the women to make decisions and weigh up choices were probably unfamiliar processes to them. As a result, the session as practiced in the setting, differed from those they were familiar with. It is suggested that the historical inequity in the health care context to which most women are accustomed to as well as the counsellors' approaches resulted in making the women's perceived voices weaker in the context of the

genetic counselling clinic. Both the counsellors and the women seemed to be aware of this and co-constructed a dialogue, which is likely to be ambivalent. The deliberate attempts to include the women, explain processes, adhere to an ethos of non-directiveness presented conflict and tension in these interactions as the counsellors had to take care and use directive techniques to guide and empower these women and enhance their autonomy. The questions of patient autonomy and patient rights are issues faced by genetic counsellors (Kirklin, 2007; Weil, 2000). In this health care context these issues are highlighted and instead of enhancing autonomy, some counsellor techniques may in fact serve to erode autonomy and highlight the asymmetry of the interaction (Pilnick & Dingwall, 2011).

The present study therefore suggests that techniques used in genetic counselling which are firmly embedded in the tradition and textbooks on this topic may need to be adapted in this context. Recent work in Hong Kong has shown that it is becoming more apparent that the setting has an influence on interactions (Pilnick & Zayts, 2011; Zayts & Schnurr, 2011). Traditional techniques of non-directiveness, decision-making and setting agenda questions (Veach et al., 2003) may not be as effective in helping the emergence of autonomy in these women as it provided an interesting contrast, by showing how techniques thought to enhance patient autonomy achieve the opposite in the interactions in this setting. If patient centeredness and autonomy are the aims in genetic counselling the contextual factors will have to be included.

The results from the present study point to the difficulty of putting into practice an endeavour, which requires education on complex topics, counselling with regard to how these issues affect the patients and their families as well as decision-making. Tensions seem to be related to having to simultaneously attending to the medical- and life world

aspects relevant to the patient. As seen the role of counsellor emerged by the strategies and structures the genetic counsellors had put into place to guide the women through the process, addressing aspects that might impact on the sessions, encouraging participation and the clearly discernable counselling segments, while the role of educator emerged in the narrow agenda, need to and the detail of providing information about AMA. This is a challenge for any genetic counselling encounter but as shown even more so in these interactions. At first glance, it would seem that the sessions in the study were somewhat unsuccessful because of all the points highlighted above. However, it was evident that there were some moments of good practice, of empathic counselling and genuine concern which points to success. As found by an analysis of a single genetic counselling sessions in the same setting (Penn & Watermeyer, 2012; Tovell, 2004), there seemed be a sensitivity to the women's needs in the sessions. The counsellors took care and effort to guide the women through the processes and helping the women in making a decision and in some cases their strategies used were successful. Further, in the counselling segments, the counsellors were able to engage the women successfully as the women shared personal issues related to their everyday life.

Success therefore does not depend entirely on the strategies used. In some sessions, it was more difficult for the counsellors to engage the women. In particular, in session P03 the counsellor struggled to engage the woman and there were several miscommunications during their interaction. There was also no consistency with regard to whether more experienced counsellors or a specific counsellor was more successful in engaging the women. The results therefore suggest that the counsellors' and the women's unique qualities also played a role in the success of the interactions. The patients seen for genetic counselling are unique individuals with their own personalities, attitudes, values, beliefs,

fears, emotions and defences (Weil, 2000). Similarly the counsellors are unique individuals, and in addition to this, they integrate their skills and experiences in differences ways. The uniqueness of the individuals in these sessions as others suggested (Kessler, 1997a; Weil, 2000) effected the interactions.

The genetic counselling interaction is complex. Consequently, evaluation of the success requires an examination of the whole, the parts and how they relate to each other. Unlike what was expected, cultural aspects did not emerge in the sessions, questioning its relevance for the participants. As a result, the success depends on a complex interplay of individual qualities of the participants in the interaction, the setting, and a range of interactional factors. Success or failure cannot be attributed to a single construct. There are nuances and complexities and differences between individuals and within separate sessions. As a result both barriers and facilitators to communication and the multitude of factors which influence these are beginning to be understood. A successful clinician working in a diverse cohort needs to strive towards understanding such influences in order to maximise patient autonomy.

10.2 Implications and Recommendations

The findings from this study have important implications for genetic counselling practice and training in South Africa. It provided insights into the interactions and the difficulties experienced in the local setting and challenged textbook principles that are firmly embedded in the profession. Informed choice, decision-making and non-directiveness (Fraser, 1974; Marteau et al., 2001; Shiloh, 1996) and the principles of a patient-centered approach, which were originally based on the ideas from Rogers' Client Centered Therapy

(Weil, 2000), have been the cornerstones of the profession from its inception. These principles have guided genetic counselling practices and the techniques developed to promote patient autonomy (Weil, 2000). As seen in the transcripts the principles on which practices are based impeded rather than facilitated the genetic counselling process in this study. As a result, it suggests that these have to be modified to some extent for patients in different contexts.

As seen in these interactions, setting the agenda, non-directiveness, educating and counselling as taught and advocated in the profession resulted in less patient autonomy in this setting. It revealed contextual influences on the interactions. The counsellors used active counselling strategies in order to guide the women through the process. On the other hand, counsellors adhering to advocated principles, as shown by counsellors' attempts to be non-directive during decision-making sequences, failed in meeting the needs of the patients and indeed limited their practice. Interpreting these strategies within the health care context of South Africa revealed the tension that exists between adhering to advocated principles and applying these in practice. It therefore highlights that it is essential that training and practice are adapted to suit the setting in which it is performed if patient-centered interactions and respect for diversity and equality are to be achieved.

In a patient-centered approach the patient is the focus and the session and interventions are determined by the patients' needs. A patient-centered approach can be aligned with Mishler's (1984) concept of the 'voice of the life world'. It is therefore suggested that in order for the genetic counselling sessions in this setting to be patient-centered the patient's life world needs to be engaged in the session. It was shown that the counselling segments provided an interesting contrast to the rest of the session. The apparent contrast was as a

result of the women's voices being heard during these segments, as they participated more actively in the interaction and the asymmetry lessened. Although most of these segments were not related to the genetic counselling agenda of advanced maternal age, but rather involved discussions about relationships, previous pregnancies or health issues, it provides evidence that the women's life world can successfully be engaged in the genetic counselling sessions in this setting. The challenge nevertheless is to bring such participation into the genetic counselling agenda, earlier and throughout the interaction. This provides evidence as others have also found (Penn, Watermeyer, & Evans, 2011), that for full patient participation, counsellors should engage with the patient's lived experience by including the voice of the life world. Contextual issues need to be combined with the goals of the session in order to meet the needs of the patients. Empowerment were found to be an important outcome of a clinical genetics encounter (McAllister et al., 2008; McAllister et al., 2010). For a true patient centred approach aimed at empowering the patient and enhancing autonomy, a model of genetic counselling should allow for the life world of the patient and the genetic counselling agenda to be integrated.

As discussed in Chapter 2 clearly defined models of practice do not exist. However, in more recent attempts to find a suitable model, the Reciprocal Engagement Model (REM) was proposed (Veach et al., 2007). The REM is based on the key tenets of education, individual attributes, outcomes and that the relationship between the counsellor and that the patient is integral to the process. While it is agreed that the tenets concerning the relationship is integral and the patient attributes are important, and that as an outcome the patient understands and applies the information, this model has several shortcomings, which limits its applicability to genetic counselling in this setting. The emphasis on

education in the model is narrowly defined which makes it less applicable in the South African setting because most patients have been found to have a limited understanding of genetic concepts and there are no words for genes, chromosomes and DNA in the local languages (Kromberg & Jenkins, 1997; Penn et al., 2009; Solomon et al., 2012). While it is agreed that education is fundamental to the genetic counselling agenda, the type of 'education' needed should rather be defined as specific relevant information which the patient requires and requests. In addition, the REM model does not appear to take the contextual influences into consideration which this research has shown to be critical.

A new approach is suggested in which the emphasis is on bringing the patient's life world into the interaction while considering the counsellor, the genetic counselling agenda and the context. A framework is required which allows respect for individuals' uniqueness within their group identity on a human rather than cultural level "....the differences between people are outweighed by the similarities, and …. understanding, empathy and acceptance are activities (or qualities) that transcend cultural and social differences" (Spangenberg, 2003, p. 53). A patient-centered model of genetic counselling is required drawing on sociological rather than biomedical principles. With this as a framework, the model should allow for the patient's life world to be included in the session. The 'Life History Narrative Model' proposed by Kenen and Smith (1995), with some modification to take into account the requirements of genetic counselling, seems generally suitable as this model relies on the professional to allow the patients to tell their stories: "By using relatively unstructured interviews, clients are invited to speak in their own voices, allowed to control the introduction and flow of topics and encouraged to extend their responses" (Kenen & Smith, 1995, p. 120).

