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The language of risk and the risk of language

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Mini-dissertation submitted in partial fulfilment of the requirement for the degree of
Master of Arts (Linguistics)

Faculty of the Humanities

University of Cape Town

2010

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: Signature Removed _____ Date: _____

Acknowledgements

I would like to thank the following people whose assistance has been of inestimable value to me:

- My supervisor, Rajend Mesthrie and my two co-supervisors, Ana Deumert and Mike Urban who have provided sage advice and encouragement throughout the process.
- To Raj Ramesar, who came like a knight in shining armour when I was a damsel in distress, and encouraged me to pursue the research in the Department of Human Genetics.
- To all the staff of the Genetics team, particularly Mike Urban and the genetic counsellors, for their assistance in organising rooms and giving their time and energy into this research.
- To Merle Futter, who kindly offered an extra pair of eyes to scrutinise every draft.
- To my husband, Geoff, who not only tolerated my many hours spent working on the thesis but also read through every word and helped make it look like a real masterpiece.
- Of course, thanks to my translators and transcribers (Anthea Adams and Thabisa Xhalisa) who gave many, many hours to help with this research and to Zay Lawrence who stepped in to help with transcription when we were all swamped.
- Thanks to the patients who agreed to participate in the study.
- An extra special thanks to Raj Mesthrie for providing funding from the Department of Linguistics to cover the costs of my translators and transcribers.
- A final thanks to the National Research Foundation for the bursary they gave me, attached to NRF chair (SARCHI) held by Rajend Mesthrie which allowed me to pursue my dream of furthering my studies in linguistics.

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Preface

This mini-dissertation is written towards an MA in Linguistics. As such, it falls within the domain of Humanities. However, its author is a doctor and the subject matter is medical, which falls within the domain of Science. The mini-dissertation thus bridges these different domains, and the references and background reading as well as the application of the research reflect this hybrid nature. A glossary of medical terms and acronyms is thus given.

In addition to being a doctor, the author is also a mother of two children. Thus the subject matter of pregnancy and its unknowns is close to her professional and personal realms of experience. For this reason, although the author has tried to be objective, she cannot pretend that true objectivity is always achieved.

Glossary of Medical Terms and Acronyms

AMA:	Advanced maternal age (>37 years in the Western Cape public health sector)
Amniocentesis: (amnio):	A procedure in which a small sample of amniotic fluid is drawn out of the uterus through a needle inserted into the abdomen. The fluid is then analysed to detect genetic abnormalities in the foetus or to determine the sex of the foetus.
Chromosome:	The microscopically visible carriers of the genetic material which are visible under a microscope. Differences in size and banding pattern allow the 23 pairs of chromosomes to be distinguished from each other, an analysis called a karyotype.
DS:	Down's Syndrome
Gene:	A hereditary unit consisting of a sequence of DNA that occupies a specific location on a chromosome and determines a particular characteristic in an organism.
GSH:	Groote Schuur Hospital
NTT:	Nuchal translucency test. A measurement of the size of the translucent space behind the neck of the foetus using ultrasound. Nuchal translucency tends to be increased in chromosome disorders such as Down's syndrome.
PGWC:	Provincial Government of the Western Cape
TOP:	Termination of pregnancy

INTRODUCTION

Down's syndrome (hereafter DS) is the most common chromosomal cause of mental retardation worldwide and amniocentesis (often abbreviated to *amnio* in informal speech) is the only test available in government hospitals in South Africa to provide a definitive diagnosis antenatally. It is, therefore, the most significant factor affecting the quoted prevalence of DS in South Africa, which is estimated to be 1.34/1000 live births (Hof, Venter & Louw, 1991). Women who are deemed to be at risk of having a baby with DS are referred to the Pregnancy Counselling Clinic at Groote Schuur Hospital (GSH) in the Western Cape. Here they are counselled about their individual risk of having a baby with DS, calculated according to their age, and then counselled about the amniocentesis: how it is performed and the risks and benefits associated with the test. In addition to being counselled about the risk of DS, and the risks associated with amniocentesis, there are other issues that may come up such as the risk of transmission of HIV from mother to baby if an amniocentesis is performed, or the risk of finding chromosomal abnormalities other than DS when the amniocentesis is done. Thus a key aspect of the counselling session involves the communication of risk.

The very notion of risk is problematic. As observed by Maibach (1999) "risk communication is inherently uncertain" and as human beings, we abhor uncertainty. In fact, a recent TIME magazine article claims that "humans actually fear uncertainty more than physical pain" (Ripley, 2009). In scientific terms *risk* is an objective, mathematically calculated probability "that is defined and rendered meaningful . . . at the level of a population" (Linell *et al* p. 196). In contrast, in non scientific parlance *risk* is a highly emotional notion linked to "anxiety about the future, fear or danger" and "is threatening on a personal level" (*Ibid* p 197). Beck (1992) makes a similar dichotomous distinction between Science and an individual saying that Science "determines risk" whereas an individual "perceives risk".

The notion of risk communication has come to the attention of several different spheres: Management, Information Technology, Sociology and, of course, Medicine. In the medical world, risk communication was thought to be so important and so much in need of attention that the British Medical Journal ran a special issue on the communication of risk in 2003. As one of the authors in this themed issue wrote, 'getting the facts right and conveying them in an understandable way are not enough' when communicating risk (Edwards, 2003 p. 691).

Mirroring the diversity of application of risk communication is the diversity of literature on the subject and, by way of extension of that, great diversity in the approach to researching risk communication. For example, to highlight a few milestones that have direct relevance on this thesis, I could start with how traditional approaches to the communication of risk exemplified the telementation fallacy described by Roy Harris (1981). He exposed the belief that a speaker could transmit the exact information from their brain into the open vessel of the speaker's brain to be a fallacy. Furthermore, many studies have

demonstrated how not only people with low numeracy levels but even highly educated people can struggle to understand statements of probability and risk (cf Gigerenzer & Edwards, 2003, Lipkus, Samsa & Rimer, 2001; Peters *et al*, 2007). To overcome these difficulties, various methods have been suggested such as the use of visual information/decision aids (cf Edwards *et al*, 2008; Barratt *et al*, 2004), while Adelsward and Sachs (1998) demonstrated how numerical risks needed to be “recontextualised” in order for patients to relate to them. In addition, researchers have come to realise that the communication of risk is not a one way transfer of information from the counsellor to the patient but a jointly constructed negotiation around the meaning of risk, in the sense of a Bakhtinian notion of dialogically-constructed meaning (cf Bakhtin, 1981, Collins & Street Jr., 2009, Sarangi & Candlin, 2003). Part of this co-construction of meaning involves negotiating a compromise between the scientifically measured risk and the personally perceived risk.

Sarangi and Candlin (2003) have differentiated between the ‘risk of occurrence of disease’ and the ‘risk of knowing’. The risk of occurrence is defined by them as the risk that the genetic disease will become clinically apparent, whereas the risk of knowing is a more contextual risk related to having to do tests to ascertain whether the genetic disease is present or not (*Ibid* p. 155). As they point out, it can be extremely difficult “for the participants to determine what does or does not count as genetic risk because the discussion of the risks of occurrence of disease ... blur with the discussion of the risks of knowing” (*Ibid* p. 168). And finally, researchers have also looked into the relationship between the presentation of risk and decision-making (Bogardus, Holmboe & Jekel, 1999).

The genetic counsellors have an undeniably difficult task. Their job is to “recontextualise” (Adelsward & Sachs, 1998) the risk for each individual. They “help patients reach an “informed” decision, but refrain from steering or directing them” (Browner, Preloran & Casado, 2003 p 1934). To further muddy the water, in the South African context the counsellors have to achieve this communication with patients of different linguistic backgrounds and under conditions hampered by resource constraints.

The purpose of this mini-dissertation was to observe the counselling given to the patients at Groote Schuur Hospital (GSH) and address the following questions:

- a) What is the linguistic repertoire and demographics of the genetic counsellors and how does it compare with those of the patients seen at the Pregnancy Counselling Clinic?
- b) What is the context in which the consultations occur and is there any evidence of language barriers within this context?
- c) If language barriers are identified what strategies do the counsellors employ to overcome them?
- d) How do the counsellors communicate risk to the patients and how does this compare with international standards?
- e) Are there any factors specific to the South African context that affect the patients’ process of making a decision?

To address these questions I went through the following process:

- i) Observing clinic and planning study
- ii) Designing a research proposal and obtaining ethical approval
- iii) Conducting semi-structured interviews with the Genetic counsellors
- iv) Running a pilot phase
- v) Completing the research

i) Background Information

I spent time observing the clinic workings and watching patient-counsellor consultations before designing the study.

ii) Designing a research proposal and obtaining ethical approval

Since the research involved working with patients and dealing with personal and potentially very sensitive information I not only had to obtain ethical approval from the Department of Linguistics, but also from the Health Ethics Committee based at GSH. Approval was obtained from both.

iii) Conducting semi-structured interviews with the Genetic counsellors

Before starting the pilot phase, I conducted interviews with the three genetic counsellors who usually counsel patients about DS. They have been given the pseudonyms of Gail, Liz and Rachel. From the interviews with them I was able to gain an idea of where they identified problems and what their perspectives were on the communication of risk and to compare their opinions with what was actually observed in the consultations.

iv) Running a pilot phase

In the pilot phase I sat in on one group consultation (where the counsellor spoke to a group of three patients simultaneously in order to provide them with the basic information about DS and amniocentesis.) They then had individual sessions which I also observed, where more personal information was discussed and where their individual risks were assessed and weighed up. After their individual sessions, I saw them for the post-consultation interview. However, I soon realised that I needed to make two adjustments to this stage of the research. I realised that the patients were emotionally and physically exhausted by the time I saw them. In fact, one patient was tired and also in some discomfort after having an amniocentesis. As a result, although she had consented to a post-consultation interview, she left. In her case, the post-consultation interview was conducted telephonically later that evening. Many of the patients were similarly tired and not interested in a detailed interview and I realised that an in depth interview was not appropriate. Secondly, I realised that it was not ideal for me to conduct an interview about language issues in my home language (English)

rather than the patients' home language. Thus I changed to post-consultation interview format to a semi-structured interview and used my two female translators to speak to the patients in their home language. One of my translators was bilingual in English and Afrikaans and the other in isiXhosa and English. Thus they could offer the patients a post-consultation interview in any one of the three major languages of the Western Cape. I was then ready to commence the research.

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CHAPTER 1

1.1 Methodology

1.1.1 Data Collection

As mentioned in the introduction there were five stages involved in my research. The first two involved planning and permission, but the bulk of the research was based on the other three. Thus this section will focus on the practical methodology involved in these three stages.

Stage One

I conducted and audio-recorded semi-structured interviews with the genetic counsellors Gail, Liz and Rachel. Although there are more counsellors involved in genetic counselling, these three were identified as being the ones mostly responsible for counselling the patients referred for DS counselling because of advanced maternal age (AMA).

Stage Two

This consisted of observation and recording of consultations between patients and the genetic counsellors (n = 13). Consultations were either in a group format (n=2) where only general information pertaining to DS and amniocentesis was discussed, or an individual format (n=11). Not everyone attended a group session, but each patient had an individual session where personal information was discussed and tailored counselling offered. Of the eleven individual consultations, five were the individual consultations of those who had also been part of the initial group consultations, the other six consultations were with patients who had individual sessions only.

One of the group sessions was conducted in English to a group of four patients, one of whom declined to take any further part in the study. The other group session was conducted in Afrikaans to a group of three patients, all of whom took part in the post-consultation interview. As not every patient in the group consultations agreed to take part in the post-consultation interviews, there is an apparent discrepancy in numbers between number of consultations (n=13) and number of patient participants (n=12).

The consultations were audio-recorded and transcribed. I transcribed all the consultations that had taken place in English and my two translators transcribed and translated the sections of the consultations which took place either in isiXhosa or in Afrikaans. Where the vernacular Afrikaans or English was used, this is reflected in the orthography of the transcription according to the intuition of the transcribers. When considering how to reproduce the oral consultation in a written form, I am in agreement with Portelli (1991) who claims that "the transcript turns aural objects into visual ones, which inevitably implies changes and interpretation" (p. 47). Similarly, Gee (1999) asserts that our transcription choices "are part

of 'imposing' a meaning (interpretation) on a text and different choices lead to different interpretations" (p. 108). Thus I opted for a transcription which aims to reflect some speech acts (such as choice of vernacular over standard, elongation of vowel for emphasis, stress on words for additional emphasis) but have not attempted to completely replicate aural objects as visual ones. Thus the transcription key is as follows:

- Underlined sections indicate emphasis on the underlined syllable(s).
- Repetition of vowels indicates lengthening ('Thee').
- Square brackets [] indicate overlapping speech.

The sample of patients chosen for this research consisted of 13 consultations selected in a stratified, purposive and systematic manner. The sample size is small, and thus not statistically significant. However it was large enough to give a spread of patients from each of the three major language groups in the Western Cape and allow for qualitative comparison of these groups. Although many studies on methodology around the discourse of medical encounters such as Waitzkin, (1990) recommend that a randomised sample is preferable, in practice, and with small numbers, I had to find an alternative method. Patton (1990) described 16 types of purposive sampling which he asserted were alternatives to random sampling and stratified, purposive sampling was one of his 16 alternative options.

- *Stratified* here refers to the fact that consultations were selected according to the language group of the patient in order to provide a sample representing the three major language groups of the Western Cape (English-, Afrikaans- and isiXhosa-speakers).
- *Purposive* means that the patients were selected, informed about the study and then, if they consented they were observed specifically for the purposes of this study and took part in the post-consultation interview.
- *Systematic* refers to the fact that I systematically went through the folders in the order in which the patients were due to be seen. I selected patients and the translators would approach them, offer information about the study and obtain informed consent. Once informed consent had been obtained, I would mark the patient's folder with a request for the counsellor to call me when the consultation began. However, if I was already observing a consultation when that patient was seen, the counsellors would not wait for me as I tried to minimise the effect of my research on the running of the clinic.

In order to try and reduce the observer's paradox first described by Labov within linguistics (1972) I tried to sit out of the patient's and counsellors' sight and not intrude on the interview. However, as I am a doctor and was introduced as such, the patients sometimes addressed comments or questions to me – which made it difficult for me to be truly "invisible." Thus my presence as part of the audience would also have been a factor (Bell, 1984). My co-supervisor, Ana Deumert, had done similarly-styled research on

her report on Language and Health (Deumert & Mabandla, 2008) and thus was able to offer practical tips on ways of minimising my presence (such as sitting out of sight, not taking notes during the consultation.)

Stage Three

The research assistants conducted semi-structured interviews with patients after their consultation with the genetic counsellor (n = 12). (See Appendix Two for an interview guide).

After the consultation with the counsellor, patients took part in a semi-structured interview with a person who was able to speak to them in the language of their choice. This happened immediately after the consultation with the genetics counsellor, except in the one instance (described above) where it was conducted telephonically later the same day. I had the help of two research assistants who were both bilingual. One was bilingual isiXhosa/ English whilst the other was Afrikaans/English. I specifically chose female research assistants to make the patients feel more comfortable. As described in the introduction, this stage of the research had to be adapted after the pilot stage. These interviews were not audio-recorded, but the answers were written down by the translators and direct patient quotes were also noted.

The fact that I was not present for the post-consultation interviews and did not have access to recordings of them means that I was reliant upon my research assistant's notes. However, in the pilot stage – when I had conducted the post-consultation interviews – they had both sat in with me and were familiar with the format and with what I was seeking to analyse. They have both been involved in other research projects and I had every faith in their ability to document the answers and patients' quotes accurately.

1.1.2 Data Analysis

Stage One (Counsellor interviews)

An initial description of the counsellors according to their demographic information was performed. (See chapter one: Profiles of patients and counsellors). I then performed thematic analysis on the interviews which I used to compare with the thematic analysis of the consultations and the patients' comments in the post-consultation interviews.

Stage Two (Counsellor-patient consultations)

The 13 consultations were observed and transcribed as described previously. I then performed three different analyses on the texts to address the *what*, the *why* and the *how* of risk communication (cf Fairclough, 2001). Firstly, no sociolinguistic enterprise is complete without a consideration of the context of situation (Malinowsky, 1923) also known as the "environment of the text" (Halliday & Hasan, 1989). As Halliday said of Malinowski "each message brought more meanings than those expressed through the words, meanings that could only be understood if accompanied by the situation" (*Ibid* p. 6). Consideration of the context of situation contributes towards understanding the *why*. Thus I devoted one chapter (Chapter 2) to a description of the context in which the risk communication occurred.

To look at how and what is communicated, I performed a thematic analysis on each consultation. Boyatzis (1998) defines a theme as a “pattern found in information” and I was looking for patterns in the communication of risk. A strength of using thematic analysis in my case is that I am medically trained and thus had a knowledge base “relevant to the arena being examined” which is said to be crucial for good thematic analysis. The thematic analysis brought out the themes shown in Table 1 (p. 10 and 11). Once the thematic analysis had been done, I was able to find common themes and to compare them with themes in the patients’ post-consultation interview as well as the counsellors’ interviews. I was also able to look at the how and why certain themes were conducted within the interview.

Since communication is a social phenomenon it is complex and subject to ambiguities and qualitative analysis is best suited to exploring this. However the nature of qualitative research means that it is often subjective and not generalisable. To strengthen my qualitative analysis I, therefore, performed content analysis on the major themes which emerged. (Chapter 3). This contributed to the *what* of risk communication. One of the weaknesses of content analysis is that it is often linked merely to word counts or frequency (Neuendorf, 2005). My analysis incorporated a grading scale for the major lexemes used to describe risk. This grading scale was thus more objective and generalisable and produced some quantitative and graphic data. However, the number of tokens, especially from the patients, was too small for mathematical calculations on levels of statistical significance to be meaningful.

Table 1: Thematic analysis of group and individual consultations

PATIENT	ED	GK	NM	MF	ST	NB	NN	ZR	LN	VD	IA	GROUP AFRI- KAANS	GROUP ENGLIS H
CATEGORY													
AGE-RELATED RISK	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
CAUTIONS AFTER AMNIOCENTESIS	yes	X	yes	yes	X	yes	yes	X	X	X	yes	X	yes
CHROMOSOME ANALYSIS	X	X	X	X	yes	X	yes	X	X	yes	yes	yes	X
CHROMOSOME EXPLANATION	X	X	yes	X	X	yes	X	X	X	X	yes	yes	yes
CHROMOSOMES AND DS	yes	X	yes	X	X	yes	yes	yes	yes	yes	yes	yes	yes
CONGENITAL ABNORMALITIES	yes	yes	yes	yes	yes	yes	X	yes	yes	yes	yes	X	X
CONSANGUINITY	yes	yes	yes	yes	yes	X	yes	yes	yes	X	yes	X	X
CONSENT	X	X	X	yes	X	yes	yes	X	X	X	yes	X	X
CONTRACEPTION	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	X	X
DANGERS	yes	X	X	X	X	X	yes	X	X	yes	X	X	yes
DEMONSTRATION OF RISK	X	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
EMPHASISES CHOICE	yes	yes	X	yes	yes	X	yes	yes	X	yes	X	yes	X
ESTABLISH KNOWLEDE ON DS	yes	X	yes	X	X	yes	yes	yes	yes	yes	yes	yes	X
REASON FOR ATTENDANCE	X	X	yes	X	X	yes	yes	yes	yes	yes	yes	yes	yes
EXPLANATION OF DS	X	X	yes	X	X	yes	yes	yes	yes	yes	yes	yes	X
EXPLANATION OF SCAN	X		X	X	X	X	X	X	yes	yes	X	X	X
FEELINGS ABOUT AMNIOCENTESIS	yes	yes	yes	yes	X	X	yes	yes	yes	yes	yes	X	X
FOLLOW UP	X	X	X	yes	yes	X	yes	yes	yes	X	X	X	X
INTRODUCTION	yes	X	yes	X	X	yes	yes	yes	yes	yes	yes	yes	yes
LANGUAGE	X	X	X	yes	yes	yes	yes	yes	X	yes	yes	yes	yes
MEDICATION	X	yes	yes	X	yes	yes	yes	yes	yes	yes	X	X	X
NEED FOR THE TEST	yes	yes	yes	yes	X	X	yes	yes	yes	yes	yes	yes	yes

Table 1 continued.