A new set of guidelines are therefore proposed for the development of a model for "Contextual Genetic Counselling". This model is informed by the findings of the research and draws on the successes and difficulties identified. The emphasis is on the interaction between the patient, the counsellor and the context and relies on taking the patient, and counsellor's individual attributes into consideration. These include their experiences and skills, unique personalities, values, beliefs, hopes, fears, defences, language, emotions and experiences. In the model, the patient and the counsellor are each represented by its own arms. The individuals in the interaction are affected by contextual influences and, this is represented by the third arm. These three elements come together and for the interaction to be successful, an environment of acceptance and openness is required. The triangle in the middle indicates the interaction between the three components, the counsellor, the patient, and the session. Figure 10.01 is a presentation of a proposed contextual model of genetic counselling.

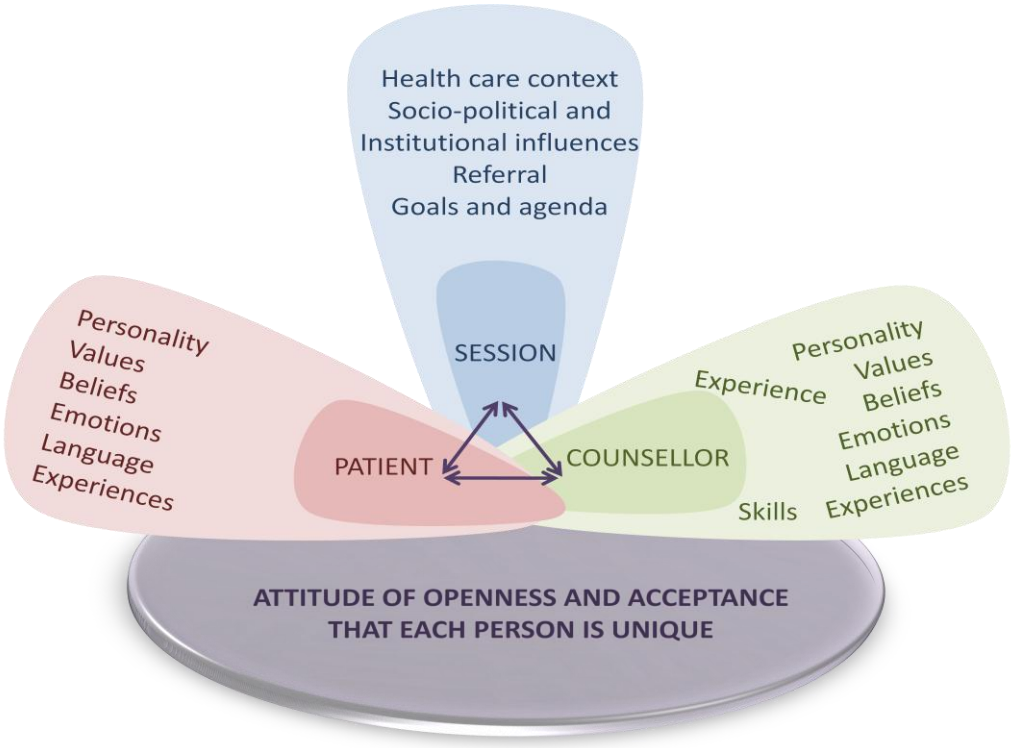


Figure 10.1. *A proposed contextual model of genetic counselling*

These principles could be achieved by specific techniques used by the counsellors. Such strategies are thought to empower the patient to participate by bringing the life world of the patient into the session and should shape how the session is structured. The types of questions, how information is communicated, how patients are helped to make decisions, how emotional aspects are dealt with, are key strategies that are thought to contribute to achieving a contextual model of genetic counselling in this setting. Adapting an ethnographic framework rather than being driven by a biomedical one. These strategies may be summarised as follows:

Session:

Requires a flexible structure. Check and adapt continuously

Opening questions:

What do know about the reason for your referral?

Follow-up questions, such as "What are your concerns about this?"

Information sharing

What do you want to know?

What do you think is the cause?

What do women/others in your community think about?

Provide information relevant to the patient

Decision-making

How do you see yourself overcoming this problem?

How can I help?

Addressing emotional aspects

How do you feel about.....?

How do you deal with problems in your family?

Who gives you support?

Active listening is a key factor and combined with pauses and encouragers after a patient's turn, will allow the patient time and space to share their views. A combination of open questions and responding techniques such as those seen during the counselling segments (continuers, paraphrasing, mirroring, circular and future orientated questions and questions eliciting dread issues) are key strategies.

Although this model is focussed on providing genetic counselling in this setting, it is thought to be applicable in other settings since it takes the contextual influences into consideration. The women in the sessions in the present study have provided some guidance and with the diversity of patients accessing genetic counselling services and the profession expanding, it is hoped that these lessons will be helpful elsewhere.

10.3 Methodological considerations

The sociolinguistic methodologies used in this research were powerful in revealing both the broad features and phases of the interactions, as well as the detail. The use of these methods allowed what actually occurred in the sessions to be revealed, because of their focus on how one action leads to another and how these influence interactions. The analytical approach in the study proved successful in revealing the nuances as well as the overall structures of the interactions. The genetic counselling interactions were found to be complex and the different phases were unique in its interactional dynamics. An analysis therefore had to draw on the different methodologies in discourse analysis to be effective in revealing these nuances. It is the combination of the methodologies that allowed the complexities of the interactions to be revealed. Combining different methods of analysis, were more effective than adhering to one specific method as each method has

strengths and weaknesses, and drawing on the strengths of each proved effective in revealing otherwise missed phenomena.

A broad description of the genetic counselling sessions was essential as this provided a context in which to interpret the in-depth analysis of specific feature. Combining this with detailed analysis on selected phases and phenomena uncovered the detail of the practice of genetic counselling in this setting. The majority of research on the genetic counselling process examined from a socio-linguistic perspective, as discussed in the background chapters, has been on examining specific aspects for example non-directiveness (Benkendorf et al., 2001; Sarangi et al., 2004), and how information is communicated (Lehtinen & Kääriäinen, 2005; Lehtinen, 2005). Studies with such a focus revealed the detail of the interaction but lacked a description of how the specific phenomena fitted into the session as a whole. In a similar vein, research which (Babul-Hirji et al., 2010; Hodgson et al., 2009) focussed mostly on a description of the entire session lacked in examining the finer points of the different sections. It is the researcher's opinion that this is a shortcoming in the literature on genetic counselling interactions. The present study therefore is thought to contribute to the existing literature not only because of its approach, which allowed the overall and detail to be revealed, but also because it examined the process in an intercultural setting with interactions provided exclusively by Masters trained genetic counsellors.

Although valuable insights were gained from the present research study, there were some limitations. The study was conducted on a small sample in a particular setting. It will therefore be very interesting to perform further research to examine how other settings might influence the genetic counselling interactions. Since the findings suggested that a

number of factors impact on the session, further studies should examine sessions in which the reason for the referral is other than AMA, for example, a diagnosis of a genetic condition, late onset conditions and cancer.

Further evaluations should also include first and follow-up sessions. It is expected that in sessions where less information is required, such as follow-up sessions where the patients have had time to absorb the diagnosis/information, the sessions would involve more patient participation. This has been observed in HIV sessions when the lifestyle check-list clinicians were required to complete, was removed from the sessions (Sheon et al., 2010). In addition, it would be interesting to examine sessions in which patients requested the service, instead of being referred as occurred in this study. It seems very likely that there would be significant differences. As a new model has been proposed, this model should be implemented and tested in variety of settings. This will enable it to be refined and adapted, as more information becomes available.

The proposed model is based on data obtained from an examination of the interactions. In the present study the views of the women were not obtained. Patient views have been useful in other studies in revealing the patients' perspective and experiences of genetic counselling (Ahmed et al., 2012a; McAllister et al., 2008) and could enhance our understanding of the process. As explained in the methodology section, the study design initially included data to be collected from the interactions, as well as from post-session patient interviews. These interviews were conducted, but provided inadequate data even though the patient participants and the interviewer were linguistically matched. It has been the experience of others in the HCP that the patients in this setting are more reserved in one on one interviews compared to when they are interviewed in groups settings. If

research in this setting is planned on the patient's experiences of genetic counselling, it is essential for interviews to be carefully considered and conducted and that interviewers are well trained to ensure that rich data can be obtained.

A further important limitation of study was that the interactions were all conducted in English, which was not the first language of the women in the study. This meant that the participants were able to communicate in English. It was found in some of the sessions that there were communication difficulties, particularly in session P03 as discussed in the preceding chapters in which some miscommunications were evident. This is an important limitation as communication difficulties due to language had been excluded by the nature of the design of the study. One of the sessions recorded during data collection was conducted using an interpreter. This session was excluded as it was the only mediated session in the data set and because a variety of factors is known to influence mediated interactions. It was felt that an analysis of one session would result in insufficient data and would not allow any conclusions to be draw. Interpreter mediated sessions are complex and deserve an extensive and comprehensive investigation to do it justice.

The proposed contextual model of genetic counselling is based on participants sharing a common language and understanding each other. Without any evidence and given that genetic counselling is a communication process, it is anticipated that a fourth arm would need to be added to the proposed model to include the influences of a medicated session. A similar argument can be made for the effect partners and other family members would have on a session, as family dynamics are known to affect the genetic counselling interactions.

10.4 Conclusion and final reflection

This research has provided insights into the actual practice of genetic counsellors during their interactions with their patients. These insights showed the impact of the setting and the counsellor led agenda on the genetic counselling process and the need for developing a contextual model of genetic counselling. The results have significance for genetic counselling practices in South Africa. The findings provided answers to some of the researcher's questions regarding what is being achieved with the services provided and how these can be enhanced. However, the results have also provided some hope that there are good practices and that with some appropriate adaptation of the training courses, services can be further improved. A recent study of a local MSc (Med) Genetic counselling student (Morris, 2013) examined how women who have had a child with a genetic condition experienced genetic counselling, and the women stated that they valued their genetic counselling experience.

In South Africa genetic services were started in the 1950, while the training of genetic counsellors was initiated in 1987 in Johannesburg and 2004 in Cape Town (Kromberg et al., 2012). South Africa is ahead of other countries including developed nations, with regard to legislation and registration (credentialing or certification) of genetic counsellors. Scope of profession and practice documents are available to guide and regulate the profession. National Department of Health guidelines have been drawn up for the provision of genetic services and medical genetics has been included in the maternity care guidelines. In addition, departments of human genetics exist within government structures, and in the National Department of Health a sub-directorate has been established. However, in provincial offices genetics is part of the Directorate of Maternal,

Child and Woman's health (MCWH) or a sub-directorate of MCWH. These developments seem very promising and well established entities but the reality is that South Africa, at present, only has six fully employed practicing genetic counsellors, in the state system. These numbers have dropped from 13 since the present research project started. The lack of employment has affected the training of genetic counsellors and both programmes have not enrolled students since 2011.

In an article by Edwards et al. (2008), genetic counselling was described as one of the 'top careers' of the 21st century and the demand for the service was expected to increase globally, as the discovery of new genes and genetic associations increase. In South Africa, the need for genetic services is as high as in the rest of the world as the rate of a serious genetic congenital disorder is estimated at the 53.4 per 1000 births (Kromberg et al., 2012). Despite the obvious need for the service, and evidence that the patients value the service, and with legislation in place, training and employment opportunities are still not being made available. According to Kromberg et al. (2012) 34.9% of posts for medical practitioners and 40.3% for nurses were unfilled in the state service. Historically genetic services were located within academic departments, and this has resulted in some of the provinces not having medical geneticists and genetic counsellors, and these staff are not being incorporated into departments of health. These factors and the lack of political support from government and employment agencies have made a significant contribution to the imminent collapse of genetic counselling services in South Africa.

As explained in the methodology section, the researcher continued to practice as a genetic counsellor while performing the research and the two roles naturally influenced each other. The researcher continued to provide a genetic counselling service to AMA women

and the results of the study influenced how this service was provided. This resulted in modifications, due to the researcher's experience rather than based on empirical evidence. Instead of the genetic counselling sessions being conducted one on one, as in the research samples, the women who arrived on the day were all seen together. Discussions were held with the women in a group session which, as with the individual sessions, contained the medical, genetic, risk, amniocentesis and ultrasound information. The demographic and information gathering were done individually after the group discussions. Although these interactions were not evaluated formally it was noted that in the group discussions, the women were less passive in the interactions and shared more information regarding what they knew about the risks involved with AMA and what they had been told by those who had referred them. Sometimes the women challenged the counsellors about the information being conveyed as their mothers or aunts had normal babies when they were 'old age'. The women also mostly showed that they were interested in hearing the information and those who did not want to hear did not stay. The women's participation was also more evident in the individual sessions that followed the group discussions. The opening questions such as "what do you think about what we discussed?" were generally more successful in engaging with the women and they shared information about who makes the decisions and their concerns and fears.

Implementing these group sessions has however not been met with great enthusiasm. There has been resistance from other medical professionals within the department as well as other disciplines. The way the service is performed impacts on other disciplines such as the nurses and the fetal medicine experts and it is understandable that changes will affect them. The group sessions has also affected record keeping protocols in the department, which further challenged its implementation. The purpose of these

interactions seems to be overlooked in the adherence to the protocols and routines in the clinics. Such protocols need to be re-evaluated and the focus needs to be shifted to the needs of the patients. Genetic counselling services are at a critical point in the country despite international acknowledgment of its importance. The uptake of services and the number of genetic counsellors in the country is decreasing. With current health care transformation it is essential that as genetic counsellors in South Africa our status is rectified. This study suggests both reasons for decline and proposes some solutions.

As genetic counselling is still thought of as "being in search of itself" (Veach et al., 2002, p. 187) and has been referred to as the "black box" (Biesecker & Peters, 2.001, p. 191), it is hoped that this research has also contributed to the international literature on genetic counselling interactions and that the insights gained here will be heeded elsewhere.

Appendices

Appendix A: Consent form – patient participants

National Health Laboratory Service

University of the Witwatersrand, School Of Pathology
Division Human Genetics

GENETIC COUNSELLING CLINIC

Hospital Street, Johannesburg 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg 2000
Fax: +27-11-489-9226

Prof A Christianson 011 489-9211 | **Prof A Krause 011 489-9219** | **Ms T Wessels 011 489-9243**

CONSENT FORM – PATIENT PARTICIPANTS

Code: _____

Researcher: Ms Tina-Marie Wessels
Supervisor: Prof Claire Penn
University of the Witwatersrand, Johannesburg

"The characteristics of the Genetic counselling process in an antenatal, multicultural setting"

I, …… understand and agree to participate in the study "The characteristics of the Genetic counselling process in an antenatal, multicultural setting". I understand that participation in the above study involves having my session with the genetic counsellor video recorded and that I will be interviewed after the session and that this interview will be audio recorded.

I give permission for the video and audio recordings to be used for:

- The research *only* and for it to be destroyed afterwards ☐
- The research *and*, afterwards for teaching and training of students ☐

Signature: _____

Witness' Full name (print): _____
Witness' Signature: _____
Date: _____

Appendix B: Consent form – counsellor participants

National Health Laboratory Service

University of the Witwatersrand, School Of Pathology
Division Human Genetics

GENETIC COUNSELLING CLINIC

Hospital Street, Johannesburg 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg 2000
Fax: +27-11-489-9226

Prof A Christianson 011 489-9211 | **Prof A Krause 011 489-9219** | **Ms T Wessels 011 489-9243**

CONSENT FORM – COUNSELLOR PARTICIPANTS

Code: _____

Researcher: Ms Tina-Marie Wessels
Supervisor: Prof Claire Penn
University of the Witwatersrand, Johannesburg

"The characteristics of the Genetic counselling process in an antenatal, multicultural setting"

I, …… agree to participate in the study "The characteristics of the Genetic counselling process in an antenatal, multicultural setting". I understand that participation in the above study involves having my session with the patient video recorded and that I will be interviewed after the session and that this interview will be audio recorded.

I give permission for the video and audio recordings to be used for:

- The research *only* and for it to be destroyed afterwards ☐
- The research *and*, afterwards for teaching and training of students ☐

Signature: _____

Witness' Full name (print): _____
Witness' Signature: _____
Date: _____

Appendix C: Patient participant information sheet

National Health Laboratory Service

University of the Witwatersrand, School Of Pathology
Division Human Genetics

GENETIC COUNSELLING CLINIC

Hospital Street, Johannesburg 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg 2000
Fax: +27-11-489-9226

Prof A Christianson 011 489-9211 | **Prof A Krause 011 489-9219** | **Ms T Wessels 011 489-9243**

PARTICIPANT INFORMATION SHEET

Researcher: Ms Tina-Marie Wessels
Supervisor: Prof Claire Penn
University of the Witwatersrand, Johannesburg

"The characteristics of the Genetic counselling process in an antenatal, multicultural setting"

My name is Tina-Marié Wessels. I am a genetic counsellor in the Division Human Genetic of the National Health Laboratory Service and the University of the Witwatersrand.

I am conducting research in this clinic on genetic counselling – "The characteristics of the Genetic counselling process in an antenatal, multicultural setting". I am interested to investigate what happens in a counselling session. I am hoping that a better understanding of this process will help our department to improve the service we are offering in this, and possibly other clinics.

I am inviting you to participate in the research. Participation in this research involves video recording the counselling session as well as being interviewed after the session. The video recording of the Genetic counselling session does not require you to do anything more than being in the session with the genetic counsellor. The interview after the Genetic counselling session will take between 30 and 45 minutes and involves answering questions about attending the clinic, the Genetic counselling session, and the information you received during the session. The interview will be audio recorded.