PATIENT CATEGORY	ED	GK	NM	MF	ST	NB	NN	ZR	LN	VD	IA	GROUP AFRI- KAANS	GROUP ENGLIS H
NEED TO DISCUSS	X	X	X	yes	X	X	yes	yes	yes	yes	yes	X	X
NO GUARANTEES	yes	X	yes	yes	yes	X	yes	X	X	yes	yes	yes	X
OBSTETRIC HISTORY	yes	yes	yes	yes	Yes	yes	yes	yes	yes	yes	yes	X	X
OFFSPRING HISTORY	yes	X	yes	yes	X	yes	yes	yes	yes	yes	yes	X	X
PARTNER'S PARENTS	yes	X	yes	yes	X	yes	yes	yes	yes	yes	yes	X	X
PATERNITY	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	X	X
PATIENT'S FAMILY	yes	yes	yes	yes	Yes	yes	yes	yes	yes	yes	yes	X	X
PATIENT'S PARENTS	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	X	X
PROCEDURE OF AMNIOCENTESIS	X	X	yes	X	X	yes	yes	yes	yes	yes	yes	yes	yes
REACTION TO THE PREGNANCY	X	X	X	X	yes	yes	yes	yes	X	yes	yes	X	X
RESPONSIBILITY FOR DS	X	X	X	X	X	X	yes	X	X	X	X	X	X
RISK OF FAILURE	yes	X	yes	yes	X	yes	yes	X	X	X	yes	yes	X
RISK OF HIV	yes	yes	yes	yes	Yes	yes	X	X	yes	yes	yes	yes	yes
RISK OF INFECTION	X	X	X	X	Yes	X	X	X	X	X	yes	X	X
RISK OF KNOWING	X	X	X	X	X	X	X	yes	X	yes	X	yes	X
RISKS OF MISCARRIAGE	yes	yes	yes	yes	Yes	yes	yes	yes	yes	yes	yes	yes	yes
SAFETY-NETTING	X	yes	X	yes	X	X	yes	X	yes	X	yes	X	X
SUBSTANCES	X	X	X	yes	yes	X	X	yes	X	X	yes	X	X
THIS PREGNANCY	X	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	X	X
TIME TO DECIDE	yes	yes	X	yes	X	X	yes	yes	X	X	X	yes	yes
TIMING OF AMNIOCENTESIS	yes	X	yes	X	X	X	yes	yes	X	yes	yes	yes	yes
TIMING OF RESULTS	X	X	X	X	X	yes	yes	X	X	yes	yes	yes	X
WHAT IF SCENARIO	X	X	yes	yes	X	yes	yes	yes	yes	X	X	yes	yes
WORK AND BABY	X	X	X	X	X	X	yes	X	yes	X	X	X	X
WORK CERTIFICATE	X	X	X	yes	yes	X	X	X	X	X	X	X	X

Stage Three (Post-consultation interviews with patients)

Similarly to the counsellor interviews, the first phase of analysis involved looking at the demographics of the patient sample. Then the results of the interview questions were analysed according to themes and compared with the consultation and with the counsellor comments. As already mentioned, the post-consultation interviews (other than those done in the pilot stage) were conducted by my two assistants. They were instructed to try and write down verbatim some of the patients' answers, and to explore answers where possible. However, as discussed, many of the patients were tired, hungry and/or emotional and some of their answers were, therefore, very brief.

Using the research assistants was a potential trade off in accuracy of transcribed answers and interview techniques. This was minimised by their past experience in research and by being trained by me. Additionally, this trade off was minimal compared with the benefit of having the patients interviewed in their own language and by somebody who was not medically affiliated – as had become apparent during the pilot phase of the research.

1.2 How representative was my sample?

As described, my sample was not randomly selected, but was chosen as a stratified, purposive, systematic sample. There were no exclusion criteria. To assess whether this sample was representative of the patients seen at the clinic I analysed the database kept by the Human Genetics department. I included all patients seen at the Pregnancy counselling clinic from when the database was commenced until the date of my initial analysis, (i.e. from 01/12/07 to 01/07/09, n = 443 patients). I found that women suspected to be at risk of having a baby with DS and seen at the Pregnancy Counselling Clinic are referred because of:

1. Advanced maternal age (AMA). (In the public sector this is any pregnant woman over 37 years.)
2. Previous child with DS or close family history of DS.
3. A positive serum screen, otherwise known as the triple test. This may be offered in private. Three hormone levels are measured in the mother's blood. The results of these tests are used in conjunction with the mother's age to provide a more accurate estimation of risk than using age alone.
4. A first trimester Nuchal Translucency Thickness (NTT) scan may also be done at 13 – 14 weeks of gestation. Patients who have had a NTT scan are usually from the private sector but the scan may be done in the government sector if the women "book" early enough. (The term booking refers to the first appointment a pregnant woman has at the clinic once she is confirmed to be pregnant). It is not a diagnostic test, but can refine the risk given using age alone.

From my analysis of the Database, most of the patients seen at the clinic were referred because of AMA. (See Figure 1.)

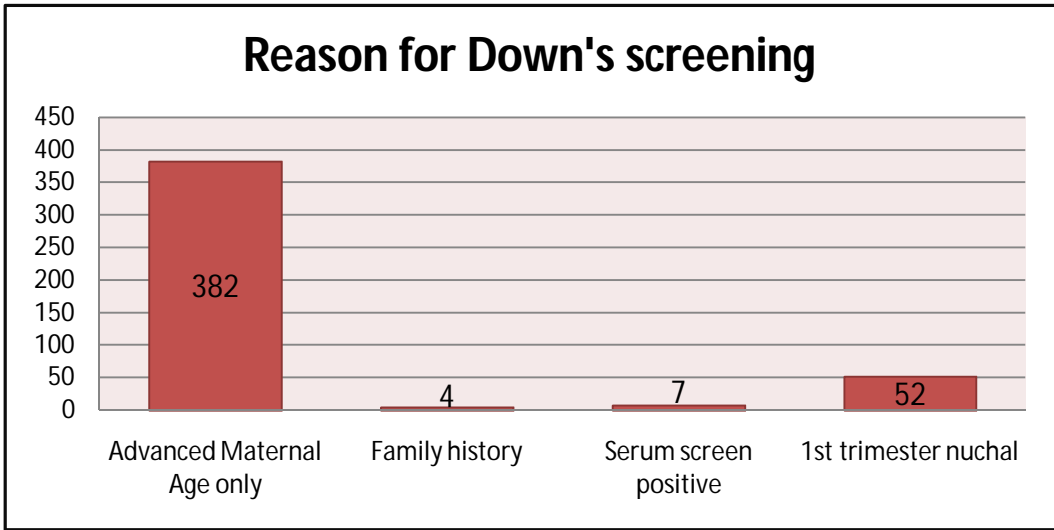


Figure 1: Reason for screening for DS during period 01/12/07 – 01/07/09 (n=443).

In my sample, all twelve patients had been referred because of advanced maternal age (AMA). It logically follows that the average age of the women will be quite high. The average age of patients in the Database was 39 years which was comparable to my sample. (See Figure 2 below).

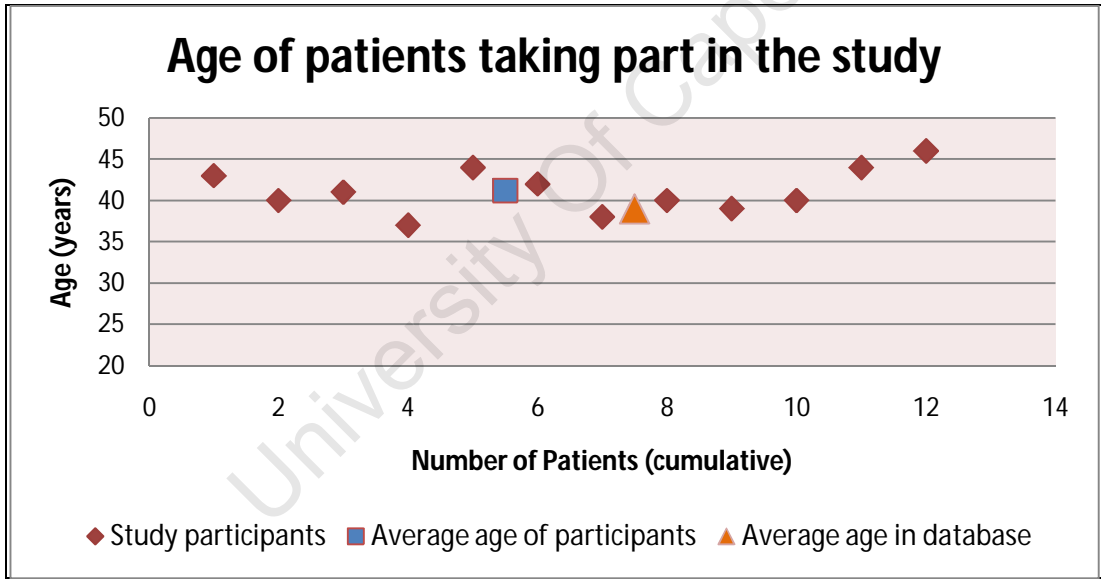


Figure 2: Scatter diagram illustrating age of 12 participants in the study.

Finding the linguistic background of patients seen was a more difficult task. The criterion "Language of consultation" was added to the database – but not used consistently. It was first recorded on 25/02/2009 but only regularly recorded after 11/03/2009 for a total of 90 patients, i.e. 20.3% of patients on the database. However, this criterion itself would not have been without problems as terms like 'mother tongue' and 'first language' may not necessarily reflect the language choice of the patient. Where it was stated it was used, but where not stated, I had to find a proxy for language.

The use of surname as a proxy for ethnic identity¹ is well recognised in medical research (Sweeney, C. 2007). I not only looked at surname, but also at first name and referring clinic. Referring clinic was used to confirm a language group rather than as a category in its own right. By first name and surname I allocated patients' language group as clearly English, Afrikaans or isiXhosa. (Analysis is not included for reasons of patient confidentiality).

This method was still problematic. There were some patients who did not belong clearly to one language group. For the most part, this occurred when distinguishing between whether patients were English or Afrikaans as many of the names could have belonged in either category. Where I encountered this difficulty, particularly if the first name indicated one language group and the surname another, the patient was denoted to be either English or Afrikaans (A/E). At the end of my analysis this group of A/E was divided in half: half the tally was then allocated to the English-speakers and half to the Afrikaans-speakers. Although not accurate, the analysis provided me with a general idea of the linguistic diversity of the patient base.

Because this methodology was crude, I compared my results with census results. The last census figures (Government report, 2001) are now out of date and, in addition, the patients seen at GSH are often patients without medical aid. Thus they are in a low income group, and would be a skewed representation compared with the whole Western Cape statistics. However as the aim of this analysis was not the major focus of the study, but merely to provide me with a comparison with my rough estimates of patient diversity, the census results were adequate. The results of the database analysis came up surprisingly similarly (see Fig 3 below) to the population distribution by language compiled during the last census.

¹ Ethnic identity can be misleading where ethnicities are in flux and where language shift either has taken place or is in the process of taking place.

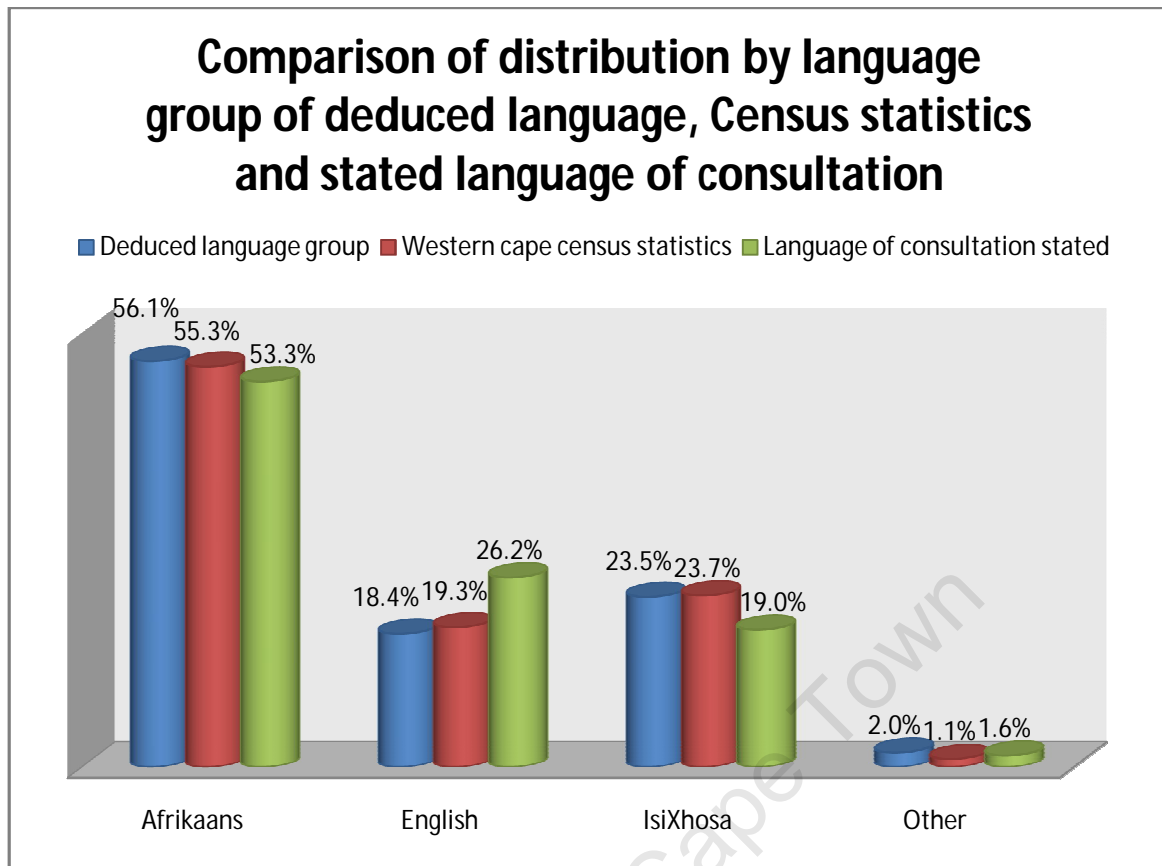


Figure 3: Language distribution of patients attending the clinic during period 01/12/07 – 01/07/09 by language deduced, Census statistics and language stated

I would like to go on to look at the results of my research, beginning by addressing the question:

- What is the linguistic repertoire and demographics of the genetic counsellors and how does it compare with those of the patients seen at the Pregnancy Counselling Clinic?

1.3 Profiles of patients and counsellors

Participants in this research (the counsellors and the patients) were asked, “Which language are you most comfortable in?” (See Appendix One for patients’ and Two for counsellors’ questions.) From the patients’ replies, the following graph was obtained (see Figure 4 below.)

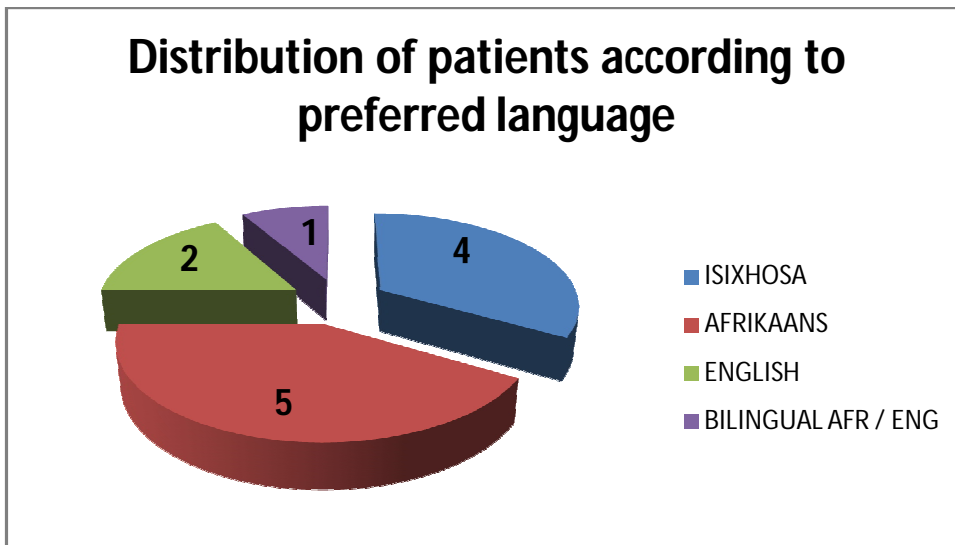


Figure 4: Patients reply to the question “Which language are you most comfortable in?” (n = 12)

What this graph shows is that Afrikaans was dominant within the sample chosen for this research but there were a number of patients who were most comfortable in isiXhosa. One patient declared that she was happy in beide (‘both’ i.e. both English and Afrikaans.) However, if we look at the language in which the consultations took place, a different picture emerges.

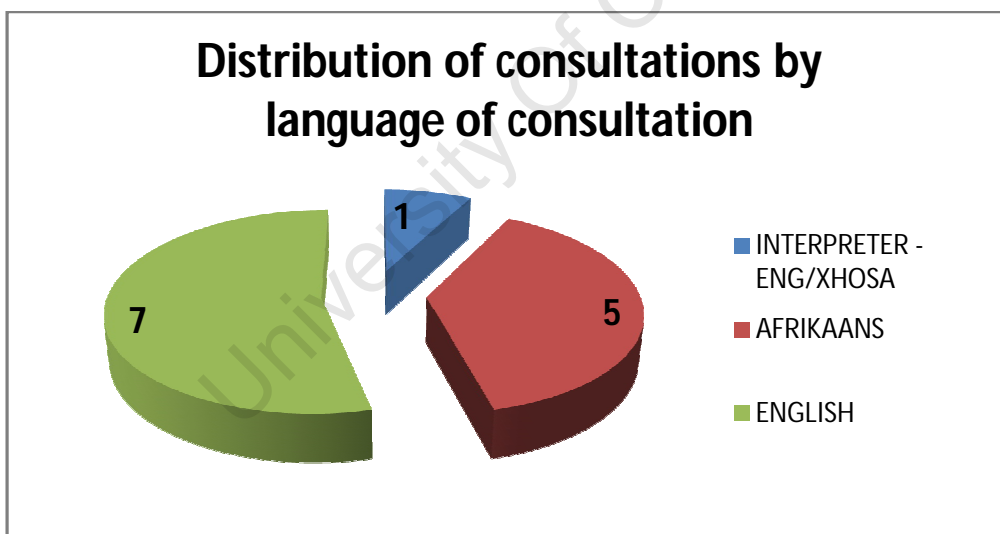


Figure 5: Language of the consultation (n = 13)

Looking at the consultations the English piece of the pie is suddenly dominant. The isiXhosa piece has shrunk and really only made an appearance because one of the patients (NN) called her husband to join her in the consultation and he then addressed her in isiXhosa but spoke English to the counsellor. (See Chapter Two section 2.1.3). So the presence of “interpreter” should not mislead anyone into thinking that a professional translator was called in. The Afrikaans piece of the pie is the only section that has remained steady. To understand why English has grown and almost engulfed the isiXhosa let me first consider the socio-linguistic context of the patients before I go on to that of the counsellors. Table 2 below demonstrates some of the features.

Table 2: Socio-linguistic profile of the 12 patients.

PATIENT	EDUCATION LEVEL	EMPLOYMENT	PREFERRED LANGUAGE	LANGUAGE OF CONSULTATION	OTHER LANGUAGE(S)
NB	Grade 10	Housewife	isiXhosa	English	English (a bit)
NN	Grade 7	Domestic worker	isiXhosa	English	None
LN	Post-matric	Security officer	isiXhosa	English	English
NM	Grade 12	Informal trader	isiXhosa	English	English, seSotho isiZulu
SC	Grade 11	Housewife	English	English	Afrikaans
ST	Grade 3	Griller (Spur)	English	English	Afrikaans
ZR	Grade 11	Housewife	Bilingual (English/Afrikaans)	English	None
ED	Post-matric	Nurse	Afrikaans	Afrikaans	English
GK	Grade 8	Domestic worker	Afrikaans	Afrikaans	English
MF	Grade 9	Machinist	Afrikaans	English then Afrikaans	English
VD	Grade 9	Supervisor	Afrikaans	English	English
IA	Grade 7	Domestic worker	Afrikaans	Afrikaans	English

I would like to highlight some of the major points that can be seen from Table 2. Firstly, there was a high level of bilingualism in all the patients, except NN who said that she only spoke isiXhosa. Also, NB stated that she spoke English but qualified it by saying that she only spoke it to a certain extent. Yet, despite these statements about limited or even no English proficiency, the consultations of both NN and NB were conducted in English. (I will be exploring the reasons for this in the next chapter).