The information from the session is confidential and anonymous. The information you share will not be linked to your personal information, only the researcher will have access to this. The information you share will be written up and will be made available in the scientific literature. You name will however never be linked to your responses. Should you choose not to participate in the research, your treatment at this or any other hospital will not be affected in any way.

For more information you are welcome to contact me or my supervisor.

T Wessels: (011) 489-9243 Prof C Penn: (011) 717-4579

Appendix D: Counsellor Participant's information sheet

National Health Laboratory Service
University of the Witwatersrand, School Of Pathology
Division Human Genetics

GENETIC COUNSELLING CLINIC

Hospital Street, Johannesburg 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg 2000
Fax: +27-11-489-9226

Prof A Christianson 011 489-9211 **Prof A Krause 011 489-9219** **Ms T Wessels 011 489-9243**

COUNSELLOR INFORMATION SHEET

Researcher: Ms Tina-Marie Wessels
Supervisor: Prof Claire Penn
University of the Witwatersrand, Johannesburg

"The characteristics of the Genetic counselling process in an antenatal, multicultural setting"

I am conducting research in this clinic (Area 157, Johannesburg Hospital) on genetic counselling – "The characteristics of the Genetic counselling process in an antenatal, multicultural setting". I am interested to investigate what happens in a counselling session. I am hoping that a better understanding of this process will help our department to improve the service we are offering in this, and possibly other clinics.

I am inviting you to participate in the research. Participation in this research involves video recording the counselling session as well as being interviewed after the session. The video recording of the Genetic counselling session does not require you to do anything more than being in the session with the patient. The interview after the Genetic counselling session will take between 30 and 45 minutes and involves answering questions about the Genetic counselling session and your perceptions of the session and the patient. The interview will be audio recorded.

The information from the research is confidential and anonymous. The information you share will not be linked to your personal information, only the researcher will have access to this. The information you share will be written up and will be made available in the scientific literature. You name will however never be linked to your responses. Should you choose not to participate in the research; it will not be held against you. Your current position and promotion opportunities in the Division Human Genetics will not be affected in any way.

For more information you are welcome to contact me or my supervisor.
T Wessels: (011) 489-9243 Prof C Penn: (011) 717-4579

Appendix E: Question guides for semi-structured interview with patient Participants

QUESTION GUIDES FOR SEMI-STRUCTURED INTERVIEW WITH PATIENT PARTICIPANTS

1. Why did you attend the clinic?
2. What did it mean for you to attend the clinic today?
3. What were you hoping to get out of the session today?
4. What did you find helpful during the session and what was not?
5. How do you think about your chances, the tests and the condition?
6. What do you think of genetic counselling?

Appendix F: Question guides for semi-structured interview with genetic Counsellor participants

QUESTION GUIDES FOR SEMI-STRUCTURED INTERVIEW WITH GENETIC COUNSELLOR PARTICIPANTS

1. What were your expectations of the session?
2. What do you think the patient got out of the session?
3. What facilitated discussion?
4. What are your feelings about the patient?
5. How do you think the patient thinks about her risks, tests and the condition?

Appendix G: An ethnographic description of the waiting area at the Specialists Clinic at RMMCH

The waiting area at the specialists Clinic RMMCH

It's a chilly Friday morning in July and we are on our way to Coro (RMMCH) clinic. It's a weekly clinic shared with the cardiologists. The clinic is nice and cosy. The area is not very large which contributes to the cosiness. The patient waiting area, to the left just after you enter, has eight long wooden benches and is decorated with bright curtains and health education posters. There are children and adults all dressed in jerseys and jackets against the cold. Children are entertained by a play corner and the adults by a television. Patients talk across the room greeting each other. Everyone is waiting for their name to be called.

Genetics were the first to call for patients. A friendly doctor comes in and asks a patient to accompany her to the consulting room. Moments later another woman was signalled to accompany a doctor. More patients enter. Sisters and other staff also come and go, chatting to patients.

We wait, entertained by soccer on the television. Some patients are having their breakfast. This makes me wonder where they travelled from, what time they had to wake up, how many taxi's or trains they had to take and how far they had to walk. A mother and her little boy arrived just after me. The little boy greeted me very friendly "hello ma'm". Why are they here? He walked with a limp and I found myself hoping he doesn't have some form of muscular dystrophy.

Only one woman was waiting without a child. She was called early. A counsellor came in to call another woman, Mary, but she was not there. The other patients said she just went out. The counsellor came back to check if Mary came back every now and again. Where did she go? She had to be of advanced maternal age. Was she a new patient or a follow-

up? I don't know how long she was there before we came. Did she leave because she was scared of what she was going to be told or was she just tired of waiting or did she have to be at another appointment? The waiting room got fuller and fuller. Patients started chatting, mothers fed their babies and the little boy watched the soccer with enthusiasm. He and his mom are playing - pushing each other left to right. As the morning progressed the children got more restless. Outside you can hear staff talking. Another patient was called – still no Mary. The counsellor took another patient. Babies babbled, a little girl played with the hand-me-down Fisher Price toys in the play corner and others watched television. A young woman played on her cell phone. She accompanied a girl and I thought she had to be the girl's sister. Where is the mother? How does this young girl feel about taking on the responsibility? Everyone was busy with their own thing. Content to wait or just used to waiting? The little boy's mom yawned.

The doctors have discussions in the passage outside the waiting room entrance. They come to the desk to write in patient files and take new ones. The cardiac doctors arrive later and shout out patient's names from outside the waiting area. The mother with the little boy starts chatting to two other women about what I think is the cardiac clinic. I just caught some words 'le check up' 'e all right' 'small operation' 'serious' 'six months'. The first cardiac patient to be called was part of the group chatting to the mom with the little boy.

The children made friends passing toys to each other. The little boy lost interest in the soccer. A new genetics patient is called. The little boy is called next – a cardiac appointment thank goodness or is it. Frenzy comes over the waiting room as patient's names are called for cardiac clinic. It becomes quiet again. The television is a good distracter. The

Counsellor checks again - still no Mary. Other doctors and clinic staff also come to look for her. Another patient is called from outside – the mother looked irritated. I wondered how she experienced the service and the doctors and what they do for her and her child. We wait.

Patients come and go. Names are called. Some leave and others came back and wait. The little boy's mother is sleeping on her arms. He rubs her back as he watches television again. No one gets upset. They wait - some for hours. The cosy waiting room becomes less comfortable and the wooden bench unyielding. Without warning a doctor shouted 'okay let's go'. The little boy waved at me saying 'bye-bye Ma'm'. All the patients got up and left……

Suddenly the waiting room was empty with only the television playing.

* * * * *

Appendix H: Patient participant demographic data

PATIENT PARTICIPANT DEMOGRAPHIC DATA

Code: _____

Date of Birth: _____
Ethnicity: _____
First Language: _____
Marital Status: _____
Employment status: _____
Income: _____
Highest level of Education: _____
Area where participant lives: _____

Number of children: P _____ G _____
_____

Pregnancy: Planned [ ] Unplanned [ ]
Ultrasound results: _____
_____
_____

Gestation at time of counselling _____
Diagnosis: _____

Appendix I: Demographic information on counsellor participants

DEMOGRAPHIC INFORMATION ON COUNSELLOR PARTICIPANTS

Code: _____

Date of Birth: _____
Ethnicity: _____
First Language: _____
Other Languages: _____
Years in the field: _____
Qualification: _____
Background: _____

Appendix J: Transcription Conventions

Transcription Conventions

VERBAL CONVENTIONS (Schegloff 2007)

Wo[rd [word	Overlap onset
Word] Wo]rd	Overlap end
word	Verbal utterance
(2.0)	Pause of 2 seconds
-	Cut-off or self-interruption
( )	Verbal utterance not heard/understood
(word)	Guess of verbal utterance
((laughs))	Description of events
.	Falling intonation
?	Rising intonation
,	Continuing intonation
↑word	Rising syllable intonation
↓word	Falling syllable intonation
word	Stress or emphasis
°word°	Softly spoken
word°	Decreasing volume
WORD	Loudly spoken
Wo:rd	Lengthened sound preceding colon
<word>	Pronounced at slower speed than surrounding talk
>Word<	Pronounced at higher speed than surrounding talk
Word>	Decreasing speed
Word<	Increasing speed
hhh	Audible aspiration
·hh	Audible Inhalation

NON-VERBAL (Heath 1986)

_____ word	Gaze directed as face of co-participant
_ _ _ _ _ _ *file*	
word	Gaze directed at object
,,,,,,, word	Turning away from co-participant
…… word	Turning towards participant
raises hand 1. 2. ------- ------- Word	Movement

Appendix K: Ethics approval

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Wessels

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M070222**
PROJECT	Genetic Counselling in South Africa-ommunication Variables
INVESTIGATORS	Ms TM Wessels
DEPARTMENT	Human Genetics
DATE CONSIDERED	07.03.02
DECISION OF THE COMMITTEE*	APPROVED UNCONDITIONALLY

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07.05.07 **CHAIRPERSON** .....
(Professors PE Cleaton-Jones, A Dhai, M Vorster, C Feldman, A Woodiwiss)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof C Penn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix L: Letter requesting permission to perform research in area 157 Johannesburg hospital.

National Health Laboratory Service

University of the Witwatersrand, School Of Pathology
Division Human Genetics

GENETIC COUNSELLING CLINIC

Hospital Street, Johannesburg 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg 2000
Fax: +27-11-489-9226

Prof A Christianson 011 489-9211 | **Prof A Krause 011 489-9219** | **Ms T Wessels 011 489-9243**

29 May 2007
Dr S Moodley
Head: Fetal Medicine Unit
Johannesburg Hospital
Private Bag X39
2193 Parktown

Dear Dr Moodley

PERMISSION TO PERFORM RESEARCH

I am a genetic counsellor in the Division Human Genetic of the National Health Laboratory Service and the University of the Witwatersrand. I am registered for a PhD in Genetic counselling at the University of the Witwatersrand a project entitled "The characteristics of the Genetic counselling process in an antenatal, multicultural setting". My supervisor is Prof Claire Penn, Head of Department Speech Pathology and Audiology.

The research proposal has been approved by the Post Graduate Committee of the Faculty of Health Sciences of the University of the Witwatersrand. Ethics Clearance from the University of the Witwatersrand's Committee for research on human subjects (medical) has granted ethical clearance to conduct the research – clearance no: M070222.

I am interested to investigate the genetic counselling process in prenatal genetic counselling in our diverse South African population. I am hoping that a better understanding of this process will help our department to improve the service we are offering to patients. Patient participation will involve video recordings of the counselling sessions and audio recordings of interviews with the patients and counsellors after the Genetic counselling session.

There is very limited research available on the genetic counselling process, and research on this topic in our South African population has never been conducted. We feel therefore that this project will provide valuable information that would inform the practice of Genetic counselling and in turn the service offered at the Johannesburg Hospital.

I would like to conduct this research in Area 157 of the Johannesburg Hospital as we have weekly Genetic counselling clinics in association with you and Dr J Jeebodh. I have discussed with Prof Guidozzi who informed me that permission can be obtained from you as head of this unit.

We hope that our request will be favourably considered.

Kind Regards

Ms Tina-Marié Wessels MSc(Med)
Genetic Counsellor

CC: Prof F Guidozzi, Dr W Mofolo

Appendix M: Letter requesting permission to perform research at RMMCH.

National Health Laboratory Service

University of the Witwatersrand, School Of Pathology
Division Human Genetics

GENETIC COUNSELLING CLINIC

Hospital Street, Johannesburg 2001
Telephone: +27-11-489-9224/9223/9211

PO Box 1038, Johannesburg 2000
Fax: +27-11-489-9226

Prof A Christianson 011 489-9211 | **Prof A Krause 011 489-9219** | **Ms T Wessels 011 489-9243**

9 October 2007
Mrs S Jordaan
Chief Executive Officer
Coronation Women's and Children Hospital

Fax No: 011-6735658

Dear Mrs Jordaan

PERMISSION TO PERFORM RESEARCH

I am a genetic counsellor in the Division Human Genetic of the National Health Laboratory Service and the University of the Witwatersrand. I am registered for a PhD in Genetic counselling at the University of the Witwatersrand a project entitled "The characteristics of the Genetic counselling process in an antenatal, multicultural setting". My supervisor is Prof Claire Penn, Head of Department Speech Pathology and Audiology.

The research proposal has been approved by the Post Graduate Committee of the Faculty of Health Sciences of the University of the Witwatersrand. Ethics Clearance from the University of the Witwatersrand's Committee for research on human subjects (medical) has granted ethical clearance to conduct the research – clearance no: M070222.

I am interested to investigate the genetic counselling process in prenatal genetic counselling in our diverse South African population. I am hoping that a better understanding of this process will help our department to improve the service we are offering to patients. Patient participation will involve video recordings of the counselling sessions and audio recordings of interviews with the patients and counsellors after the Genetic counselling session.

There is very limited research available on the genetic counselling process, and research on this topic in our South African population has never been conducted. We feel therefore that this project will provide valuable information that would inform the practice of Genetic counselling and in turn the service offered at the Hospital.

I would like to conduct this research in the Specialist Clinic of the Coronation Women's and Children Hospital as we have a weekly Genetic counselling clinic. The research will not disrupt the normal services provided to patients.

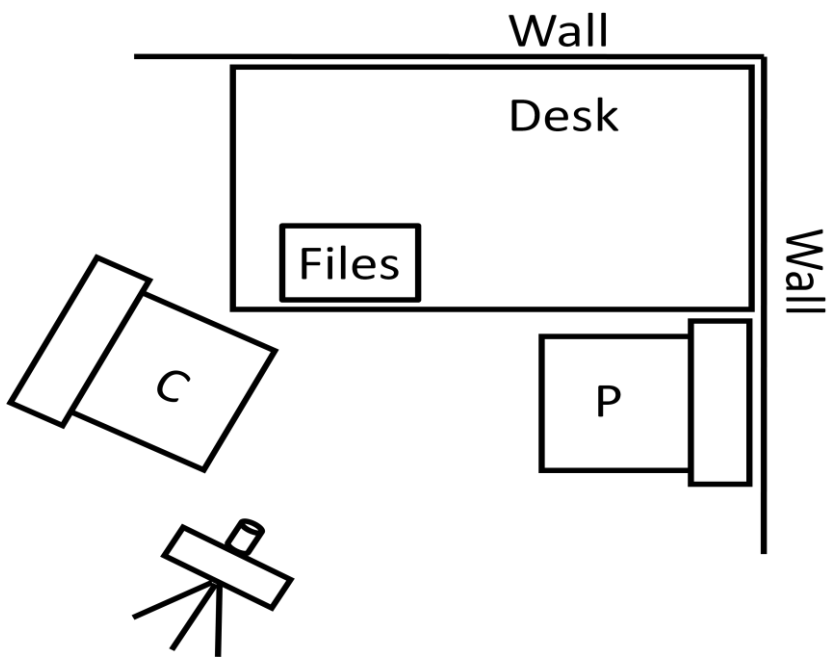
I hope that my request will be favourably considered.

Kind Regards

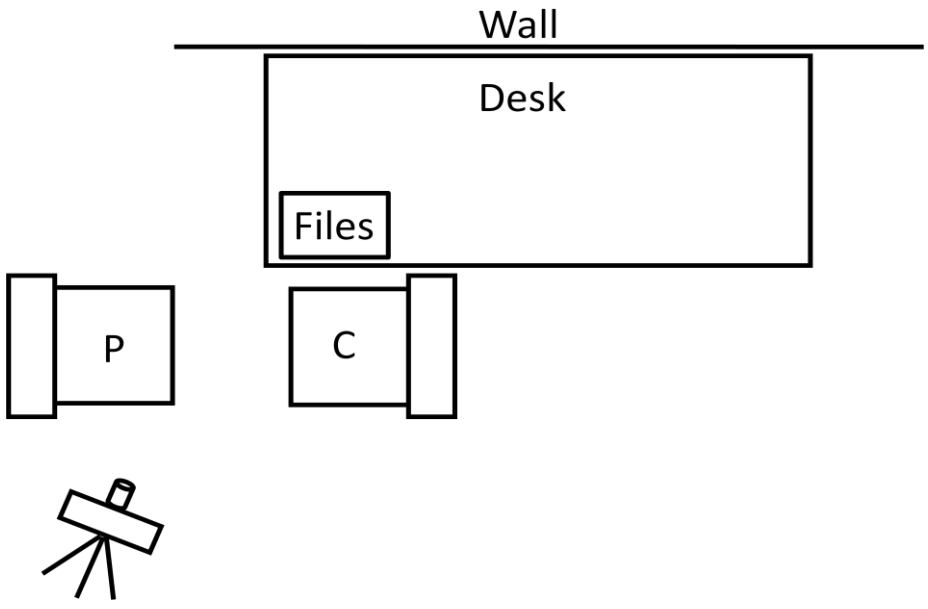
Ms Tina-Marié Wessels MSc(Med)
Genetic Counsellor