Secondly, out of the twelve patients there was a wide spread in terms of level of education. Three patients had only been educated up to a primary school level (IA, NN and ST). At the other end of the

spectrum, two had received post-matric education: ED had a nursing certificate and LN had a National Diploma in Labour Relations. (LN, however, was unable to find work related to her field so was working as a security officer.) Nearly all of the patients who were in paid employment were in unskilled labour, with the exception of ED who was a nurse. ED was also exceptional in that she was the only private patient out of the 12 in the sample.

Since the point of this chapter was to look at whether there was a match between the profile of the counsellors and that of the patients, I now turn to the profile of the counsellors. There were three counsellors who took part in this research. They are the three counsellors who do most of the counselling for DS, and all three of them agreed to take part in the study. I have given them the pseudonyms Gail, Liz and Rachel. Although all three women have a similar function in the clinic, they have differences in their own backgrounds and experience. The table below shows some of their demographic features.

Table 3: Socio-linguistic demographics of the genetic counsellors

	AGE	EDUCATION LEVEL	LANGUAGE MOST COMFORTABLE IN	OTHER LANGUAGE(S)	YEARS AS COUNSELLOR
GAIL	28	Masters in Genetic Counselling	Afrikaans	English	3
LIZ	54	Nursing diploma and courses in genetics counselling	English	Afrikaans Hebrew	13
RACHEL	57	Nursing diploma and courses in genetics counselling	English	Afrikaans	11

The profile of the counsellors also indicates a high level of bilingualism. However, where there is a mismatch between the languages spoken by the counsellors and that of the patients is that there is a notable absence of any isiXhosa. Before I expand on the issue of language, let me briefly point out some of the other similarities and disparities between the three counsellors and the patients.

Another evident discrepancy is between the level of education of the counsellors and that of the patients. In this context, a higher education level is going to be associated with technical jargon or register, relevant to the medical context. The use of the medical register can be problematic even for people who are first language English speakers but is bound to add to the complexity of communication when other languages are involved and English proficiency may be limited (cf (Deumert & Mabandla, 2008; Rapp, 2000).

Looking at the profile of the counsellors it is evident that there are differences between the counsellors themselves. One of the disparities is the difference in age between Gail and the other two. Both Liz and Rachel viewed their age as advantageous as it gave them a great deal of “life experience.” However, when asked to comment specifically on whether she found her young age to be a significant factor in her interviews, Gail replied, “If something’s not there, you can’t notice that it’s missing.”

Another disparity is that whereas Gail had a Masters degree in genetic counselling, with a background in medical science, Liz and Rachel came from a nursing background initially, and had later taken short courses in counselling. Again, Liz and Rachel considered their nursing backgrounds to be extremely advantageous for the job. Their training Rachel referred to as “in-service” in contrast to Gail’s more academic training. When I asked Liz how the nursing experience had helped she replied, “Patient-related background and all the sort of things you pick up on the way and you sort of counsel patients as a nurse from day one.”

Rachel made another interesting observation about her nursing background. She said, “People relate to the word sister. . . To them that has a certain meaning and they know how they can approach you what they can say, what issues they can raise. And I think that doesn’t come with genetic counselling. It’s a new thing. There’s a young girl in front of them.”

Returning to the issue of language, as the table shows, each of the counsellors is bilingual in both English and Afrikaans. This means that, using the patient composition by language referred to earlier (see chapter 1 sections 1 and 3), they are able to address a significant proportion (around 76%) of the patients in the language in which they feel most comfortable. Unfortunately, where they also all share a feature it is that none of them is able to speak isiXhosa. When asked directly if they could speak any Xhosa, they all answered in the negative as shown:

Gail:	No. Well, a few words, but I wouldn’t even count those words - besides the odd word you learn on the ward in ICU that you need your patient to understand like <i>kohlela</i> (‘cough’).
Liz:	Not a word
Rachel:	No

What this means is that every patient who would say that they are most comfortable in cannot be counselled in the language of their choice by these counsellors. (There are still ways of achieving an effective consultation either through the medium of another shared language – such as English – or through the use of translators). And yet South Africa’s Patients Rights Charter specifically makes reference to the fact that patients have the right to health information in the language of their choice. The Charter reads: “health information that includes the availability of health services and how best to use such services and *such information shall be in the language understood by the patient.*” (Patient’s

Rights Charter, www.doh.gov.za/docs/pamphlets/patientsright/chartere.html, emphasis mine.) The wording of this allows a certain degree of flexibility as the Charter does not make specific reference to phrases such as “mother tongue” or “home language”.

How did the patients feel about the mismatch between their language of choice and the language of the consultation? To answer this question, patients were asked during the post-consultation interview, whether they found the language of the consultation to be helpful. One would anticipate that where there is a match between the preferred language and the language of the consultation, this would be helpful for the patient and vice versa. The former holds up under scrutiny, as in the case of IA, a 46-year old Afrikaans-speaking patient, with two grown-up children and who was employed as a char. Her consultation was conducted in Afrikaans and when asked if the language of the consultation was helpful she replied, “Yes, because they explained it in my home language.” However, the converse of this did not always hold.

For example, consider the case of the Afrikaans-speaking patient, VD, who was a 44-year old mother of five children, employed as a control room supervisor at a toll plaza. When asked about the language of the consultation she stated that she had preferred the consultation to be in English, even though she herself was more comfortable in Afrikaans. She explained that this was because “English is better for talking and reading because I don’t understand big Afrikaans words.” NB, an isiXhosa-speaking 38 year-old mother of 1, who was educated up to Grade 10 and was currently unemployed, explained that the consultation was conducted by a white person, but that she “didn’t have any problems with the English.”

However, for two out of the four isiXhosa-speaking patients, this mismatch caused problems. When asked whether the language of the consultation was helpful, NN, a 39 year-old domestic worker educated to a Grade 7 level, replied that she only understood everything because her husband translated into isiXhosa for her. She suggested that isiXhosa-speaking translators should be available. However the need for a translator was not just limited to those who had a lower level of education. LN, a 38 year-old security officer, who had been educated up to a post matric level, commented in the post-consultation interview that she had understood everything. However, she then also made the suggestion that isiXhosa-speaking translators should be available implying that, despite her understanding of English, she would have preferred to carry out the discussion in her home language.

I would now like to address my second and third questions namely:

- What is the context in which the consultations occur and is there any evidence of language barriers within this context?
- If language barriers are identified what strategies do the counsellors employ to overcome language barriers?

The reasons that it is vital to identify and address any language barriers identified have been addressed in other studies. In 2002 the Western Cape Language Audit found that only about 50% of isiXhosa-speakers in the Western Cape had a level of proficiency in English that enabled them to explain a simple problem in English (Western Cape Language Audit, 2002). On an ethical dimension, Schlemmer and Mash (2006) voiced a concern that the language barriers at a “typical district hospital” (such as GSH) can lead to “an erosion of the patient’s right to confidentiality and informed consent and the reduction in quality of care” (p. 1087). A study of communication between English-speaking doctors and isiXhosa-speaking patients at Red Cross Children’s hospital showed how language barriers presented practical difficulties (Levin, 2006b). Levin concluded: “Language and cultural barriers were cited by more parents as a major barrier to health care than structural and socioeconomic barriers” (p. 1076). Internationally, studies have similarly demonstrated how language barriers affect health care at every level from access through to delivery (cf. Flores, 2006). Based on my rough language statistics, approximately 22% of the patients seen at the clinic are likely to be isiXhosa-speaking, thus the potential for language barriers is extremely high. The next chapter addresses whether this potential for problems was realised.

CHAPTER 2

2.1 The risk of language differences in the pregnancy counselling clinic

As mentioned in the introduction, consideration of the context of situation is vital to understand the *how*, the *why* and the *what* of risk communication. This chapter is an exploration into the different layers of context. Dell Hymes (1962) was one of the first to suggest a series of different layers of context, all of which contribute to the meaning of a speech act. Kay McCormick (2009) has done something similar, but expanded the layers of context to include a slightly different slant, incorporating layers like ideology and history. Since history, ideology and language are particularly entwined in South Africa, I have chosen to use McCormick's model to address the context of situation.

In addition to explaining the different layers of context, I will pick out areas where there is evidence of language barriers and I will assess what strategies were used to address these barriers. Language barriers occur where the speakers have different mother tongues and thus there are inter-language barriers. However, even when speakers used English, there is also a great deal of intra-language variation. If the counsellors were not themselves speakers of South African English, this variation could pose a problem. I will argue, however, that although there is variation at this level, English speakers in South Africa are used to the phonological, syntactic and lexical variability and this level of variation does not tend to cause problems.

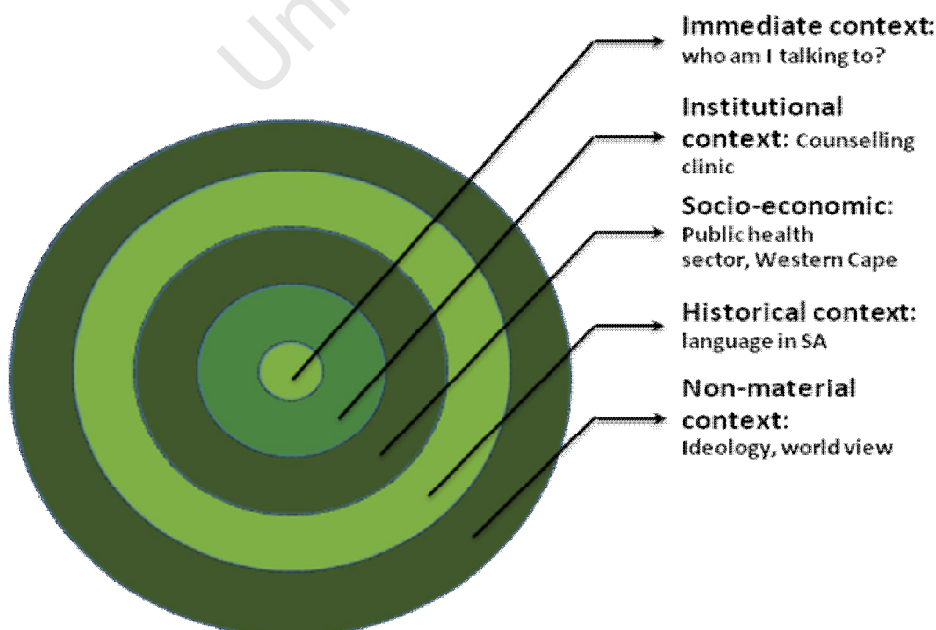


Figure 6: McCormick's layers of context (2009)

2.1.1 Immediate Context

If we take the inner layer, of who is talking to whom, the counsellors and patients have already been described in the previous chapter. (Refer to Tables 2 and 3). The focus in this section is to look at whether there was any evidence of language barriers between the counsellors and patients and, if so, how they were addressed. The first question to consider is how the language of the consultation was selected. To answer this question, I turned to my thematic analysis and looked at all the consultations where the theme of *Language* emerged.

This theme occurred in nine out of the thirteen consultations. In both of the group consultations I arrived after the introductions and after they had decided what language to choose. Thus although it is not recorded as present, the counsellors said they had asked about the patients' language choice for the session. For the patients who had been in the Afrikaans group and had thus already indicated a preference for Afrikaans (GK, ED, MF) Liz did not bring the theme up again in the individual session. However, after the group interview in English, Rachel asked both ST and MF about their language preference in the individual session.

There were two consultations where the theme did not come up at all, and that was for two of the black patients, LN and NM. Here the consultation just progressed in English without any choice being offered to the patients. However, as I was not with the counsellors when they went to fetch the patients from the waiting room, it is possible this question could have come up then.

In all of the seven consultations where the theme of language was recorded, it was at the beginning and in the form of a question asked by the counsellor. What was also interesting was that the question was always asked in English, even where the counsellors' first language was not English (for example Gail's first language was Afrikaans.) So it would seem that factors in another layer of context were contributing to the English dominant effect. (I will discuss this later under the non-material context.) There were slight differences between the ways the question was framed for the Black² patients, compared with the Coloured patients. Coloured patients were generally offered the language choice as a *wh-* type question, as occurred in the consultation between Rachel and ST:

² The terms Black, Coloured, Indian/Asian and White are used in the context which the official population census (Statistics SA) and institutions categorise people in order to measure outcomes of affirmative action and Employment Equity put into place to address the political and socio-economic inequalities of the past in South Africa. 'Black' is used to refer prototypically to South Africans who self-identify as Black and speak a Bantu language, 'Coloured' to people of mixed ancestry, 'Indian/Asian' to people of Asian descent and 'White' to descendants of European settlers. In this study individuals are classified according to self-perception and self-classification not on legal definition. Capitalisation of the words is used in recognition of a growing grass-roots sentiment that as distinct ethnic groups they deserve a capital letter (Crwys-Williams, 1999).

- (1) **Rachel:** *And do you prefer to speak English or Afrikaans?*
- ST:** *Any language is fine.*
- Rachel:** *Any language?*
- ST:** *Because English is much better to understand than Afrikaans.*
- Rachel:** *Honest? Alright. (Laughs)*

However, when addressing the Black patients, if the question was asked, then the emphasis was on whether or not the patient could speak English in the form of a *yes/no* question. For example, after Gail had introduced herself, she then asked LN about her language preference in the following excerpt. (LN was a 39 year old lady, whose first child had died “of evil spirits”. She was currently employed as a security officer, although she had post matric education in the form of a National Diploma in Labour Relations.)

- (2) **Gail:** *Okay, is it alright if we speak English or do I need to get someone to thetha Xhosa*
- LN:** *I understand English.*
- Gail:** *Shall we see how it goes, and if you feel you not understanding me, then just tell me*
- LN:** *OK*
- Gail:** *and we can get a translator.*
- LN:** *OK.*
- Gail:** *So at any stage you feel you not following me because some of the information is quite complicated, then you just tell me then I can get someone to translate for us, is that alright?*
- LN:** *Okay*

There are problems associated with asking about language as a *yes/no* question in the negative, particularly to speakers of Black South African English (cf Mesthrie & Bhatt, 2008 p. 87-88). I will illustrate how even a positive answer to a *yes/no* question should not be taken at face value using the excerpt below where Rachel asked NN about her language. (NN was a 39 year old mother of 3, working as a domestic worker, and educated to a Grade 7 level.)

- (3) **Rachel:** *Do you speak English, Mrs N?*
- NN:** *Ja.*
- Rachel:** *You do. OK.*

The answer given here by NN contradicts her post-consultation interview, where she stated that she spoke no other languages besides isiXhosa. So why does she answer *Ja* above? The reason is pragmatic rather than structural. Herselman (1996) showed how patients feared “risking anger or ridicule” from medical staff if they admitted they were not proficient in English. Also, as mastery of English is associated with education and prestige, many patients may feel that admitting they do not speak English is equivalent to admitting that they are uneducated (De Klerk, 2006). Another South African study, by Schlemmer and Mash (2006) found similarly that patients tended to express agreement as a face-saving strategy lest they appear ignorant.

Another factor that might cause NN to answer *Ja* is related to the fact that in the Pregnancy Counselling Clinic there are no fixed appointments, but rather a “first come, first served” approach. Thus the consultation is extremely precious. Patients may be afraid that asking for an interpreter might mean an additional waiting period, and jeopardise their position in the queue.

There may also be factors from the counsellors’ side, which mean that they are happy to accept an answer of *Ja* without exploring it further. For the counsellors, the answer *Ja* means that they can continue the consultation and that they do not need to call for an interpreter and this can pose a challenge. Gail explained that, “It is very difficult firstly just to find a translator in the hospital. . . It’s one of the biggest difficulties. It’s not ideal just to use another patient or a cleaning lady”. (See later section on challenges with interpreters.)

When I asked the counsellors whether language differences were an issue for them, this is what Gail and Rachel replied:

- | | |
|-------------|--|
| (4) Gail: | Our patient population which we’re seeing, many of them are Xhosa- speaking. And some of them their English is conversational but I mean we’re not talking about things that are, I mean, it’s complex information. Even explaining it to someone in their first language it’s abstract and difficult to understand. So I mean, it’s definitely not ideal to be explaining those things and exploring their feelings and how they feel about it in a second or a third language. |
| (5) Rachel: | I know I can do it with Afrikaans, but where I’m battling with language - I think I’ve lost them by the time I bring out the chromosome pictures.* For people who don’t have a concept of a cell and now you’re bringing out a new word and they haven’t heard the word genes anyway and you’re battling because their English is poor. |

(*To look at the pictures referred to here see Appendix 7).

These excerpts identify that Gail (who is L1 Afrikaans) and Rachel feel competent at explaining concepts – even ones potentially as alien as chromosomes in English and Afrikaans. But where language was a barrier (particularly in the isiXhosa speakers, as identified by Gail) they struggled to explain the concept. Since the particular content of the interview is related to the particular context of the clinic, I shall discuss this issue further in the next section.

2.1.2 Institutional context

The very nature of the Counselling clinic means that much of the content is medical. Rapp (2000) refers to the use of everyday terms rather than medical jargon as “code switching” in consultations but I would call it a register shift. Halliday (1978) defines register in opposition to dialect. He says that dialect is variation in language according to the *user* whereas register is variation in language according to *use*. This definition is helpful to understand this layer of the context as it is the unique nature of how language is used in this particular medical setting which resulted in problems. Before I turn to the problems, let me start with some positive findings.

To assess what the patients thought about the counsellors’ communication skills, I looked at what the patients said in the post-consultation interviews. All twelve of the patients spoke positively about the communication skills of the counsellors. When asked “Was the language of the consultation helpful?” many patients interpreted the “language” as meaning the vocabulary of the consultation. Although this ambiguity was unintentional, it helped provide some feedback about the patients’ opinions of the instrumentalities. The comments, coming from Afrikaans-, English- and isiXhosa-speakers alike, included phrases like *It was very accessible*, *Yes, it was very easy* and *She explained everything clearly*.

At the level of lexical items, all three counsellors spoke consistently in everyday language, using lay terms where possible. So, for example, the word uterus was only used in one out of the 12 interviews, and that happened to be the group interview where one of the patients was a nurse, (ED). In all the other consultations lay synonyms such as *womb*, *water bag*, *sack* and *huisie* (‘little house’) were used.

In addition to everyday lexical items, the counsellors also used analogies relating to everyday occurrences. For instance the theme *Chromosomes and DS* was explained in every one of the 13 consultations. Here is a typical example where Gail has just explained how the chromosomes come together at conception using the diagram. The words *that egg cell* (marked with a *) refers to the diagram shown in Appendix 8.

(6)	Gail:	<i>Sometimes, as women get older, instead of that egg cell having 23* sometimes it has 24 packages.</i>
	NB:	<i>Mmmm</i>
	Gail:	<i>It means there’s an extra bit of the in the inherited material. And that means there is 24 plus 23 – the baby ends up with 47 packages. And that recipe then is out of balance. If you think about it – you maybe bake a cake</i>
	NB:	<i>Yes</i>
	Gail:	<i>And the recipe says add two cups of flour but by accident you add 3 cups of flour – then the ingredients are out of balance completely with flour, baking powder – it’s not in balance. Our recipes are much more complex – more complicated. But in a similar way if there is some of the plans of the</i>

body extra – then it means that the baby with the extra packet – the 47 instead of the 46 – the brain does not form in the same normal way, the face forms differently that’s how we can recognize – okay – and that is what causes the Down syndrome.

Liz, inspired by the presence of builders outside her window, chooses an analogy around building as follows:

- (7) **Liz:** *Now these instructions, these plans are called the inherited material – genes. Have you heard the word genes or chromosomes?*
- LN:** *No.*
- Liz:** *OK. So the chromosomes is what um, carries all the instructions. And they’re little packages, and they’re in us, all over in us, and these little packages, every little package inside has got a job to do.*
- LN:** *MMhmm*
- Liz:** *A job to build the brain to build the teeth to build the bones, to build the heart. Everything has a job to do. Now sometimes, when the plans aren’t correct, then the jobs get all mixed up. OK? And they’re not doing their job properly. So something doesn’t get put together right. It’s like these builders here who are building this building (INDICATES BUILDERS AT WORK OUTSIDE WINDOW)*
- LN:** *Yes.*
- Liz:** *If somebody there doesn’t do his job right, he doesn’t mix the cement together properly, the building’s not going to last.*
- LN:** *Mmhhmm.*
- Liz:** *It’ll collapse. The same with us. If we’re not built properly, something will go wrong.*

However, this strategy of everyday language was not always successful at both a lexical and analogy level. Where it failed at a lexical level was when the counsellors did not realise that there was a difference between the medical meaning and the everyday meaning of a lexical item. Again, I will illustrate this with an example, this time between Mr N, NN and Rachel.