Appendix N Set up in the 17 counselling sessions

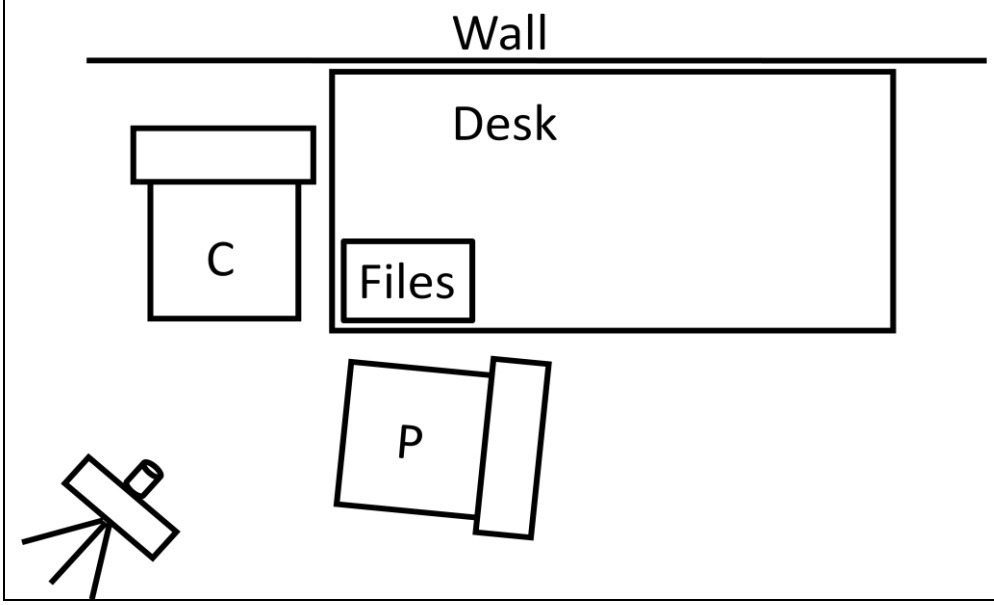
Session P01



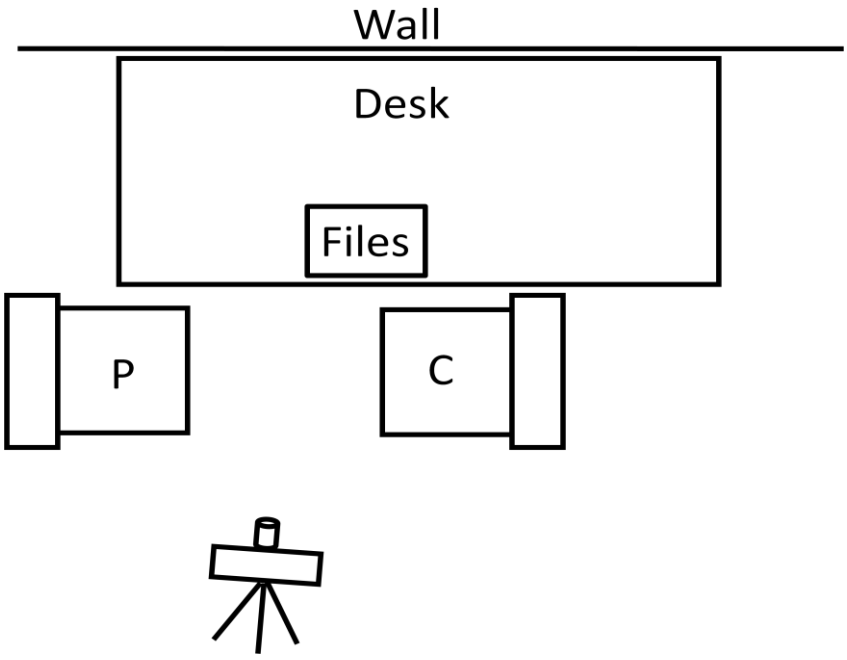
Session P02



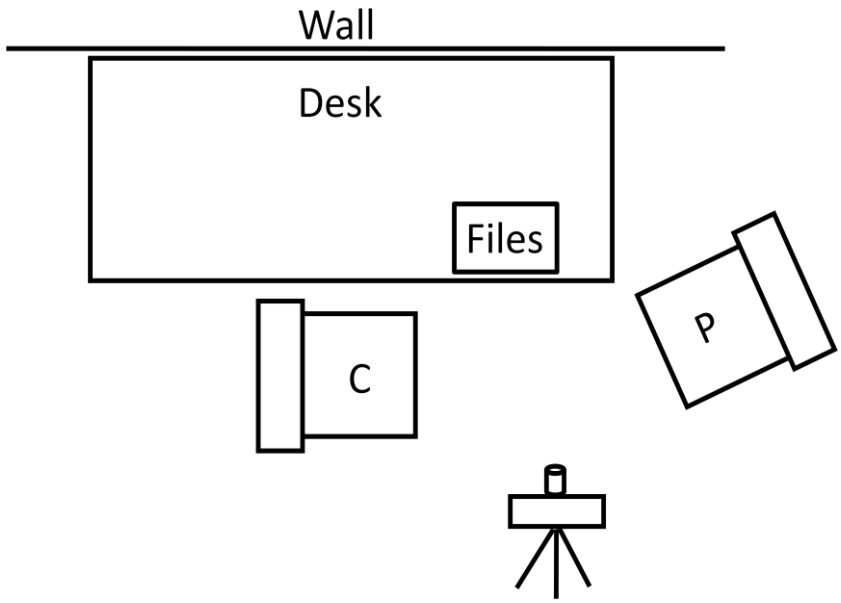
Session P03



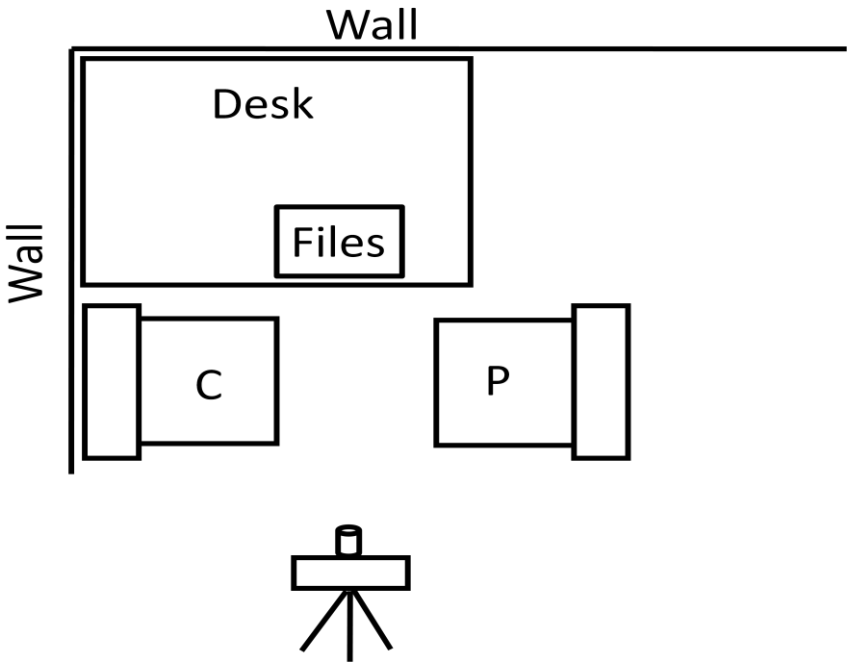
Session 01



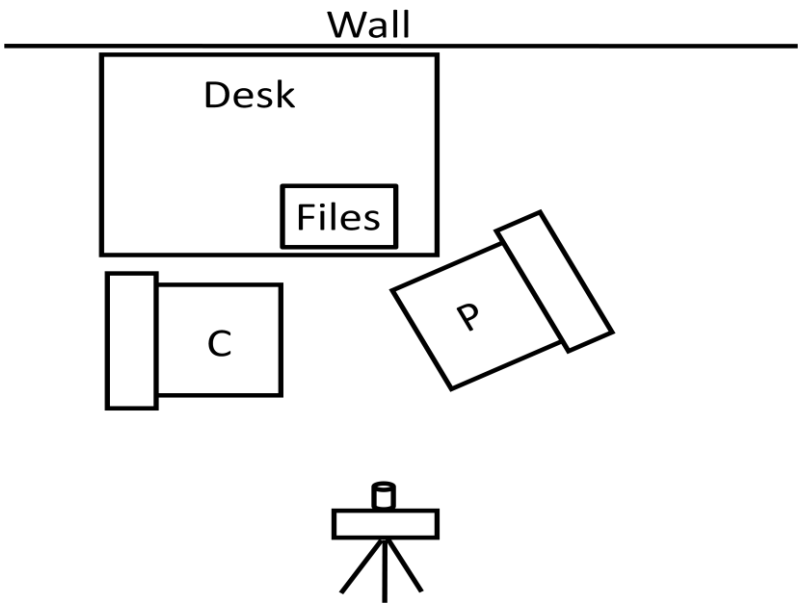
Session 02



Session 05



Session 06



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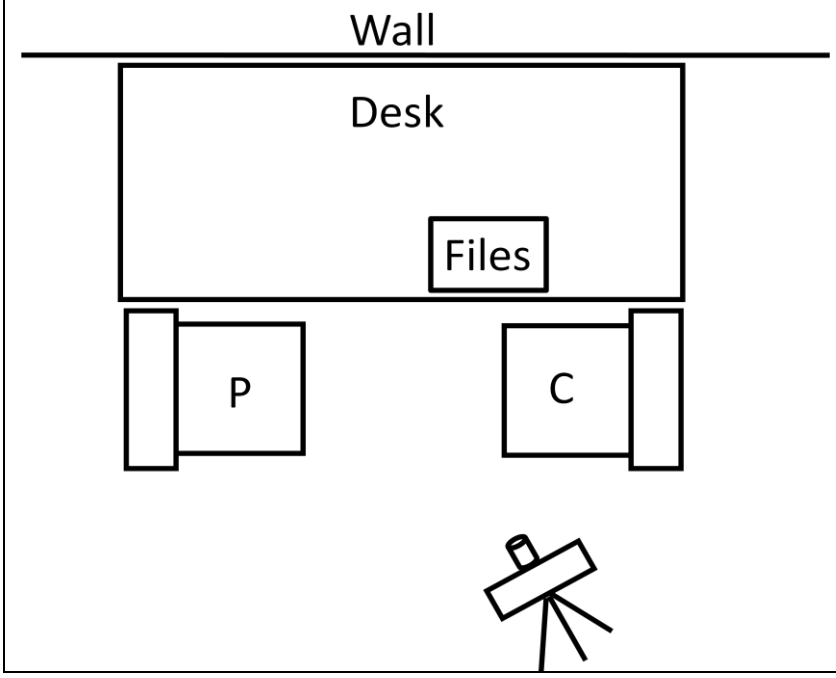

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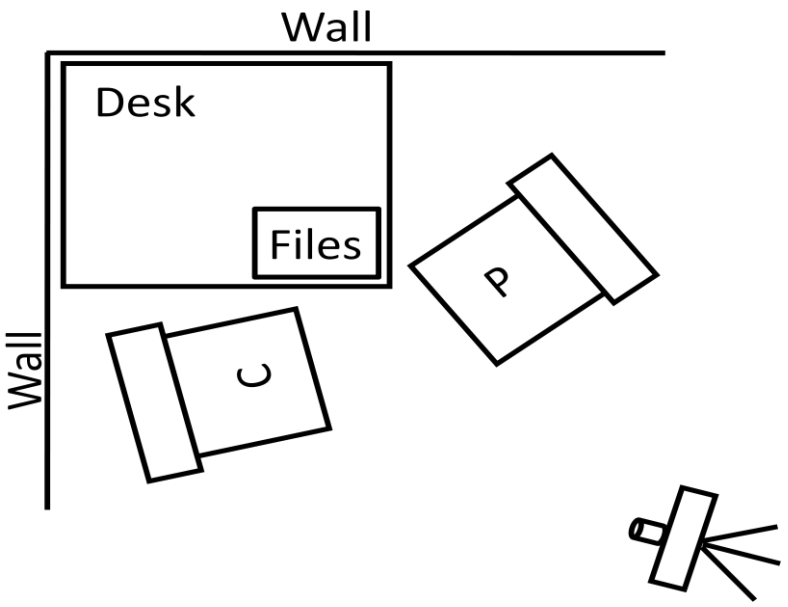

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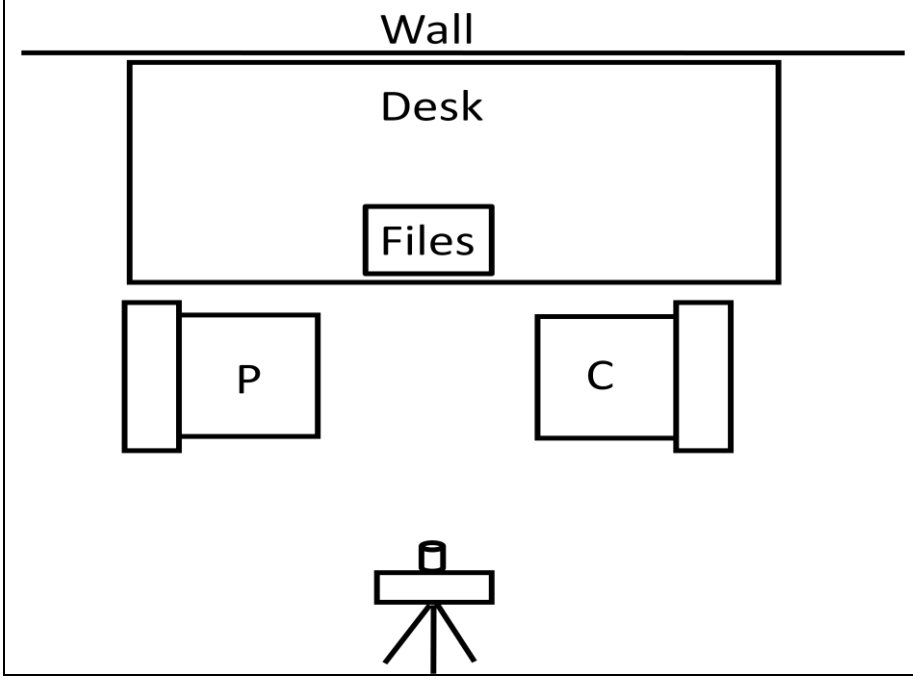

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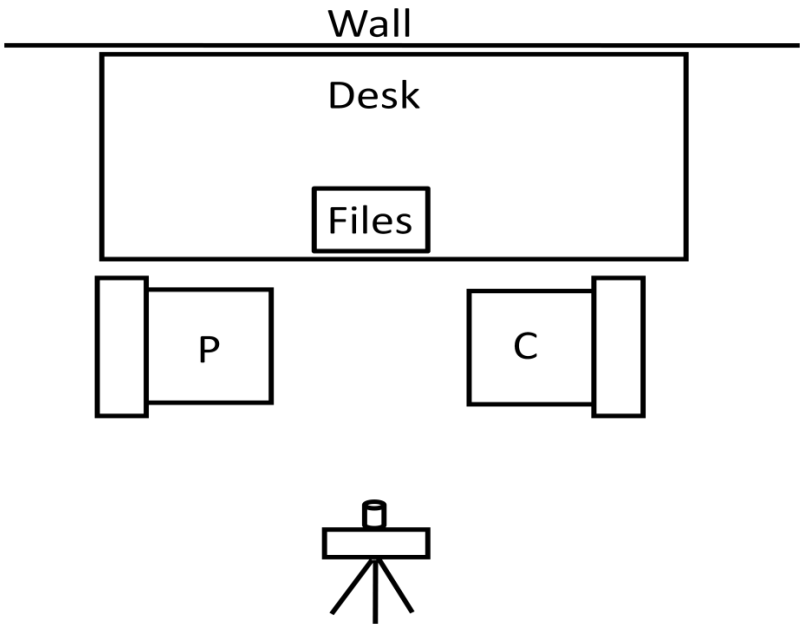

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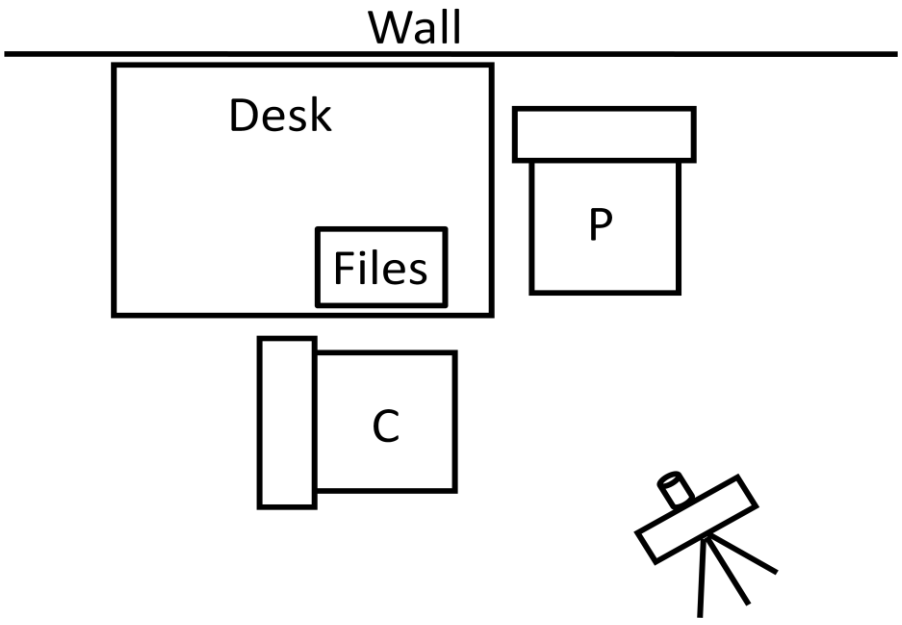