As a nurse, Rachel knows that needles can be a port for either giving a substance to a patient or withdrawing a substance from a patient. It is this latter function that the needle performs in an amniocentesis as has been demonstrated to Mr N using the diagram in Appendix 4. However, most patients only ever experience needles when they are given a substance (such as immunisations) via a needle. Mr N, based on his experience with needles, deduces that something is going to be injected into the baby – but that Rachel is withholding the nature of this “something” from him.

(8) **Mr N:** . . . *but the problem is that we are fear about the injection and maybe it's going to make another danger there. Yes. Uh. I'm very . . . I don't know. Uthi masenze njani kuba mna ndicinga izinto ezimbini kuba kaloku kuza kufakwa le naliti kuloo mntwana. Asibazi aba bantu nokuba bazakufaka inaliti enjani na, uyaqonda?*

What do you think we should do because sthere are two things: they are either going to inject the baby with the needle but [the problem] is that we do not know the type of injection they are going to use? Do you understand?

The example of misunderstanding around the term *needle* is similar to results from research conducted in the USA on Mexican patients whose first language was Spanish. They were informed about a test for a “protein”. However, for them protein was a major food group and, therefore, if the protein level was raised, they thought this was due to a healthy diet rather than understanding that the raised protein was an indicator of a potential problem (Browner,Preloran & Casado, 2003).

At the level of analogy, the everyday example also failed sometimes. Two of the other patients (IA and GK) admitted in the post-consultation interview that they didn't fully understand the section on chromosomes. Here is an excerpt from the consultation between Rachel and IA when Rachel explains what a chromosome is:

(9) **Rachel:** *Wat ons weet van daai kinders met die Down Syndrome – hulle het in hulle liggaam – amper elke sell van die liggaam het hulle 'n extra ietsie – wat ons 'n kromesoom noem – ooit gehoor van so 'n word?*

IA: *Nee*

Rachel: *That's absolutely fine I had never heard of it either when I came – OK – so daai word – hier staan dit in engels dit is “Chromosome” of ons praat in Afrikaans van kromosome – nou verbeel joy dat elke kromosome so 'n ballejie ball is – okay en wat 'n mens kan doen*

What we know about those children with Down's Syndrome – they have in their bodies– almost every cell of the body has an extra something – what we call a chromosome – ever heard of that word?

No

That's absolutely fine I had never heard of it either when I came – okay – so that word – here it says in English a chromosome or when we speak in Afrikaans of kromesoom – now imagine that if every chromosome is a small ball –

	<i>is jy kan daai ball uittrek (MIMES UNRAVELLING A BALL OF WOOL) – so unravel – what is unravel in Afrikaans? (Laughter) Maar jy weet waaroor ek praat?</i>	<i>okay and what a person can do is to pull it out (MIMES UNRAVELLING A BALL OF WOOL) – so unravel – what is unravel in Afrikaans? Laughter – but you know what I'm talking about?</i>
IA:	Uitrafel	Uitrafel
Rachel:	<i>Uitrafel – okay – so verbeel elke een van ons het 46 van die Chromosomes maar daai kinders het 47 – en waaruit bestaan daai ball – daai Chromosome – al wat ons daai uitrafel – that's actually all your genes – jy't gehoor van genes?</i>	<i>Uitrafel – okay – so imagine that every one of us have 46 of these chromosomes but those children have 47 – and what does that ball consist of – that chromosome –if we unravel it– that's actually all your genes – have you heard of genes?</i>
IA:	Ja	Yes

The counsellors seemed aware that this concept of chromosomes was difficult to communicate – even using analogies, particularly if a language barrier added to the difficulty of the task. When language was a barrier Rachel said the following:

(10) Rachel: I try to make my English as simple as possible. I trim it down and leave off the chromosome stuff.

The “chromosomes stuff” came up in three themes:

- Chromosomes and DS
- Explanation of chromosomes
- Chromosome analysis.

In all 13 consultations, the link between chromosomes and DS was explained. The final section, on chromosome analysis, was not always necessary if the patient had already decided against an amniocentesis or (as in the case of ZR) was unsure about the decision. However, the explanation of what a chromosome is and the difference between a chromosome and a gene is important for understanding what the amniocentesis can offer to patients. (I.e. only the chromosomes are analysed and, therefore, there is the possibility that chromosomal disorders other than DS could be diagnosed), and also for understanding an amniocentesis’s limitations (specific genes are not looked at and, therefore, normal chromosomes still does not guarantee a ‘normal’ baby.) By omitting this information, the counsellors are in danger of proving Schlemmer and Mash (2006) right in that the inability to speak to patients about this topic results in “the erosion of the patient’s rights to . . . informed consent” (p. 1087).

And yet, despite its importance, although the explanation was offered in both of the group sessions (and therefore included the patients ED, GK, MF and ST) an explanation of chromosomes was not given to four patients (NN, ZR, LN and VD). Of these four patients two were isiXhosa-speaking but two were bilingual English/Afrikaans suggesting that language is not the only barrier to offering this explanation. If the counsellors truly wish to achieve informed consent in their patients then they need to look at alternative ways of explaining or illustrating chromosomes that makes them feel confident to engage with every patient. I would now like to turn my attention to the next level of context, the socio-economic context.

2.1.3 Socio-economic context

The Pregnancy Counselling Clinic is offered to patients in the public health sector. There are only two hospitals in the whole of the Western Cape region which offer Genetic counselling (Tygerberg and GSH) and thus the patients can come from anywhere within the region. As with any government hospital, resources are limited and there is a considerable burden on the staff to perform under these conditions but local policies have been published (*Costing the Western Cape Language Policy*, 2003). These issues of “patient load” and “stretched resources” were mentioned by all three counsellors in their interviews.

The Provincial Government of the Western Cape (PGWC) is responsible for the maintenance of GSH and its resources. It is thus this level of the context that is responsible for providing the rooms, and putting up the signs in the hospital. Hospital signage should reflect the three main languages of the region. As Deumert and Mabandla (2008) point out, “Providing trilingual signage is not only a practical necessity, but also an important symbolic act, providing visible respect and recognition for the main languages of the patients” (p. 15). However, the signs in GSH remain stubbornly monolingual, as illustrated in the photographs below. (The quality of one of the photographs is poor as it was difficult to take photos without patients in them and, for ethical reasons, I could not include the photographs of patients without informed consent and prior ethical approval.)

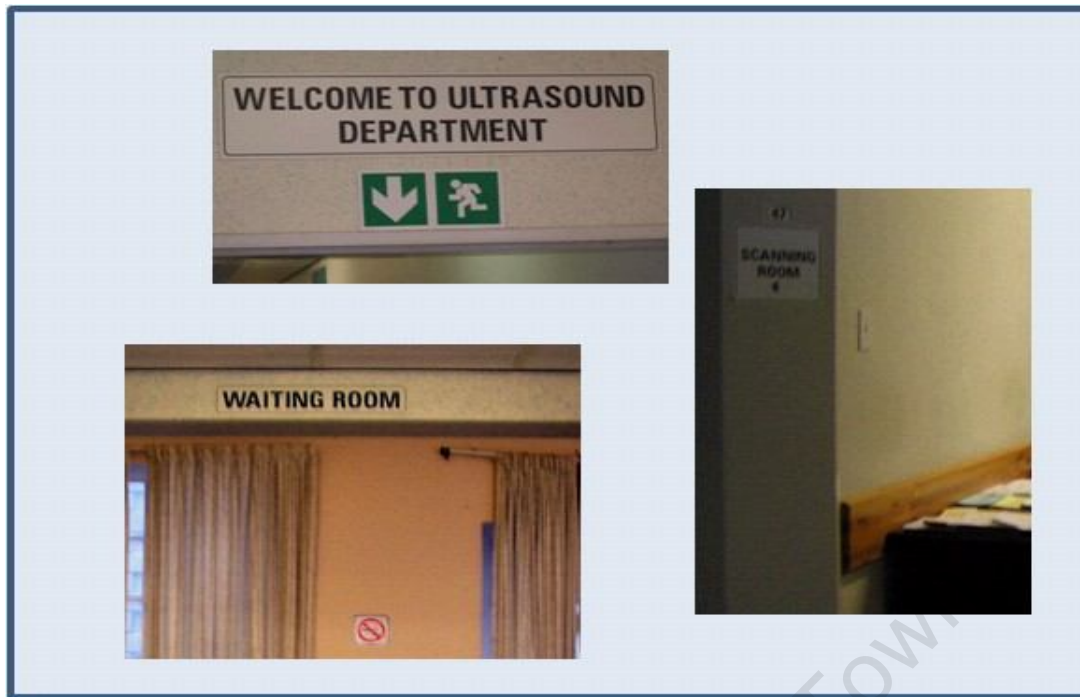


Figure 7: Photograph of signage around the Pregnancy Counselling Clinic at GSH Reads clockwise from top-left: *WELCOME TO ULTRASOUND DEPARTMENT*, *SCANNING ROOM 4* and *WAITING ROOM*.

It is also PGWC who should be responsible for paying for professional interpreters. In their article concerning another hospital in the Western Cape in 2006, Schlemmer and Mash concluded that “the effects of the language barrier were considerable and persistent despite an official language policy in the province. The training and employment of professional interpreters as well as teaching of basic Xhosa to staff are recommended” (p 1084). Deumert and Mabandla (2008) make the damning conclusion that “little has changed since Soahatse and Crawford published their research on interpreting practices in South African hospitals” (p. 40) (cf Crawford, 1991, Saohatse, 1998, Saohatse, 2000). What was the evidence within my sample of the need for and attitude towards interpreters?

Within my sample, there was only one consultation where an interpreter was used. However, he was not a professional interpreter but the husband of the patient (Mr N). As discussed previously Rachel had asked NN at the beginning of the consultation whether she spoke English and NN replied *Ja*. As the consultation progressed, NN continued to give only monosyllabic answers to questions, leading Rachel to ask her at various points *Do you understand then*, *Are you sure you understand me*, *Do you know what I’m asking?* and *Do you understand the question?* Finally, after explaining the amniocentesis procedure and risk of miscarriage, Rachel addresses NN:

(11) Rachel:	<i>So, what do you think now, so far, from what I have told you?</i>
NN:	<i>Mmm. (Sighs)</i>
Rachel:	<i>It's difficult.</i>
NN:	<i>I can tell my husband.</i>
Rachel:	<i>Can you phone him?</i>
NN:	<i>Well, he's working here.</i>
Rachel:	<i>Oh is he? That's nice. At Grootte Schuur?</i>
NN:	<i>Yes</i>
Rachel:	<i>Good. Alright. Um, can he come and we can talk to him?</i>
NN:	<i>Yes</i>

Mr N arrived panting, and Rachel ran through all the information she had already tried to communicate to NN. He then acted as an interpreter on two occasions. The first instance of interpreting occurred when Rachel reached the point where she asked them if they would like a test (see later in this chapter.) This second instance of interpreting was given previously, when Mr N illustrates his different perception of a needle (as shown earlier in the chapter.)

All of the counsellors, despite acknowledging that language could be a significant factor, also expressed ambivalence about the use of interpreters as shown below:

(12) Rachel:	I think some interpreters put their own spin on what they hear. . . They think they're here to say doctor wants you to have the test so sign here.
(13) Gail:	Just having a session with a translator is - umm - difficult. It takes so much time. Obviously you always lose some of the context of the answers. . . If you are asking an open-ended question, I found the translator often changed it because the answer turned out to be yes or no.

They justified their reserve by citing specific problems with the interpreters. For example, as illustrated by the excerpts above there may be a discrepancy between what is actually said and what is translated. The problems associated with the use of non professional interpreters were categorised by Vasquez and Javier, based on their Spanish research in 1991, into five basic error types: Omission, Addition, Condensation, Substitution and Role exchange (Vasquez & Javier, 1991). I have summarised these first four under the umbrella term *Discrepancy*. Other authors such as Swartz (1991) have provided a good description of some of the problems associated with the use of interpreters.

To this list I could add one other problem cited by the counsellors at GSH which I would call *Disengagement*. Gail explained to me that the counselling session is already quite long, requiring

concentration. When an interpreter is used, there are long periods of time where the patient may not be a part of the consultation if the communication is happening between the counsellor and the interpreter. In such instances, the patients “lose focus” and the communication fails. Of course, repair is possible, but multiple acts of disengagement will eventually result in a breakdown in communication. However, although NN was largely silent during the consultation after her husband joined the consultation as a translator, she still ultimately made the decision to take the test and did not seem to have lost focus. (See below.) Mr N turns to his wife and says:

(14) Mr N:	<i>Mmmmmm. So Uthi uSista kuba iminyaka yakho iyi-40 ufuna ukutesta. Akutshiwo ukuba umntwana ungoluhlobo ufuna unje ukukutesta and then abone ukuba umntwana unje. Emveni koko sidisayide ukuba ngaba loo mntwana mhlawumbi unale ngxaki ayithethayo.</i>	<i>Mmmmmmm. So, the sister wants to do the test because of your age but this does not mean that the child is like this [meaning that the child has Down's]. She just wants to test you and check the baby's health status after that we will have to make a decision</i>
NN:	<i>Hayi manditeste.</i>	<i>No³, I will do the test</i>
Mr N:	<i>OK.</i>	
Rachel:	<i>Would she like [the test]?</i>	
Mr N:	<i>No, she would like the test</i>	

Another reason cited by the counsellors as being problematic with interpreters was that, as Gail put it, “It takes so much time”. However, if we consider the consultation between Rachel and NN, it seems to be the lack of interpreter that has actually resulted in a delay, rather than the presence of one. This consultation was the longest individual consultation (52.5 minutes compared with an average of 37.6 minutes. See Appendix 3). All the information that had been given to NN by Rachel had to be repeated to Mr N. His sections of translation were actually brief and not responsible for the longer consultation. So, in this instance, having a translator (either Mr N or a professional one) there from the start would have resulted in a significantly shorter consultation. The question that needs to be asked at this level of the context is why there are no professional interpreters available as part of the team at the Pregnancy Counselling Clinic, especially since a government report, *Costing the Western Cape Language Policy* was written in 2003 stating, “The Department of Health has a major and urgent need to improve access to health service by providing interpreting services between patients and health workers” (p xv). The government needs to be called to account.

³ ‘No’ can also mean ‘Yes’ in isiXhosa, as in South African English *No, fine* for *Yes, fine*.

2.1.4 Historical context

For the purposes of this research, the historical context I wish to discuss is with respect to the intra-language variation in South African English. South African English is a 'New English' which is defined as a variety of English which is used as an L1 (first language) variety outside America, England and Australia (Mesthrie & Bhatt, 2008). New Englishes are traditionally described ontologically so I will provide a brief summary of the history of English language acquisition relevant to the varieties present in my study (namely White South African English (WSAfE), Black South African English (BSAfE) and Coloured South African English (CSAfE). Indian South African English is another well-described sub-variety of South African English, but there were none of these speakers in my sample.

Some have argued that there is no homogenous version of BSAfE, but that each Black language community speaks a variety of English influenced by the substrate language. However, as Mesthrie and Bhatt (2008) point out, "it is becoming clear that few WEs (World Englishes) are tied down by the stranglehold of their substrates" (p. 49). Additionally, many WEs share certain features suggesting that linguistic universals are more likely to account for the features (cf *Ibid*; De Klerk & Gough, 2002).

English was introduced to South Africa as a result of colonisation. Prior to formal colonisation, records indicate that English explorers and traders who visited the land began to introduce some vocabulary (Silva, 1996). However, the formal colonisation began as a complex one involving an initial battle between the Dutch and the English. Although the history is complex Kamwangamalu (2006) usefully describes it as occurring in three stages. The first colonial invaders were the Dutch, from 1652 – 1795, followed by the British from 1795 – 1948. From 1948 to 1994 the Afrikaners ruled until 1994 when the first democratic elections were held heralding the birth of the new South Africa.

The Afrikaners declared Afrikaans to be the main language when they came to power in 1948. Officially, English still had co-official status but some would argue that English only had "Cinderella status" (Kamwangamalu, 2006). In 1953 whilst the Afrikaners were in power, they passed the Bantu Education Act, limiting Blacks' access to English whilst making Afrikaans the medium of instruction. After the tragic Soweto uprising the education policy was changed to increase access to English but the change came too late for many who had been denied access to teachers, resources and L1 speakers. As de Klerk puts it, "The long-term effects of under-funding, overcrowding and teacher incompetence, combined with limited contact with native English speakers, led to characteristic patterns of pronunciation and syntax becoming entrenched as norms of spoken BSAE" (De Klerk, 2006 p. 165). Since 1994, English and Afrikaans have remained official languages, but another nine indigenous African languages have also attained this status.

The Coloured population, although they did not have access to the resources of the Whites, were not totally separated as the Blacks had been. They were able to live in close proximity to White areas and thus had much more opportunity for interaction with English-speakers. According to Mesthrie and Bhatt

(2008) English as Second Language (ESL) varieties typically arise in countries where English was introduced in the colonial era and where there was face-to-face interaction with a community of English-speakers. This is also termed "The Outer Circle" according to Kachru's model (1985). In general terms, South African English is difficult to box into one specific category. As Schneider (2007) points out "South Africa would qualify for both of these categories (i.e. Inner or Outer Circle) at the same time, and also for neither of them depending on which aspect of its language situation is emphasised" (p. 174). Categorising black South African English using an EFL or ESL distinction is also problematic. Because the majority of Blacks were limited both in their access to English through the education system and in their face-to-face interaction, even though English was an official language, the Blacks learned English which had more features of English as a Foreign Language (EFL) than an ESL variety. The Coloureds' English, on the other hand, approximates more to an ESL variety.

White South Africans had no problems with access to English via education or contact. The New English that developed in the Whites developed along a spectrum which Lass (Lass, 2004) divided into three. His "trichotomy" of Type 1 (Conservative), Type 2 (Respectable) and Type 3 (Extreme) South African English was based largely on phonetic differences. Type 1 approximated to Received Pronunciation (RP) whilst Type 3 was associated with low socio-economic status, unskilled employment and, "in extreme forms . . . difficult to distinguish from second language Afrikaans English" (Lass, 2004, p. 373). Type 1 accents were associated with early generations of settlers and has largely fallen away now, and even highly educated people (such as the genetic counsellors in this study) tend to have Type 2 accents. Typical features of this accent include a monophthongisation of diphthongs such as [au] and [ai] to [a:] (Lass, 2002).

When talking about BSAfE and ColSAfE, this trichotomy is not useful. Instead Mesthrie (1992) uses Platt's adaptation of the descriptors of Creole languages to the spectrum of speakers of New Englishes and adds two of his own. Thus he describes a spectrum of five grades from pre-basilectal, basilectal, mesolectal, acrolectal to post-acrolectal where those varieties at the basilectal end of the spectrum carry features that mark the variety as being most removed from the target language whilst acrolectal is closest to the target language. Post-acrolectal applies mostly to Black, Indian and Coloured South African English which is so far along the continuum that it is indistinguishable from WSAfE. In this study, the patients were largely in unskilled labour (with the exception of one patient who was a nurse.) All of them had received at least some education, but as they were in their 30s or 40s they were educated under the apartheid regime with its policy of segregation. Thus their English varieties tend to show mesolectal features. Even NN (who answered that she could not speak any languages other than isiXhosa) was able to communicate a little in English, and features in her speech had more in common with mesolectal features than a true basilect.

I looked at some features of these different English varieties to see if they were likely to cause communication problems. I did not focus on phonological differences, but on some syntactic and lexical features evident in the consultations. Although there was evidence of variety in the different Englishes

used, there was no evidence of these differences causing communication to break down. However, even a finding like this is important to point out both for the sake of completeness and to highlight how speakers of English in South Africa are able to negotiate meaning with each other.

Firstly, at a lexical level there are differences between the several English varieties. Some of these are well known in medical circles such as *high blood* for high blood pressure (evidenced in two consultations.) An example I found in both ColSAfE and BSAfE concerned a semantic shift of the adjective *clever*. In standard English, *clever* generally means 'above average intelligence', whereas in this context the meaning was 'not intellectually impaired'. This meaning was clear from the context.

(15) NB (BSAfE): *He can't eat right, and even if he talk, he talk nicely – but he is clever.*

Another example of semantic differences in ColSAfE from Standard English was in the terms used to describe death. Often cultural restraints mean that euphemisms are introduced (Mesthrie and Bhatt, 2008 p. 114). However, in the example below, there was a euphemism not relating directly to cultural restraint, but rather illustrating semantic widening in the word *bumped* meaning 'knocked over' – describing how her grandfather was killed by a car.

(16) ZR (ColSAfE): *They bumped him*

A neologism described in the literature which might cause misunderstanding to people not familiar with it, is the use of last of last week to mean 'the week before last' as in the following:

(17) NB (BSAfE): *Last of last week I came here in ultrasound*

On a semantic level, one of the features of World Englishes (WEs) concerns the use of the article. In Standard English differentiation between the definite article and the indefinite article has the function of differentiating the specific from the general. It can also be used to signify what information is new (by using an indefinite article) and what information can be considered already given (by using a definite article) (Mesthrie and Bhatt, 2008 p. 47-52). Although there were several instances of article deletion, insertion and interchangeability, (as shown below) none of them led to misunderstanding.

(18) Mr N (BSAfE): *So it's not first time*

(19) NM (BSAfE): *So after second one in 2003 they had pains in the stomach. So I ended up having ultrasounds.*

(20) LN (BSAfE): *Sometimes when I eat something, then I feel pain, it's the ulcer.*

(21) NB (BSAfE): *Someone was killing him with the knife.*

A typical feature of many WEs is the variability in the marking of plural nouns, and/or over-generalisation of the plural -s. Again, the context or other lexical items (such as numerical descriptors) indicate the plurality of the noun, so it would not cause any misunderstanding.

(22) NM	(BSAFE):	<i>I have three miscarriage</i>
(23) VD	(CoISAFE):	<i>maybe the doctor do some damages</i>
(24) NN	(BSAFE):	<i>now I see some baby in my place</i>

In the verbal phrase, sometimes there is a mismatch between noun and verb. Again, the meaning is clear from the context so it does not cause misunderstanding.

(25) ST	(CoISAFE):	<i>He have two daughters, he have two sisters</i>
(26) ST	(CoISAFE):	<i>his children's all well</i>
(27) ZR	(CoISAFE):	<i>All of them is girls</i>

Tense is encoded slightly differently from Standard English in many WEs. Often, adverbial phrases locate the utterance in time, or tense appears to be neutralised in a co-ordinate or subordinate clause.

(28) ST	(CoISAFE):	<i>then May it was just a drop and it disappear</i>
(29) NB	(BSAFE):	<i>I only know at 2003</i>

Sometimes there appears to be over-generalisation of the rule when applying 'weak' suffix markers to indicate tense for 'strong verbs'. Strong verbs are those which form the past tense by changing the vowel of the root verb without adding a suffix, (Crystal, 2009). One example I found was as follows:

(30) LN	(BSAFE):	<i>So they said she caught some bad spirit outside.</i>
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Another way in which tense was sometimes indicated was with an unstressed *do*. Stressed *do* usually functions to counter listener presupposition. The use of unstressed *do* is rather to highlight salient activity (Mesthrie, 1999).

(31) VD	(CoISAFE):	<i>I did fell on the sports field</i>
(32) Mr ED	(CoISAFE):	<i>we did agree on that</i>

Negation is another area of grammar which showed some variation. Example 34 below shows a combination of variation with respect to negation, tense and plural marking. Once again, the meaning of the utterance was clear despite some differences from how Standard English would negate.

(33) VD	(CoISAFE):	<i>there's nothing nobody can do until the baby's born or whatever</i>
(34) LN	(BSAFE):	<i>No, I don't got any child</i>

As illustrated by the many examples, although there was evidence of significant intra-language variation within English, the non-standard features did not lead to problems in understanding meaning i.e. there

seems to have been some historical accommodation between L1 and L2 English (even rudimentary L2 English) in South Africa.

2.1.5 Non-material context

This level of the context refers to the ideology of the context. I would like to refer to the introduction (Figures 4 and 5) where, in the consultations, the English piece of the pie was seen to grow and engulf most of the isiXhosa piece of the pie and also to Section One of this chapter, where I mentioned that the counsellors not only greeted all the patients in English but also defaulted to an English-speaking consultation when the language of the patient was not asked (see section 1.1 of this chapter). The explanation for this English dominance was shown not to be counsellor dependant (as Gail's first language was actually Afrikaans) nor was it patient-dependent (or the isiXhosa piece of the pie would not have shrunk so much.) Therefore, the explanation for the dominance of English lies at this level of the context, the ideological level.

Ideology does not only relate to groups and social institutions but also to individuals. The dictionary defines ideology as "The body of ideas reflecting the social needs and aspirations of an individual, group, class or society" (Houghton Mifflin Company, 2009). For the individual patients, their social needs and aspirations relate to the future of their unborn child and the entire counselling session is really about this. Results in this study show that, in the post-consultation interview, 12 out of 12 patients (100%) said that they were happy with the service they received in the clinic.

Fairclough (2001) explains the link between ideology and language as follows: "Ideologies . . . are a means of legitimising existing social relations and differences of power, simply through the recurrence of ordinary, familiar ways of behaving which take these relations and power differences for granted. Ideologies are closely linked to language, because using language is the commonest form of social behaviour" (p. 2). Therefore the familiar practice of using English as a default setting needs to be actively tackled, as put by Desmond Tutu, "Language is very powerful. Language does not just describe reality. Language changes the reality it describes" (Tutu, 1999).

In South Africa, there is a vast corpus of research in the area of language and ideology – which brings together linguistics and sociology. Mediating between social structures and forms of talk, such ideologies are not only about language. Rather, they link language to issues such as identity, power, ethics and epistemology. Through such linkages, language ideologies underpin not only linguistic form and use, but they relate to the individual, the community and society in terms of fundamental notions of person and community and the functions of significant social institutions – like hospitals. This issue is far too large and complex to address within my research but is well tackled by others (cf Blommaert, 2005; McCormick, 2002; books by Ricento, 2000 and Schieffelin, Kroskrity & Woolard, 1998).

CHAPTER 3

3.1 Meaning of *risk*

When I asked Rachel, with her 11 years of experience as a counsellor, if there was anything that she found difficult to communicate to the patients she laughed and replied, "Yes. Risk!" But what exactly is meant by RISK?

One of the first assessments of RISK was done by Fillmore and Atkins in 1992, using a Frame analysis⁴ of 1770 dictionary entries for risk. They concluded: "A close study of the sense differentiation of risk in ten major monolingual dictionaries shows that there is no commonly held view about the semantics of this word. In particular, there are several important sources of confusion, both with verb senses and with noun senses" (Fillmore & Atkins, 1992 p. 356). They ultimately defined RISK as the possibility of an unwelcome outcome such as 'harm' (*Ibid* p. 79). However RISK did also have a positive outcome. The positive outcome from a decision they defined as *chance*. Thus they asserted that the RISK frame is characterized with two sub-frames, CHANCE (which has a positive connotation) and HARM (which has a negative connotation.)

More recently, and with the aid of Corpus Linguistics, Hamilton *et al* (2007) looked at the meaning of RISK using Collins Wordbanks*Online*, a corpus of British and American usage of the word. They argued: "scholars often talk about the meaning of 'risk' without sufficient empirical linguistic evidence for what that 'meaning' is. As linguists, we find this situation unfortunate" (*Ibid* p. 165). By looking at the empirical evidence contained in the corpus they looked at the different contexts in which risk was used. They were able to demonstrate how often RISK occurs in medical encounters and how, in this context, it is almost always used in a negative sense. Thus if we compare it to the frames defined by Fillmore and Atkins (1994), in medical settings RISK carries a negative outcome associated with the meaning of harm.

⁴ Frames were first defined by Goffman based on the assumption that "definitions of a situation are built up in accordance with principals of organization which govern events [...] and our subjective involvement in them; frame is the word I use to refer to such of these basic elements as I am able to identify" (Goffmann, 1974). Based loosely on his work, frame analysis can look at any basic cognitive structure (such as a noun, a preposition, or a phrase) and use this to find "the minimum amount of background that would allow consensual interpretations of discourse" (Scheff, 2005).

Hamilton *et al* (2007) went on to look at collocates (i.e. words that most frequently occur in the immediate co-textual vicinity of the word in question,) and at least seven of the 40 most frequently occurring collocates of RISK are related to the context of human health or illness.

In my research I looked at the use of the lexeme RISK and its synonyms. I not only considered the English synonyms but also looked at synonyms in other languages used in the consultations. Since there were only two short spurts of isiXhosa between a patient and his wife, the synonyms analysed are from English and Afrikaans. Using content analysis I was able to look at whether the word RISK (or its synonym) referred to a positive outcome, negative outcome or was neutral. On this basis, I was able to draw up a rating scale to allow for graphical presentation of the data as well as the descriptive analysis. Multiple examples will be given later to make the application of this scale clear. The scale of positivity/negativity I devised is shown in Table 4. Application of this scale to the content analysis will be illustrated through selected examples. For a full analysis of results see Appendices 10 and 11.

GRADING	MEANING
-3	DIRECT, QUANTIFIED LINK TO HARM
-2	DIRECT, NON QUANTIFIED LINK TO HARM
-1	VAGUE LINK TO SOMETHING HARMFUL
0	NO POSITIVE OR NEGATIVE CONNOTATION
1	VAGUE LINK TO SOMETHING POSITIVE
2	DIRECT, NON QUANTIFIED LINK TO SOMETHING POSITIVE
3	DIRECT, QUANTIFIED LINK TO SOMETHING POSITIVE

Table 4: Positivity scale for meaning of lexemes pertaining to risk

3.1.1 Risk and its synonyms

There are many elements that comprise communication including the lexeme, the utterance, the tone, the context (to name but a few). At its most basic level, the smallest unit which can be analysed for the communication of risk is the lexical item and this was the focus of my analysis. To identify the lexical items pertaining to RISK I first performed a thematic analysis on the consultations. (See Chapter 1, Table 1). The major themes where risk was important were (listed alphabetically):

1. Age-related Risk of DS
2. Dangers for the mother / baby
3. Demonstration of age-related risk
4. Risk of HIV
5. Risk of Infection
6. Risk of Knowing
7. Risk of Miscarriage after amniocentesis

I then went through the themes identified and performed a content analysis identifying sections of the consultation specifically discussing risk. From these segments I was able to identify the individual words used to talk about risk. Once the lexical items had been identified I was able to do a word search of all the consultations to identify lexical frequency and analyse how the different words were used. Thus my results identified:

- a. The different lexemes pertaining to risk
- b. The frequency of use of these lexemes
- c. The way in which these lexemes were used (descriptively and by applying the grading mentioned previously)

As mentioned in the methodology, numbers of tokens from patients were too small to allow for any statistical tests that could be meaningfully interpreted. Tabulated results are attached in Appendix 12. The focus of the chapter is therefore not on statistical analyses but on the variety of lexemes used and the variety in connotation of meaning associated with each lexeme.

3.1.2 Identification of the different lexemes pertaining to risk

The main English lexemes pertaining to risk were RISK, CHANCE, POSSIBILITY and DANGER. In the Afrikaans consultations, there was some code-switching present so several of the lexemes occurred in their English forms. However, in addition there were also the Afrikaans lexemes RISIKO, KANS and MOONTLIKHEID. The Afrikaans equivalent of DANGER (such as GEVAAR) did not occur in this sample. The results are illustrated graphically in Figures 8 and 9 below.

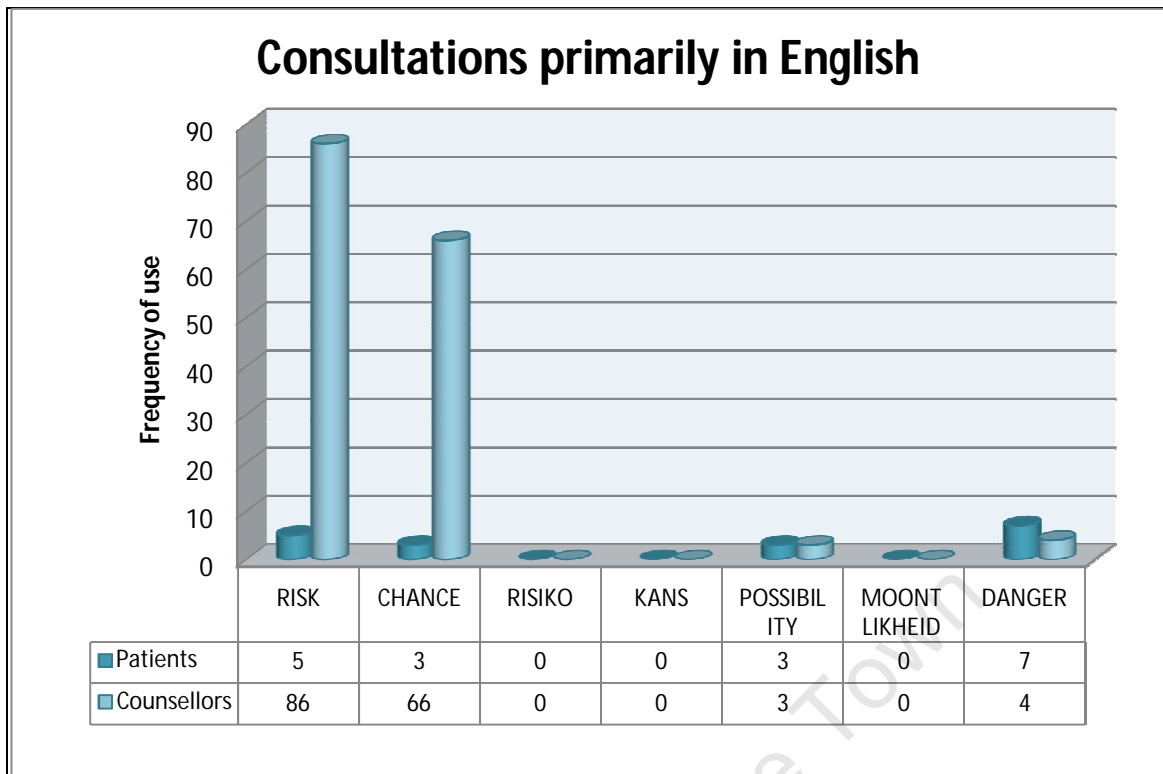


Figure 8: Distribution of the lexemes relating to risk as used in the consultations conducted in English.

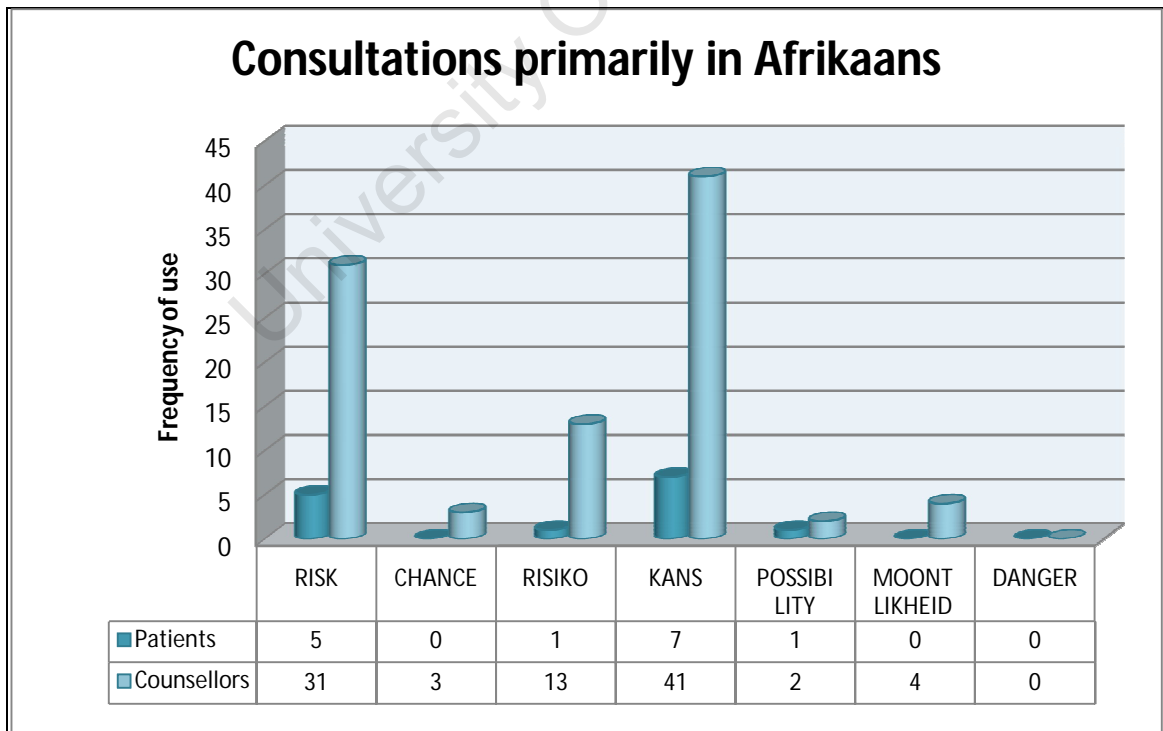


Figure 9: Distribution of the lexemes relating to risk as used in the consultations conducted in Afrikaans.

The frequency of use of these lexemes

As is apparent from the graph below, the use of lexical items referring to risk was predominantly initiated by the counsellors. The only word where there was a reversal of this pattern was with the lexeme DANGER. (This issue, under the theme of Danger will be addressed later in this chapter).

It is interesting to note that despite the importance of the lexemes used to talk about risk, and despite the potential diversity of interpretation of the lexeme, not even in one consultation were any of the lexemes defined by the counsellor. In one consultation (Gail with VD – quoted above), Gail does check that NB understands what she is talking about, but she doesn't go on to further either to offer an informal definition or request one from the patient to check understanding.

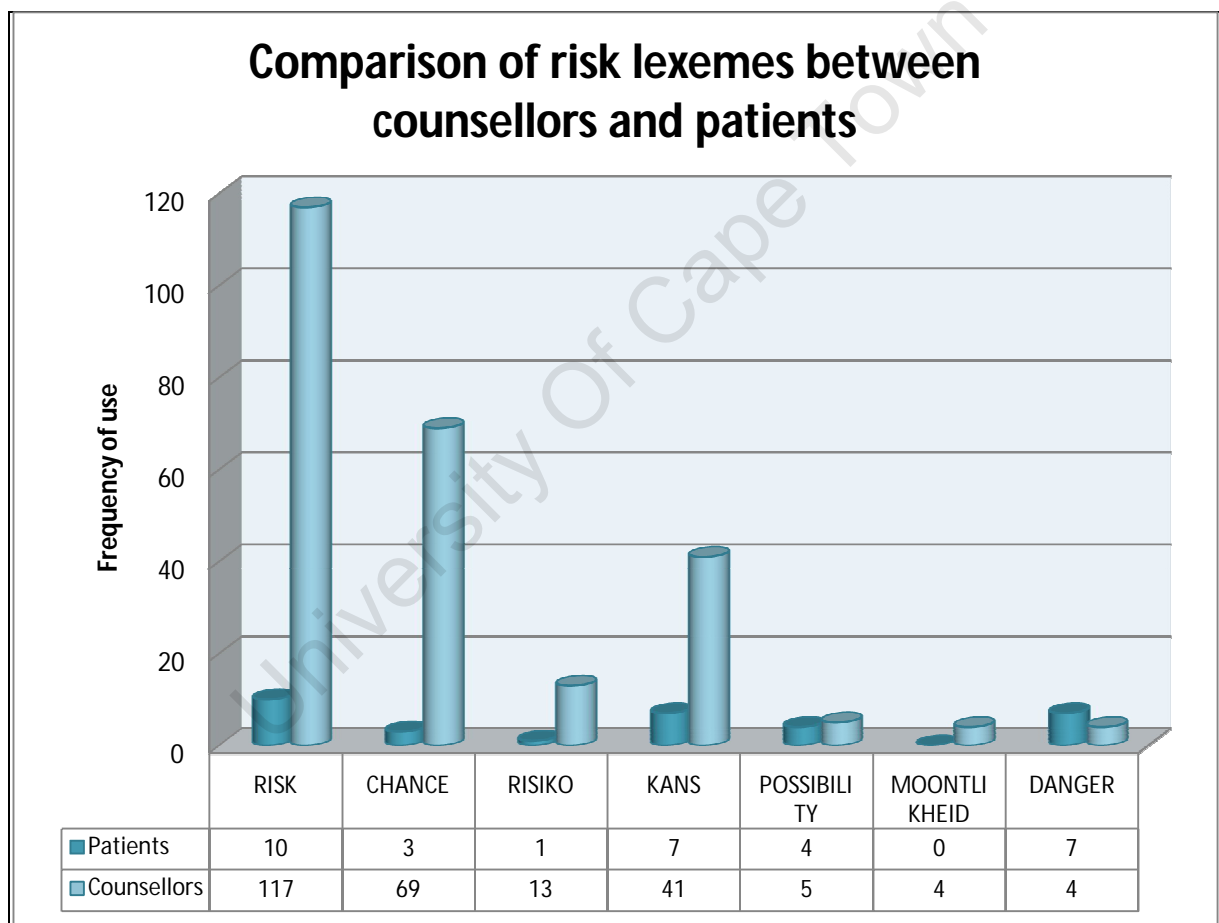


Figure 10: Comparison of risk lexeme use between counsellors and patients

3.1.3 The way in which different lexemes were used

The next question to be addressed was what was the pattern of lexeme use and was there any evidence for different nuances in meaning or does RISK equate exactly to RISIKO and CHANCE to KANS? The first point to make is that both RISK and CHANCE can be used as either verbs or nouns or, with minor adjustment, as adjectives. However in every instance of use in the consultations, both words occurred only as nouns. Typical examples include:

- | | |
|-------------|---|
| (1) Rachel: | when you're 20 the <u>risk</u> is one out of fifteen hundred |
| (2) Liz: | julle dit hoor dat daar is 'n <u>risiko</u> vir die kinners
'You hear this that there is a <u>risk</u> for the children' |
| (3) Gail: | So there's still a much bigger <u>chance</u> that the baby will be fine |

The lexeme DANGER was the only one which was used as an adjective as in the following:

- | | |
|------------|--|
| (4) Mr NN: | But , eh, the problem is we, you, we care about dangerous, you know. |
|------------|--|

As outlined at the beginning of the chapter, according to both Frame analysis and corpus linguistics analysis, RISK usually carries negative connotations whereas CHANCE carries positive connotations. The following statement exemplifies this distinction and in this instance RISK is directly and quantifiably linked to something negative (the risk of DS) whereas CHANCE is directly and quantifiably linked to a positive outcome (a normal baby). Thus RISK scored -3 in this instance and CHANCE scored 3.