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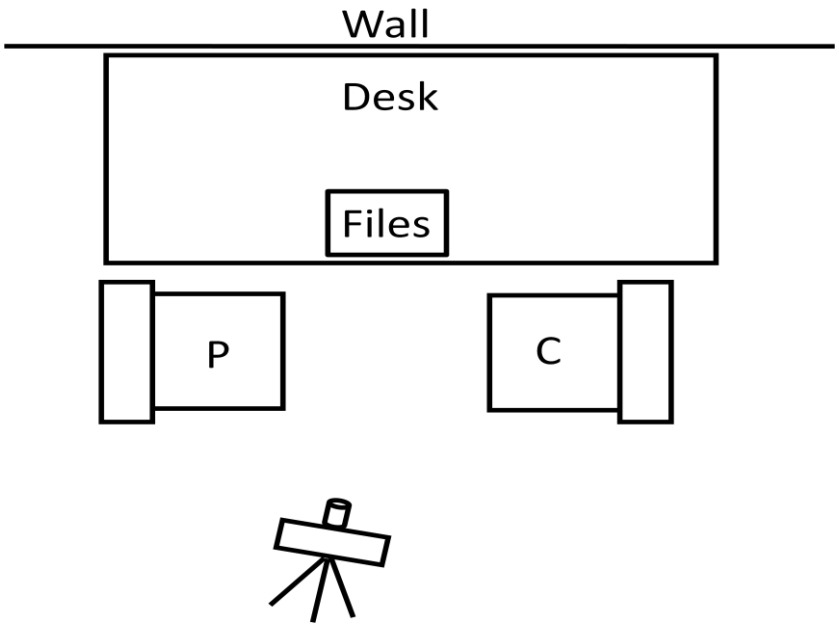

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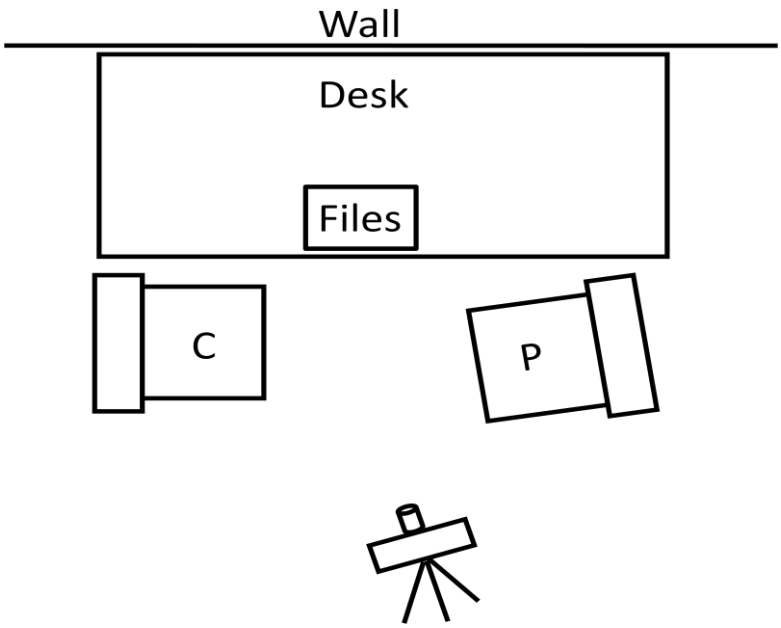

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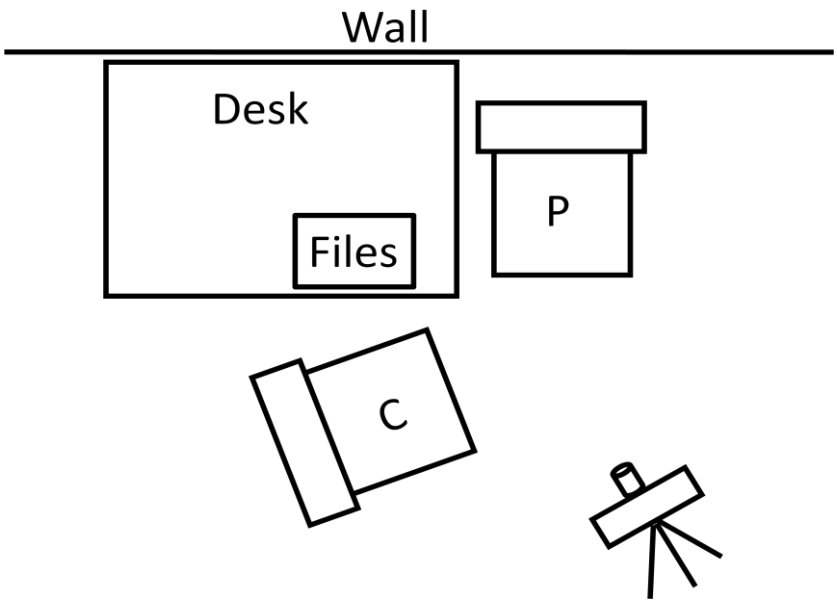

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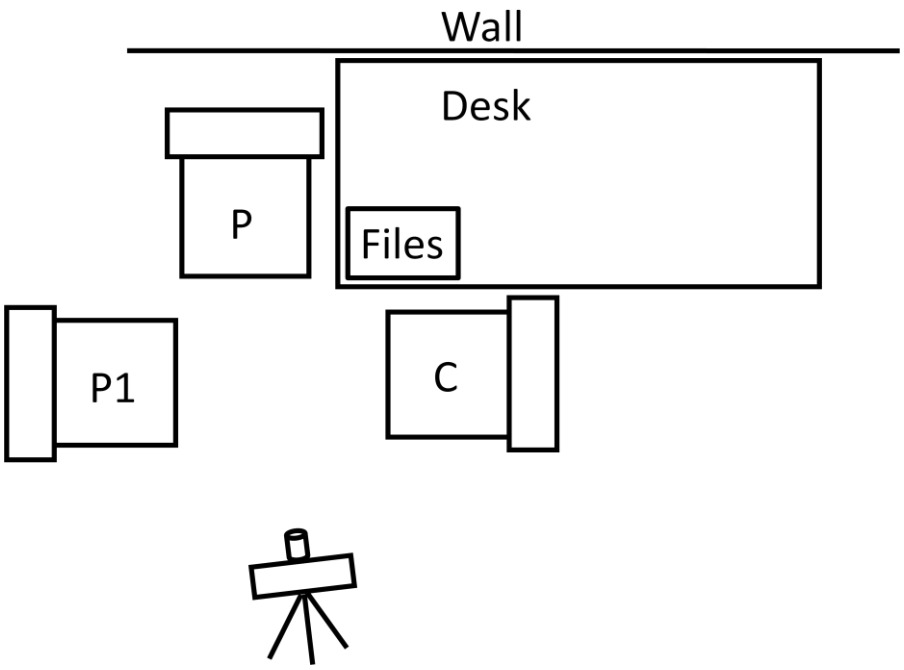

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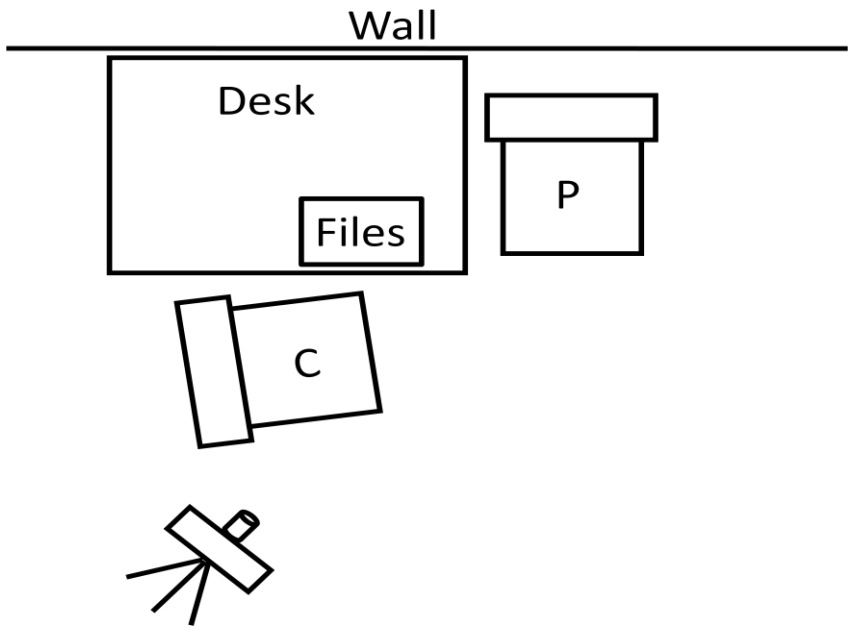

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