- | | |
|-----------|--|
| (5) Gail: | there is a 3 percent <u>risk</u> but that means there's a 97 percent <u>chance</u> that the baby's going to be fine. |
|-----------|--|

But does this distinction between RISK being negative and CHANCE being positive always hold? In my research of all the lexemes, RISK was the most frequently used with a total of 127 tokens (10 by patients and 117 by counsellors.) RISK was used in the English consultations and was also often used as a code-switched term in the Afrikaans consultations (31 tokens from the counsellors and five from the patients.) RISIKO was only used once by a patient and 13 times by a counsellor (with 12 of those tokens coming from one counsellor.)

Considering the lexemes RISK and *RISIKO* I found that they were always associated with a hazard or the potential of a hazard when used by the counsellors. The hazard was sometimes direct and either not quantified or else quantifiable either numerically or descriptively (as illustrated above) or there was just a vague reference to something negative. Typical examples include the following:

- | | | |
|-------------------|--|------|
| (6) Liz to group: | ons praat oor die <u>risiko</u> op julle ouderdom en die toets | |
| | 'We talk about the risk relating to your age and the test' | (-2) |
| (7) Rachel to MF: | Okay daar is die <u>risk</u> vir iemand van 37 | |
| | 'Okay there is a risk for anyone of 37' | (-2) |
| (8) Gail to VD: | from 20 – 45 the <u>risk</u> of Down Syndrome is never zero | (-3) |

On the few occasions when patients used the lexeme RISK or *RISIKO*, there were three occasions when it was used similarly to that described above as in the following examples:

(9) ED:	<i>I'm not comfortable with the, the <u>risk</u> at my age, the idea</i>	(-2)

(10) NM:	<i>If you take the test, there's a <u>risk</u> of miscarriage</i>	(-2)

On five occasions, the lexemes were used in association with a hazard, but it was a poorly defined, vague concept of something hazardous rather than a quantified, measurable probability. Again this is unsurprising as the patients, at least at the beginning of the consultation, are unaware of the direct and quantifiable risks associated with their age and with amniocentesis. Examples include:

(11) Mr ED:	<i>But but tell me one thing say for example there is a <u>risk</u></i>	(-1)

(12) ZR:	<i>I know I'm turning 40 and there is a <u>risk</u> I'm taking.</i>	(-1)

(13) VD:	<i>due to my age I'm 44 and that's going to be a <u>risk</u> just now</i>	(-1)

GK used the lexeme RISK also with a poorly defined idea of something hazardous, in the sense of taking a chance. However, she was not referring to the risks associated with the test, but the complete opposite. She was referring to taking a chance of not finding out whether her baby had DS. The use of the lexeme RISK in this vague way may just have reflected her state of mind as she was completely undecided about what decision to make concerning the house (as described in the next chapter.)

(14) GK:	<i>Ek gan ma'n kans vat ek gan ma die <u>risk</u> vat. Ek salit ma los.</i>	(-1)
<i>I'm going to take a chance, I'll take a risk. I'll leave it.'</i>		

A graphical representation compares the use of RISK and *RISIKO* according to the grading scale. (Refer to Table 4 for devised scale of positivity and negativity.)

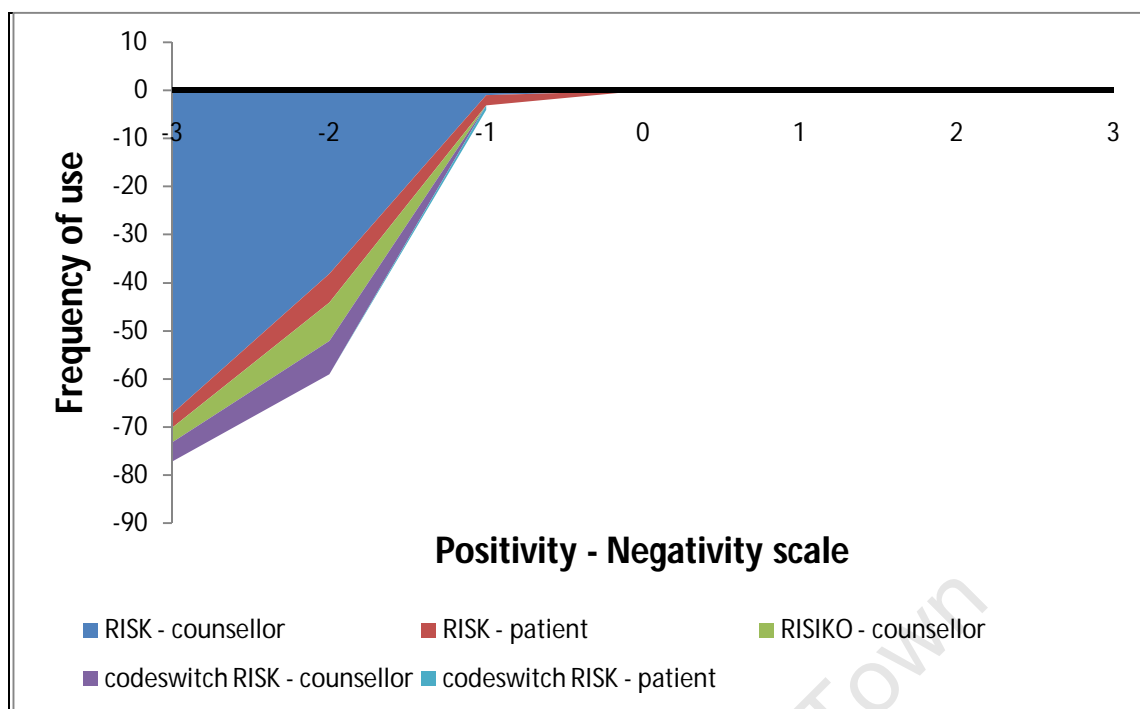


Figure 11: Positivity-negativity values for the use of RISK and RISIKO

This graph illustrates that, in keeping with corpus linguistic analysis performed by Atkinson *et al* (2007) RISK in this medical setting used with a negative outcome equating to harm. *RISIKO* is used similarly by the counsellors. For patients and counsellors alike, RISK and *RISIKO* never crossed the zero line to be associated with anything positive. For the patients there is a slight difference in use from the counsellors and that is although RISK does have a largely negative connotation, for a larger proportion of the tokens the notion of hazard is a -1 (i.e. vague and not quantified). This use is unsurprising considering that the counsellors know the direct links to the hazard (such as age linked to DS) and their mandate is to explain the potentially negative outcomes to patients whereas patients do not. Another point of interest is that where counsellors codeswitched to use RISK in Afrikaans consultations, the lexeme still carried the same overall negative connotation as RISK in English consultations and *RISIKO* in Afrikaans ones.

Turning now to the alternative frame of CHANCE suggested by Fillmore and Atkins (1992), I found 48 tokens of *KANS* (7 used by patients and 41 by counsellors) and 72 of CHANCE (3 by patients and 69 by the counsellors). Out of these there was a positive connotation in only six instances. Such as:

- (15) Liz: *daar is 'n kans en as die chromosome normaal is ons kan vi julle sê die babatjie sal nie Dowsindroom hê nie* (+3)
 'There is the chance that if the chromosomes are normal, we can tell you that the baby won't have Down Syndrome'
- (16) Gail: *So there's still a much bigger chance that the baby will be fine* (+3)

The majority of time (90 out of a total of 120) however, *KANS* and *CHANCE* carried the same meaning as *RISK*. In fact, there were instances where they were successfully juxtaposed as exact synonyms as in the following:

(17) GK:	<i>Ek gan ma 'n kans vat ek gan ma die risk vat. 'I'll take a chance, I'll take a risk.'</i>	(-1, -1)

(18) Gail:	<i>So you can see that the risk is quite low the chance is quite low</i>	(-3, -3)

CHANCE and *KANS* often were also used in a less explicitly synonymous way where they were still linked to a hazard. Typical examples were:

(19) Liz:	<i>en ons kan vi jou sê wat die <u>chance</u> is op jou ouderdom om so 'n babatjie te kry</i> (-2) 'And we can tell you what the <u>chance</u> is at your age to have a baby like this'	

(20) Gail:	<i>there is an increased <u>chance</u></i>	(-2)

Another use of both *CHANCE* and *KANS* was with the nuanced meaning of 'possibility'. Here there was a hint that there was something negative when the question was posed to the patients by the counsellor (see below). However the link was not made explicit or quantified (i.e. it was graded as -1). This occurred in seven consultations, always used by the counsellor, as in:

(21) Rachel:	<i>En enige <u>kans</u> dat jy en hy miskien bloedfamilie is</i> (-1) 'And any <u>chance</u> that maybe you and he are related'	

(22) Liz:	<i>Any <u>chance</u> that you and your boyfriend are from the same family?</i>	(-1)

There were also occasions when *CHANCE* and *KANS* were used in ways that were neither negative nor positive. The instance of *CHANCE* having no positive or negative meaning was when the counsellor started to check the patients understanding in the following:

(23) Gail:	<i>Do you understand when I say <u>CHANCE</u>:</i>	(0)
NB:	<i>(Nods)</i>	

Returning to uses of the lexeme *KANS* and *CHANCE* there was some distinction between the use of Afrikaans *KANS* versus the English *CHANCE*. In Afrikaans, *Ek sien nie kans* means 'I don't see fit' and it was used by MF twice, but not by anybody else. The following utterance is from MF concerning her feelings about abortion:

(24) MF:	<i>ek sien nie <u>kansie</u> ek wil nie gaan nie.</i> (0) <i>'but I don't see it fit I don't want to.'</i>	
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KANS was also used to mean opportunity in one instance, where Rachel asks if MF would like to phone her partner:

(25) Rachel: *sal ons jou kans gee om te gaan bel?* (0)
 'Shall we give you a chance to go and phone him?'

The positivity/negativity values of CHANCE and KANS are depicted graphically in Figure 12 below.

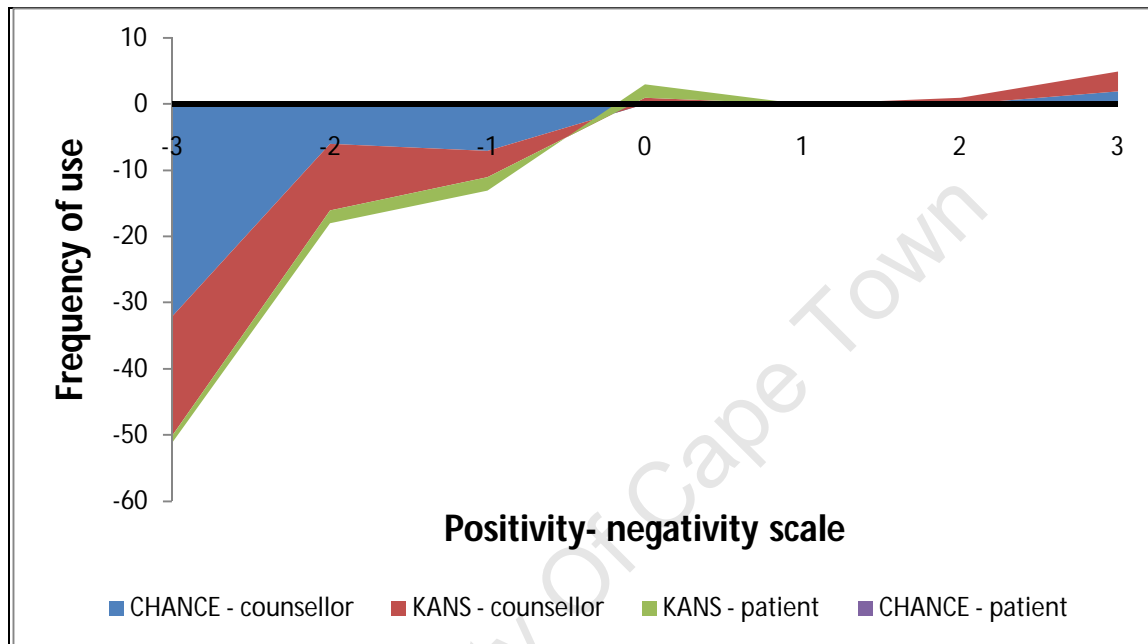


Figure 12: Positivity scale for the use of CHANCE and KANS

Although the majority of usage is negative, in contrast to the graph of RISK and *RISIKO*, this graph shows that CHANCE and KANS do occasionally have a positive value. However the counsellors are tending to use CHANCE and KANS similarly and often synonymously with RISK. The overall tokens used by patients are small, but it does suggest that, in contrast with the counsellors, KANS does not carry the exact same meaning as CHANCE (which barely makes any appearance at all in the patients' speech).

The other lexemes (like POSSIBILITY and *MOONTLIKHEID*) occurred too infrequently to depict any trends graphically. The distribution of POSSIBILITY showed an almost even distribution between the patients and the counsellors (five tokens versus four respectively) whereas *MOONTLIKHEID* was only ever used by the counsellors (three times by Rachel and once by Liz). The lexeme POSSIBILITY was largely used in the context of some far distant, or vague (*something else*) and usually non-quantified sense when the counsellors used it. This use of POSSIBILITY by the counsellors is thus comparable to the patient's use of RISK (as illustrated above, scoring a -1.) However, when the patients used POSSIBILITY, it was usually with the counsellors' meaning of RISK, and was linked to a specifically mentioned hazard such as DS.

(26) Rachel:	<i>but there is a possibility that something else could be found</i>	(-1)
(27) ZR:	<i>There's a possibility not a possibility but it's – at this age you get Down's Syndrome.</i>	(-2)
(28) Mr ED:	<i>So say for example if there's a possibility for for Down's [unclear] what's the the the alternative</i>	(-2)

I would now like to consider the lexeme DANGER. As shown in the earlier part of this chapter, the lexeme DANGER was the only one relating to risk that was used more by the patients than the counsellors and the use of it is worth exploring in some detail.

Firstly, this lexeme was actually first introduced by the counsellor and not by the patient. It was apparent that the patient had limited proficiency in English and, although the counsellor speaks Standard South African English, as the example below illustrates, she changed the style of her English to match that of the patient's, and the lexical substitution of danger for risk appears to be part of this convergence. As illustrated:

(29) Rachel:	<i>But, for this test, there is a small danger for a miscarriage</i>	(-3)
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The patient then calls in her husband, who is more proficient in English than her, to join the consultation. When the counsellor, Rachel, explains the risk to him, she reverts to her normal standard English style with lexemes like CHANCE and RISK and she does not use DANGER. However, at the end of the amniocentesis explanation he asks the question:

(30) Mr NN:	<i>Ok. So, so the test is not dangerous.</i>	(-1)
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Again, when asked to make a decision Mr NN reiterates his concern twice:

(31) Mr NN:	<i>We care about danger for the child also</i>	(-1)
(32) Mr NN:	<i>Oh it's not dangerous that water maybe going to cause something dangerous for the child.</i>	

He summarises his concerns to the counsellor in English, but then turns to his wife to explain in isiXhosa what the risks of the test are:

(33) Mr NN:	<i>but the problem is that we are fear about the injection and maybe it's going to make another danger there</i>	(-1)
--------------------	---	-------------

These exchanges illustrate some interesting points. Firstly they confirm that people with many languages at their disposal have many resources from which to choose. (For example, the counsellors can choose from CHANCE, KANS, RISK, RISIKO, POSSIBILITY, MOONTLIKHEID and DANGER when talking to patients who understand English and Afrikaans.) However, with this patient and her husband whose first language was isiXhosa and whose proficiency in English was extremely limited, the range of options available was

limited and the counsellors tend to choose more extreme lexemes (like DANGER). It is certainly possible that the introduction of this word was partly responsible for the patients' belief that the test must, therefore, be dangerous. But the limited resources available to the patient and the counsellor to find ways to explain RISK in less extreme terms contributed to the fact that their concerns about the "dangerous" test were not fully understood or addressed.

To summarise the results presented above, there is a variety not only in the lexemes used to talk about risk, but also in the way those lexemes are used. On the whole, the use of the lexemes relating to RISK was largely introduced by the counsellors, with the lexeme RISK dominating for both the counsellors and the patients. In this medical setting RISK was comparable with the corpus linguistics analysis, carrying a notion of hazard – which tended to be well-defined and quantified when used by the counsellors, but remained vague and poorly-defined when used by the patients. Thus the use of the lexeme by patients and counsellors tended towards being *discordant*, to use Levin's term (Levin, 2005) in terms of the nuances of meaning. However the tokens used by the patients are too small (ten in total) to make the comparisons statistically significant. When patients used RISK it was comparable to the way the counsellors used the lexeme POSSIBILITY. CHANCE and KANS were often used synonymously with RISK and seldom, therefore, carried a positive connotation. However, they did have a wider application meaning 'possibility', 'opportunity' and, in the Afrikaans KANS, meaning 'see fit'.

As mentioned in the introduction, there has been a move from viewing risk communication as a unidirectional transfer of information from health care practitioner to client to considering it as a two-way exchange of information. Researchers have begun to focus on the dialogic nature of the consultations and to view the meaning of risk as co-constructed (Collins & Street Jr., 2009; Sarangi and others, 2003). However a barrier to this co-construction is differences in meaning and interpretation of the lexemes used to communicate risk, especially in a multilingual setting such as South Africa.

CHAPTER 4

4.1 Interpreting risk

Collins and Street (2009) differentiate between analytic reasoning and experiential reasoning. Analytic reasoning tends to be used by clinicians, who use expressions of risk which are based on epidemiological and clinical assessments. They then communicate the risk through one or more of three formats: numeric, visual and verbal. In contrast to this, patients typically rely more on experiential reasoning and respond better to information presented in a narrative format rather than a dry prose format. Experiential reasoning is defined by Collins and Street as “a multidimensional process that explains how perceptions of risk are constructed from patient’s personal life experiences and their emotions” (*Ibid.* p. 1507).

This ties in well with Linell *et al* (2002) who point out that a health practitioner’s understanding of risk is “a mathematically expressed probability that is defined and rendered meaningful only at the aggregational level of a population” (p. 196). In contrast to this, a patient’s understanding of risk is much more experiential. They define it as follows: “for the individual human being, on the other hand risk means anxiety about the future, fear, or danger, that is, something emotionally highly charged that is threatening on a personal level” (*Ibid* p. 197, emphasis in the original). Because of this difference between the experiential (affective) and analytical (referential) approach to risk, the ultimate conclusion of the Systematic review on risk communication produced by Edwards *et al* (2008), unsurprisingly, was “the supportive or emotional elements of counselling provided more benefits to users than the informational or educational elements” (p. 4).

The difference between this analytic, population level of risk and the experiential, affective view of risk was captured in the exchange between Rachel and ZR. Rachel gives ZR a numerical value of risk, based on scientific population studies but ZR’s reply shows that the experiential aspect of risk for her as an individual has not been addressed. Rachel’s response does not address ZR’s concern, but reiterates the scientific view of risk:

(1) Rachel:	<i>I could say 99 out of a hundred , 99% it’s a perfectly safe procedure. Is that a surprise for you?</i>
ZR:	<i>Yes. (laughs) So you doesn’t know what your chances is?</i>
Rachel:	<i>Well, we say your chances are one out of a hundred. OK?</i>

In this study, I found that the counsellors did tend to use a varying combination of numeric, visual and verbal formats. When considering numeric formats, all the counsellors were aware that numeracy was a problem with many of the patients that they see as can be seen from the following excerpts from the counsellor interviews:

- (2) Rachel: I know very well that the term 'percentage' to very many people is meaningless. Umm. That they wouldn't be able to translate it into something if you told them that they're getting a 10% increase in salary they wouldn't be able to tell you what that means. Umm. So I sometimes feel I'm handing out numbers because that's sort of my brief to do it but it might be better if I said you've got a small, medium or high risk.
- (3) Liz: Sometimes they don't quite get the risk. They can't sort of internalise that risk. So I try different ways of explaining what that risk means. You know. If I'm sort of reading their sort of body language or facial expression then I'll try other ways of getting that risk across. If there's a 30% chance of rain as opposed to a 1% chance of rain will you still take your raincoat with you or your umbrella with you.
- (4) Gail: I think it's more important to give them an idea of perspective. A chance that it could happen, but it's not going to happen to most women. You realise it's so important the way you put the risk. You can say that there's a 1 in 100 chance of having a miscarriage or that the test isn't 100% safe it's 99% safe. They have the same facts but a different weighting. So I try to put it both ways.

The literature confirms that understanding of numerical expressions of risk is problematic, not only for the patients but sometimes even for medical professionals (cf Gigerenzer & Edwards, 2003; Keller & Siegrisk, 2009).

All three of the counsellors used some form of visual aids. This is in line with best practice as many studies have demonstrated that decision aids are generally valued by the patients and lead to better understanding and risk perception accuracy (Edwards and others, 2008, O'Connor and others, 2007, Sackett & Torrance, 1978) and, as Dale Carnegie said: "Images are like cannonballs, penetrate deeply into the mind of the reader and stay there." Each of the counsellors compiled her own folder of aids – which were thus slightly different from each other. Rachel and Liz used a table stating a woman's age and then her risk of having a baby with DS. Rachel used a ruler to make sure the patients saw the correct risk with the correct age as in the following extract and, using a ruler to indicate age on the table (see Appendix 6) she explained increasing risk as follows:

- (5) Rachel: So, if we look at this chart, it gives the risk, for Down's Syndrome if we go by the mother's age. When the mother is 20 years old, the risk is one in one thousand five hundred. Ok? When she's 30 years old, it's one in about two hundred. And when she's 40 years it's one in about a hundred and ten.**

Gail had a similar table but she preferred to use a graph showing the increasing risk in age and expressing the risk both numerically and as a percentage (See Appendix 5). The Systematic Review on risk communication by Edwards *et al* (2008) concluded that “people’s preferences for different formats varies, usually with bar charts found to be most preferred. However, preferences for receiving information in a particular format have not been found to be linked to improved understanding and flexibility is required to be able to offer different formats for different people” (p. 21). Gail demonstrated age-related risk to VD as follows:

(6) Gail: *I’m going to talk about what causes Down’s Syndrome in a second I’ll get back to that but let’s just first have a look at what is the chance according to your age. (Gets folder open to graph). So if you look here you’ll see that, even when you’re 20 the chance isn’t zero. That line in zero and the dot is slightly above that line. So even if you’re 20 any mom can have a baby with Down’s Syndrome.*

VD: *Mmm.*

Gail: *But the chance of having it does increase with age. OK. So you can see that the risk is quite low the chance is quite low*

VD: *Mmm*

Gail: *and then in your 30s and in your 40s it goes a bit higher.*

VD: *[It goes bigger]*

Gail: *OK. So, if we then look at your age you’re 44 years old. The chance of having a baby with Down’s syndrome is one in 35. OK. . . So I want you to remember that the risk at your age*

VD: *[Mmm]*

Gail: *is one in 35. Some people feel that they understand better when they think about percentages? OK? So one in 35 is almost (pointing at chart) 3 percent*

VD: *[3 percent]*

Gail: *Ok. So 3 percent chance which means there’s a 97 percent chance that the baby is not going to have Down’s Syndrome. OK.*

The numerical format and the reference to graphs and charts often present the facts as definite (i.e. categorical). In fact, although these aids do support highly modalised discourse, it is ironic that the information and analysis in graphs and charts is often debatable and different institutions use different risk figures. In fact, Gail pointed out to me that the Ultrasound machines used in their Unit had been programmed with a different set of data linking age to risk and thus often gave a slightly different risk from the figure that the counsellors quoted to the patients! Such is the uncertainty of science`.

To return to the issue at hand, the numerical format was often presented as utilitarian dry prose as illustrated above. Best practice suggests that patients respond better to narrative prose (Collins & Street Jr., 2009) and need the numerical risk to be “recontextualised” (Adelsward & Sachs, 1998). From my

observations, the genetic counsellors at GSH are performing in keeping with best practice as they always take the numerical risk and try to recontextualise it for the patients. As before, I am just going to choose typical examples to show how risk is recontextualised.

(7) Gail: *So, it is important to know that this test is not one hundred percent safe.*

VD: *Mmmm.*

Gail: *It's 99 percent safe. OK. So one woman out of a hundred, 1 percent – excuse me (coughs) might have a miscarriage because of this test. OK. So, say in a year we do a hundred tests, 99 women won't have any complications but one woman might have a miscarriage because of having the test. Whether that baby had Down's Syndrome or not.*

(8) Rachel: *Alright. And just to give you an example if I was speaking to 20-year olds today, and I went out in the Cape Peninsula and I looked for pregnant 20-year olds and I found one thousand five hundred. So I've got a thousand people on this chart. (SHOWS DIAGRAM OF 1000 PEOPLE*) That's one thousand. So they're all young – 20 years old, all pregnant, and I find one thousand and get another five hundred. I put them all in the Good Hope Centre? And I'm speaking to these 20-year olds and I say young ladies, there's one thousand five hundred of you. One (HOLDS UP INDEX FINGER) will have a baby with Down's Syndrome. Fourteen ninety-nine will be fine. OK? Then what is the risk as you get higher and you said you're 39 now? Is that right? When's your birthday?*

Patient: *[September]*

Rachel: *September. Ok. And you're going to be the big 40. (Laughs) So let's have a look um here what it says. This chart gives you the risk of Down's Syndrome going by the mother's age. So here it says if the mom's 20 years old her risk is one out of one thousand five hundred. OK. When you're 30 it's one out of nine hundred. When you're 39 it's one out of a hundred and fifty. So that means if I'm speaking to women of your age today, I don't need the Good Hope Centre any more, because I could put a hundred and fifty we could gather you all together in the waiting room, and in the passage and we could say Ladies you're 39 years old. There's a hundred and fifty of you. One of you will have a baby with Down's Syndrome. Good news is a hundred and forty-nine will be fine.*

(* To see this diagram refer to Appendix 9.)

Sarangi *et al* (2003) have pointed out that risk not only needs to be recontextualised but it also needs to be relativised. What they asserted was that “In a given counselling session, both types of risk – the strictly genetic risk of occurrence of disease, and the more contextual risk of knowing – become conflated, and in fact the risk of occurrence of disease is understood in the light of other, external risk factors” (p. 155). To address the risk of knowing, they assert that the notion of risk has to be relativised to the patient's context. However, the risk of knowing is one of the themes that may run countercurrent to the

counsellor who is trying to communicate the theme age-related risk and the risk of knowing (which is unquantifiable) is seen by the patient to be greater than the risk of the test (which is quantifiable). In my sample, I found that the risk of knowing occurred as a theme in two consultations: VD and ZR.

Consider the following excerpt from ZR's consultation with Rachel:

(9) Rachel: *we could say Ladies you're 39 years old? There's a hundred and fifty of you. One of you will have a baby with Down's Syndrome. Good news is a hundred and forty-nine will be fine. OK? So does that, sound like a high risk, a low risk or a?*

ZR: *Still the same. If I know now, I'm going to have a problem if I know later on*

Rachel: *[You'll deal] with it*

ZR: *I'll have to deal with it.*

Rachel: *Mmm.*

ZR: *But if I know now, I'm only 4 months I have 5 more months to go and*

Rachel: *MMM. Ok.*

Even when the risk was explained to her in numeric terms, and contextualised in a narrative form, ZR's response was that the figures didn't change her perception that the risk of knowing was too great to justify taking the test. VD felt similarly, as illustrated below:

(10) VD: *Um, to be honest, if something is wrong*

Gail: *Mmm*

VD: *then it's in the hands of of the Lord.*

Gail: *Mmm.*

VD: *There's nothing I can do. Because even if I have to go through all those tests and then probably it's a Down's Syndrome child or whatever's wrong.*

Gail: *Mmm*

VD: *There's nothing nobody can do*

Gail: *Mmm*

VD: *Until the baby's born or whatever. It will just give more um, stress on my mind that something is wrong, it will stress me out. That is what I will – it will stress me out.*

In both of these instances, the *Risk of knowing* was either not addressed or still remained the dominant fear for the patient and thus, in both the case of ZR and VD, they opted not to 'risk' an amniocentesis.

This brings me on to my next section, which is that of decision-making by the patient. To come to a decision, the patient has to weigh up the risk of her baby having DS with the stated and perceived risks of the amniocentesis, and literature on risk communication typically emphasises the relationship between risk and decision-making (Adelsward & Sachs, 1998; Bogardus, Holmboe & Jekel, 1999; Sarangi and others, 2003). The values of the patient, defined as “the unique preferences, concerns and expectations” of each patient are also part of this weighing up process and have also been studied (Sackett & Torrance, 1978). The values which are particularly pertinent to the decision-making are around weighing up the acceptability of having a child with a mental disability versus the acceptability of a TOP. Other authors (Linell and others, 2002) have stressed the importance of considering contextual factors relating to the decision. I am, therefore going to focus on contextual factors that have not been looked at other literature, but which are relevant to our South African context.

4.2 The process of making a decision

One could say that the ultimate aim of the counselling session is for the patient to reach an informed decision about whether or not she would like to undergo an amniocentesis. Yet the emphasis of the counselling session is not so much on the ultimate decision, but rather on the process of making the decision. Best practice emphasises the need for patient autonomy – i.e. the patient’s having the ultimate responsibility to decide on aspects concerning their own health (Declaration of Helsinki, 2008). Thus the thrust of genetic counselling is that “it seeks to help clients reach an informed decision but refrains from steering or directing them” (Browner, Preloran & Casado, 2003). However, the focus of this chapter is not to consider the content and interpretation of risk, but rather on other factors that either help or hinder the process of making a decision. The chapter also demonstrates the dynamic nature of this process, and how the decision swings backwards and forwards in response to many different factors from within the women (such as those cited above) and from without (still to be discussed.)

Much of the literature on risk communication does not reflect on how these other factors may influence the process of making a decision. This may well be because some of the factors found in this study are unique to South Africa, or, in more likelihood, to low or middle income countries, and the large body of research on risk communication thus far, comes from high income countries. For example, the 2008 Systematic Review of studies on risk communication by Edwards *et al* demonstrates how the studies looked at four main areas:

- **Outcome of session** (i.e. Test acceptance or refusal)
- **Knowledge gained on risk or test**
- **Emotional effect of counselling session** (for example anxiety, satisfaction)
- **Duration of consultation**

From my thematic analysis of the observed interviews, as well as on the interviews with the counsellors, I identified four major factors which could affect the process of making a decision. These four factors are identified below, and the themes identified during the consultation analysis are mentioned in brackets. (See Appendix for summary of Thematic Analysis).

- I. Misconceptions / lack of understanding about why the patients had been referred to the Genetic Counselling clinic (Theme: *Reason for the patient's attendance*)
- II. Who will make the decision (Theme: *Emphasises choice*)
- III. Need to involve others in the decision-making process (Theme: *Need to discuss*)
- IV. Need for time to consider the options before making a decision. (Themes: *Timing of amniocentesis, Timing of results and Need for time*)

4.2.1 Misconceptions / lack of understanding about why the patients had been referred to the Genetic Counselling clinic

Theme: Reason for the patient's attendance

The first point to note is that many of the women in this study arrive without any suspicion that they are going to be required to make a decision, let alone of the enormity of the decision at hand. The counsellors interviewed identified this as a significant problem. As Rachel put it, "The ideal would be for them to come in with their questions and with an idea of what's going to be raised in the session." Unfortunately, the reality is far from this ideal. In the thematic analysis it is not surprising, therefore, that Reason for attendance occurred in every interview.

In most of the interviews, the reason for attendance was elicited in the form of a question asked by the counsellor. Only in one interview was the reason stated, rather than elicited. In this interview (LN), Liz states the reason for attendance as part of her introduction.

(11) Liz: *OK, lovey, I'm Sister L, and we're just going to talk a little bit today. I'm going to ask you some questions about you and about your other children. Ok. And your brothers and sisters. And then we're going to talk generally about having babies at a little bit of an older age. Because I believe you're 40 now, is that right.*

LN: *Yes*

Liz: *OK. So there are just some things that we have to discuss about having babies when you're a little bit older. [Alright]*

LN: *[Yes]*

Out of the 12 patients in this study, ED, who was notable in being the only private patient, was also notable in being very well-informed about what the session entailed. As she put it in the post-consultation interview she "knew everything about it." ST, ZR and VD had some idea, mostly because they had had previous pregnancies when they were also deemed to be at risk. In fact, VD had been through the counselling before several years previously. ST and ZR both understood that there was some

association between age and DS, but were not aware that they were coming to discuss the possibility of a test for DS.

The other eight women attended the clinic without knowing exactly what they were there for. When asked, during the post-consultation interview, what her background knowledge was about the reason for coming to the clinic, SC replied “none”. Several of the other patients were under misconceptions like attending for medical problems or because they needed another scan. Liz summed up her experience in the following way: “A lot of them are very worried about why they’re there - they think there’s something wrong.” Rachel, with her 11 years of experience as a counsellor, has encountered these misconceptions so often that she explained: “I start by explaining they’re there because of their age, not because of a problem.”

Since we are looking at the issue of language, it is worth noting that out the eight women who were unsure of the reason for their attendance, each of the four isiXhosa-speaking patients did not have a correct idea of why she was attending the clinic. LN and NB thought the appointment was something to do with having an ultrasound whilst NM was concerned about her multiple medical problems, and kept wanting more information about these. When asked why she was attending the clinic NN replied with the answer, “Because I’m pregnant.” When her husband was called and came rushing in to join in the consultation, he seemed under the impression that there was a problem with the scan as can be seen in the following exchange.

(12) Mr N: *So there’s no problem , no problem with the scan*

Rachel: *[No problem.] We haven’t seen any*

Mr N: *You are are aware about *his er age.*

Rachel: *Yes*

Mr N: *As *he got the 40 years so you want to er see the baby does not have any er problems*

Rachel: *Ja*

Mr N: *Now I understand, Sister, I understand clearly now. I understand. So I was not clear.*

*(He refers to ‘she’. Such variation in expressing gender is a feature of Black South African English (Mesthrie & Bhatt, 2008). For a brief discussion on variation within South African English refer to Chapter 2.)

Even NB, who had recently spent some time as an inpatient in GSH did not have any idea of why she was being seen as is illustrated in the following:

(13) Gail: *So can you tell me what did you understand why did they ask you to come to this clinic today?*

NB: *Mmm I can't remember, I don't know.*

Gail: *You don't know*

NB: *OK*

Gail: *Okay and have you been in the ward? For diabetes?*

NB: *Yes*

Gail: *Okay, and how have you been, how's your health been?*

NB: *Pardon?*

Gail: *How have you been feeling?*

NB: *I'm OK now.*

Gail: *Okay, okay that's good. And so they didn't tell you why you had to come to the clinic today, did they say anything about your age?*

NB: *No.*

The fact that all four isiXhosa-speaking patients attended a clinic without knowing the correct reason for their referral is extremely worrying. Because of the size of the sample, it is not, of course, conclusive evidence, but it does suggest that those who lack fluency in English are being put at a disadvantage before they have even commenced their hospital visit. And this is in keeping with other literature which suggests that it is often the isiXhosa-speaking patients who are disadvantaged in the current Western Cape public health sector (cf Deumert & Mabandla, 2008, Schlemmer & Mash, 2006, Levin, 2006b, Crawford, 1991, Saohatse, 1998, Levin, 2006a).

4.2.2 Agency of decision-making

Theme: Emphasises choice

Returning to the theme at hand, we need to consider how the patients reach a decision. All the counsellors mentioned the importance of stressing to the patient that the ultimate decision is actually their choice. This is in keeping with best practice on the principle of patient autonomy, but has been called into question when the patients have limited education and/or when the counsellor and patient are from different linguistic backgrounds (Browner, Preloran & Casado, 2003).

Both Rachel and Gail described how this notion of informed consent in genetic counselling, although ethically ideal, may pose practical problems, especially if it is the first time the patient has experienced patient autonomy. From their descriptions it appears that the practice of autonomy, a key aspect of any health professional – patient interaction, is not being routinely practised. This is how they voiced their concerns.

- (14) Rachel: And then this whole autonomy of the patient - this might be the first time that they've ever, ever been asked as patients what do they think and what would they like to do and even after all of that it's so strange that they might say well, what shall I do?
- (15) Gail: One has to take into account that them being there and being offered the test does in some way have an underlying pressure . . . the test is there and it's offered and compared with other tests they have in their pregnancy – those aren't really optional.

In the interviews, the counsellors did try to make the point that the patients had the freedom to choose whether or not they wanted to have an amniocentesis. This theme did not emerge in every consultation, but only in six consultations. (The group consultation by Liz to ED, GK and MF; then the individual consultations between Gail and VD; Rachel and NN; and Rachel and ZR). Analysis shows that this point was not only emphasised by one counsellor, nor was it only emphasised to a particular group, such as only those who refused the test, or only those who opted for the amniocentesis. In the light of what Rachel and Gail said above, they are aware of the difficulty associated with practising autonomy yet they don't routinely mention it. This may be due to time pressure or, as the Liz explained to me, "There are so many patients that by the end of the morning you don't know what you've covered with which patient". Once again, because of length limitations I shall illustrate this with one typical example in the consultation between Gail and VD:

- (16) Gail: *It's important to understand from the beginning that that test it's your decision. If you want to have the test***
- VD: *[Is that the genetic] test?***
- Gail: *Yes. It's called an amnio test? And we're going to discuss that in detail – all the benefits that we can tell you , the risks involved with the test and then when I've given you all the information you can decide whether it's something you want or not.***
- VD: *Mmhmm.***
- Gail: *OK?***

In both of the group interviews I observed, the counsellors also stressed the point that the counsellors were not there to push the patients in any direction. I did not find any evidence of the patients expressing any desire for the counsellors to make the decision. However, in her individual session, MF did question whether it was compulsory for her to have the test.

(17)	MF:	<i>Issit 'n moet dat ek die test moet doen nou?</i>	Is it a <u>must</u> for me to take the test now?
	Rachel:	<i>Nee</i>	No
	MF:	<i>issie 'n moet ie</i>	It's not a must
	Rachel:	<i>Nee ons uhm ons vra vir jou wil jy die toets hê</i>	No we uhm we ask you if you want the test
	MF:	<i>Mmm</i>	Mmm

The emphasis on patient choice seems, therefore to be initiated mostly by the counsellors (as happened with five out of the six patients where the theme emerged.) What seems to be more of an issue for the patients is the need to discuss the issue with others – which I discuss in the next section of this chapter. Entwistle (2008) refers to this need to consult others as “intellectual outsourcing” and, to a degree, she is right. However, as I have already pointed out in the previous section, a significant part of risk perception is affective and experiential and it may be more true to say that the patients are looking for emotional support rather than purely outsourcing their intellect.

4.2.3 Intellectual outsourcing

Theme: Need to discuss

In the “western world” and in medical literature, patient autonomy is prized. Yet this medical understanding of autonomy has critics who argue that this understanding of autonomy assumes that the individual is a rational island and that collaboration with others might compromise rather than promote autonomy (McKenzie & Stoljar, 2000). As one author put it “(a)lthough autonomy relates to individuals, it is both developed and exercised in the context of social relationships. People who use “intellectual outsourcing” to help shape their opinions, and who do not process detailed data for themselves before they choose or act, do not necessarily fail to exercise autonomy” (Entwistle *et al*, 2008 p. 1591).

Within this sample, the need to discuss with others was a theme in seven out of the eleven individual consultations (NN, MF, GK, ZR, VD AND IA). Most of the time, the need to discuss was recognised and introduced by the counsellors rather than the patients, as in the consultation with IA, LN, GK, MF and VD and MF. The excerpt below is from the consultation between GK and Liz and is typical of this theme:

(18)	GK:	<i>Ek sal 'n bietjie dink eeste.</i>	<i>I'll first think a bit.</i>
	Liz:	<i>Okay. Wil jy 'n bietjie - wil jy met jou man gaan praat of</i>	<i>Okay. Do you want to a bit - do you want to go talk to your husband or</i>

GK:	<i>[unclear]</i>	<i>[unclear]</i>
Liz:	<i>En Vrydag jy kan nie inkom as ek as ek [unclear]dit kan volgende week doen.</i>	<i>And Friday you can't come in if I if I [unclear] can do it next week.</i>
GK:	<i>Okay okay</i>	<i>Okay okay</i>

The consultation with ZR was different in that she was the one to introduce the topic of *Need to discuss*. In the following excerpt, she indicates how even her interpretation of risk needs to incorporate some discussion with her husband.

(19) ZR:	<i>So you doesn't know what your chances is?</i>
Rachel:	<i>Well, we say your chances are one out of a hundred. OK?</i>
ZR:	<i>I'll discuss it with my husband.</i>
Rachel:	<i>You'd like to discuss it with your husband. Ok.</i>

Although the counsellors recognised the patient's difficulty in making a decision without someone to share the process with, they expressed some ambivalence about whether the patient's partners should be present in the consultation. In response to the question, "Do you think that the patient's partners should be present in the consultation?" Liz replied: "For them most of the time I would say yes. But, having said that, the decision comes from the mum. So it's not crucial he's there." Rachel expressed a similar ambivalence in her reply, "I generally prefer it if they are there but have come across some men who make the decision and answer for their partners and personally something inside me reacts to that."

In contrast to this, Swartz specifically states that "future fathers should be invited to attend" (Swartz, 1998 p. 163). To find out what the patients' attitudes were to whether they would like their partner to be present or not they were asked about it during the post-consultation interview. (See Appendix 2). The results are illustrated graphically in Figure 13 overleaf.

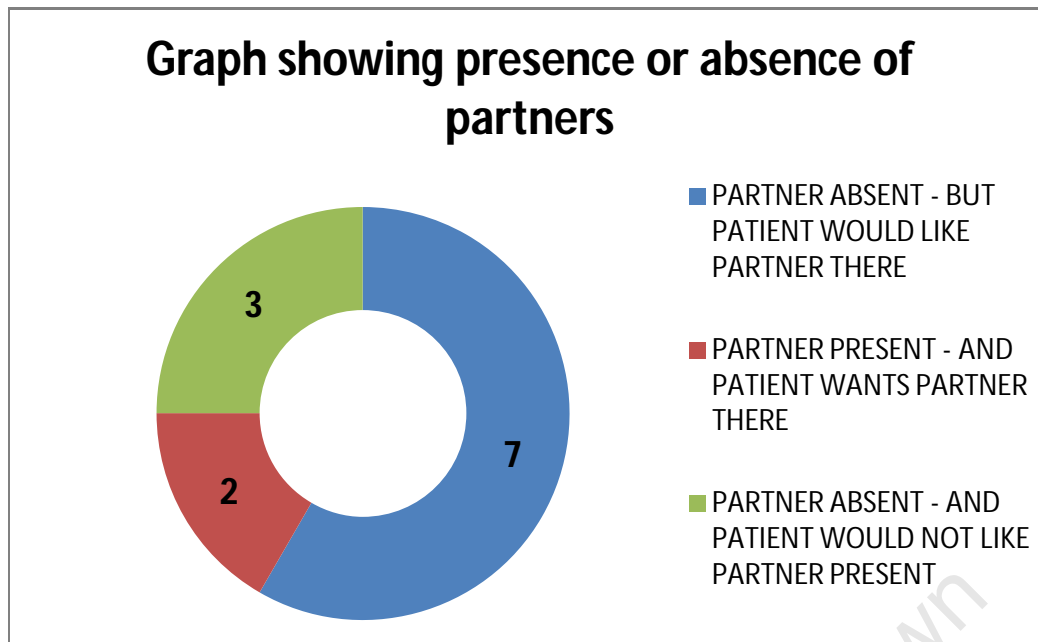


Figure 13: Presence or absence of partners in the interview and the patients' desire to have their partners present or not.

As is illustrated, only the minority of patients (two) actually attended with their partners. Of significance is that both of these husbands arrived part way through the interview. Mr ED knew that he was invited to attend, but Mr NN and his wife did not seem to be aware that he could come. He was only invited to come part way through the interview to help with both the practical task of translation and the more difficult task of making a decision (as will be illustrated later.) However, in the post-consultation interview NN placed great value on him being there both for the translating and for the decision-making. She specifically mentioned, as one of her key facts that whatever decision she made should also be approved by her husband. She then reiterated that she wanted them to make a joint decision when she was told about the possibility of a miscarriage. Her husband was obviously also important in the decision-making around a possible TOP as she replied that she would terminate the baby if it were diagnosed with DS – but she hedged it by saying “only if my husband doesn’t have a problem with that.”

Although only these two husbands were present, the majority of the patients would have liked their partners to have been there (nine out of twelve). Those whose feelings about their husbands were written down during the post-consultation interview showed some evidence of a patriarchal-type philosophy (for example, ST said she would have liked her partner there “because he’s my husband and the father of the baby.”) NB expressed a more affective need saying “because he’s the only close contact I have in Cape Town.”

The three patients who did not want their partners there (VD, ZR and LN) were all happy to relay the information back to their spouses, and, of these, ZR was not making a decision on the amniocentesis until she had spoken to her husband. This group of three patients is quite diverse. Both VD and ZR were similar in that they were English-speaking, they were in stable relationships and had four and five other

children respectively. LN, however, was isiXhosa-speaking, had no living children and was in a fairly new relationship. Other studies have reported that the absence of male partners during counselling was a strong predictor that the patient would refuse to have an amniocentesis (Browner *et al* 2003). In my sample, this observation only held true for five of the patients. The two ladies whose husbands were present did decide to opt for an amniocentesis. However, amongst the other ten whose husbands were not present, four went on to have the amniocentesis, one was undecided as she wanted time to discuss it with her husband, and the other five did not choose to have the test.

For most of them, the reason that partners weren't there was due to work. The fact that partners could also be given certificates off work by the clinic was not widely advertised. (I had to ask a counsellor to find out as none of the patients I spoke to knew the answer!) However, for those whose jobs are informal (like NM's husband who has a roadside store) even this would not have helped.

The issue of whether or not the spouse was present overlaps with the first theme, the *Reason for patients' attendance*. ED, who knew the reason for her clinic visit, also came prepared for the issue. In the excerpt below she mentions her doctor, Dr M. This doctor had previously done sessional work in the Department of Obstetrics and Gynaecology at GSH and thus would have been very well-informed about the Pregnancy Counselling Clinic's function. Thus, for ED, she had already thought about the issues and part of the decision-making process had already occurred. Her husband was present for most of the consultation – missing a section of the group interview only. ED and her husband had obviously discussed the issues at stake before attending the clinic, and had, in essence, already made a decision at home, as is illustrated by this exchange at the beginning of ED's individual session with herself, her husband and Liz.

(20) ED:	<i>Dr M. het mos vi os veduidelik oor die am- die amnio</i>	<i>Dr M. has explained to us about the am- the amnio</i>
Liz:	<i>Okay</i>	<i>Okay</i>
ED:	<i>soos wat suster nou vi os vertel het os verduidelik het.</i>	<i>like sister told us now explained to us</i>
Liz:	<i>Okay [unclear] oor die kansse Down sindroom</i>	<i>Okay [unclear] about the chances Down syndrome</i>
ED:	<i>Ja, ja</i>	<i>Yes, yes</i>
Liz:	<i>[unclear] Okay, kan jy daai uh nommer onthou wat die kans is wat [unclear]</i>	<i>[unclear] Okay, can you remember that number the chance is that [unclear]</i>
ED:	<i>Eerstens is is is one out of forty [unclear] een uit vyftig. Hoe ouer jy is uh hoe skraler word die kansse. As jy veertig is is it</i>	<i>Firstly is is is one out of forty [unclear] one out of fifty. The older you are uh</i>

een uit 'n honerd uit. As jy forty-three is is it een uit vyftig. Os het gebesluit os gannie ek willie [unclear]die amnio lat doen.

the slimmer the chances become. If you are forty it is one out of a hundred. If you are forty-three it is one out of fifty. We decided we can't I don't want to [unclear] do the amnio.

NN and her husband had not been prepared for the consultation (as shown previously). So even though he was present in the interview, they still felt the need to discuss the issue further before they felt able to complete the process of making a decision. For NN and her husband, the issues at stake were so complex that their plea was for more time. And this is the focus of the next section.

4.2.4 Need for time

Themes: *Timing of amniocentesis, Timing of results and Need for time*

Time impacts on the decision-making process in three ways which emerged under three themes. Firstly, the gestational age of the fetus with respect to the *Timing of the test*; secondly with reference to the *Timing of the results*; and thirdly with the option of *Time to decide*. All three of these are interwoven, and thus I have grouped them together.

The first theme, the *Timing of the test* is important because the amniocentesis should ideally be performed between weeks 16 – 20 of the pregnancy. This is because the results take three weeks to be processed, so, in order to comply with the law on abortion and GSH's Unit Policy (which allows abortion for medical reasons up until the 24th week of pregnancy) a gestational age of 20 weeks is the upper limit of gestation at which the test can be performed (Choice on Termination of Pregnancy Act no 38, 2004). The Pregnancy Counselling Clinic only offers a weekly service and thus the women who are already 20 weeks pregnant need to have the amniocentesis done that day, or they will be over the gestational limit by the following week. Those whose pregnancy is not as far along, may have a few weeks in which to consider the decision before they reach the 20 week deadline.

In considering this issue of timing of the initial consultation, one needs to consider the process before the woman arrives at the clinic. There are multiple stages in this process and the delay could have happened or could have been prevented at any number of steps. To mention just a few: there could be a delay in the patient making her first booking visit; there could be a delay in the peripheral clinic making the referral; or there could be a delay in the Genetics Clinic offering an appointment. One could even extrapolate further back and say that prior to conception (for example at Family Planning clinics) the issues associated with pregnancies in women with advanced maternal age could have been brought up to forewarn patients (Watcham, Schön & Christianson, 2007). One of the patients, NB, mentioned this fact in

her post-consultation interview. When asked about ideas for improving the service, she commented that people should be told about “these issues” when they go to the clinics for contraception.

However, from my period of observation and witnessing the ease with which follow-up appointments were arranged, the Genetics clinic does not have a long waiting list, and patients are almost invariably seen in the next clinic, when needed. So the problem of referral needs to be addressed at one of the earlier stages. One study done at Hanover Park (Urban & Mentoor, 2009) identified a significant problem with this stage of the chain. Before I look at some of the disturbing findings of this study, it is necessary to contextualise Hanover Park clinic.

It is a large clinic and, as far as referrals to GSH's clinic go, it is one of the top three as illustrated in figure 14 below, obtained from my initial analysis of the Genetics Database.

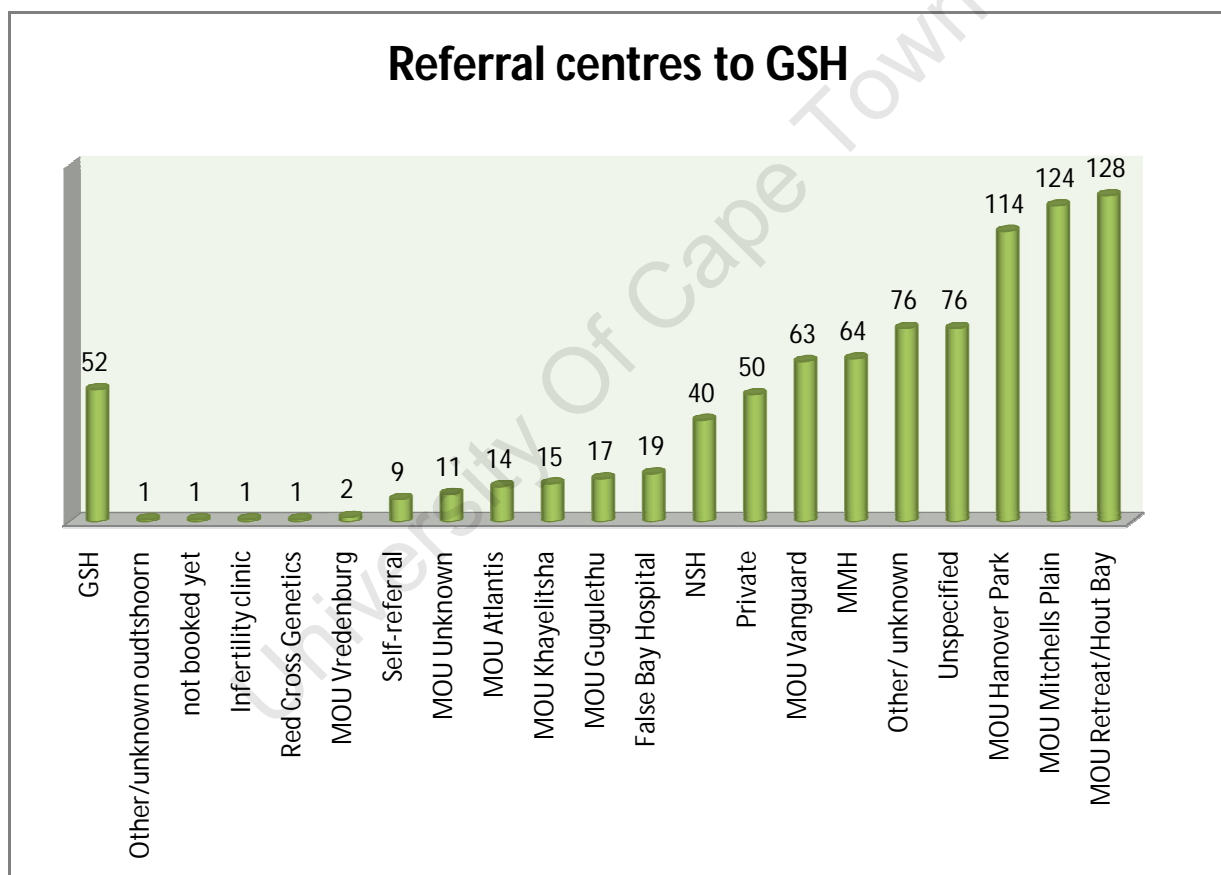


Figure 14: Numbers of patients referred to GSH from various centres (n = 443) during the period 01/12/07 to 01/07/09.

Despite being responsible for a significant proportion of referrals, the study by Urban and Mentoor (2009) demonstrated that the midwives at Hanover Park had several barriers to referring involving knowledge, beliefs and attitudes about the test. Thus it is not surprising, although it remains distressing, that only 16% of AMA mothers who delivered their babies at Hanover Park had ever been referred to GSH's Pregnancy Counselling Clinic.

In keeping with my observation, both Liz and Rachel raised the issue of late referrals as being a significant problem for them and a possible area for improvement in the future.

The significance of the *Timing of the test* was a common theme which emerged in eight out of the thirteen consultations. It did come up in both group sessions. Liz explained the significance of the timing of the test during the group interview (which included ED and GK) as follows:

(21) Liz:	<i>En as as jy nou twintig weke is en ek dink iemand is twintig weke</i>	And if you are twenty weeks and I think someone is twenty weeks
Patient:	<i>Ja</i>	Yes
Liz:	<i>Mevrou is twintig weke ons gee die ons maak die toets nie tot twintig weke want uhm die toets vat nou drie weke om terug te kom en dan as as daar 'n 'n decision gemaak word van om uh die baba te laat nou die swangerskap te laat stop ons kan nie verder as drie of vier-en-twintig weke gaan met die met die termination okay? Maar as julle tyd het as julle voor twintig weke is het jy tyd om te laat dink as jy nie vandag seker</i>	Ma'am is twenty weeks we give the we do the test not until twenty weeks because uhm the test takes three weeks to come back and then if a a decision is made to uh the baby to stop the pregnancy we can't go beyond three or twenty four weeks with the with the termination okay? But if you have time if you are before twenty weeks then you have time to think if you're not sure today
Patients:	<i>[unclear]</i>	[unclear]
Liz:	<i>is wat wat julle gaan maak. Miskien wil julle nou met julle man gesels.</i>	what you are going to do. Maybe you want to talk to your husband now.

The second theme relating to time concerned the *Timing of results*. This was explained to the patients in five of the consultations. Mostly this theme emerged in those consultations where the patient had opted to go for an amniocentesis. In the case of MF, the theme was surprising by its absence – as she did choose to have an amniocentesis. However, she and the counsellor had to negotiate the timing of her follow up scan around a pending court case involving MF, and she could only return to the clinic in three weeks. So the need for explaining the timing of the results was obviated.

The third issue relating to time was the one that seemed to be most significant for the patients and most distressing for the counsellors and patients alike. This theme is linked to theme one (the *Timing of the amniocentesis*) as many of the women did not have time to go home and think about the decision – the decision had to be made that day. So I have called this theme *Time to decide*. As Liz put it during the counsellor interview:

(22) Liz: (They) have never considered having a child with a disability, never considered terminating a pregnancy, and they're hearing it all for the first time and they're having now to think about this and hear that they're now at risk of this and **the cherry is when they don't have time to go home and discuss it with their spouses.**

The theme *Time to decide* came up in seven out of the thirteen consultations. It came up in both of the group interviews, but was only mentioned in five of the individual sessions. For only two out of these patients was there the time to go home and discuss the decision. Both ZR and VD had the opportunity to come back in subsequent weeks as they were only 17 and 18 weeks pregnant respectively. For the other three, the clock was against them and they were under pressure to decide there and then. The issue was so blatantly distressing that I think each of their three cases merits inspection.

The first time to decide came from NN who wanted to speak to her husband. In the middle of the consultation she decided to call him and, as he happened to be employed at GSH, within a few minutes he arrived, panting, to join in the discussion. Even once he was there, the decision was difficult and he made a plea for time.

(23) Mr N: *But we, we think about the child also, otherwise we need a child, never mind how it's, how is it.*

Rachel: *Ok.*

Mr N: *Ja. So the same thing if we still going to discuss about if she want to*

Rachel: *OK*

Mr N: *We're going to discuss about it*

Rachel: *Yes*

He reiterates his plea for time just before the interview closes:

(24) Mr N: *So you can't give us another day, we must discuss now, there's another problem now we must sit down. We can't just decide now. It's uh*

Rachel: *The doctors have gone to a meeting now and I know theywon't be back till after 1 o'clock, so we can give you half an hour now - is that enough?*

Mr N: *(Laughs) Nooo.*

Rachel:	<i>But unfortunately</i>
Mr N:	<i>Can't they make it a day. At least another day. Can't be another day, ah so then we can .</i>
Rachel:	<i>Unfortunately, we're already, we like to - the safe time for this test is between 16 and 20 weeks of the pregnancy and Mrs N-'s already 20 weeks.</i>
Mr N:	<i>Mmm.</i>
Rachel:	<i>Over 19 weeks so we can't put it off till next week. OK. . . .</i>

The case of GK illuminates the dynamic process of decision-making. In the process of arriving at her ultimate decision she swings between deciding to take the test and then refusing it, as is illustrated by the following:

(25) GK:	<i>Wat ek nou gou vi u wil vra, issit noodsaaklik dat dit vedag moet gedoen raak?</i>	What I'd like to ask you now quickly, is it necessary that it <u>must</u> be done today?
Liz:	<i>Miskien kan ek vra as mevrou op Vrydag kan inkom want somtyds doen hulle die toetse ook Vrydae oggende as hulle nie tebesig met die ander klinieke is nie.</i>	Maybe I can ask if ma'am can come in on Friday because sometimes they also do the tests on Friday mornings if they're not too busy with the other clinics.
GK:	<i>Ek salit ma vedag doen dokter want because ek wek op Vrydag.</i>	I'll do it today doctor because because I'm working on Friday.
Liz:	<i>Okay</i>	Okay
GK:	<i>Ek salit ma vedag [laughs]doen ek vat ma die kans.</i>	I'll do it today [laughs] I'm taking the chance.

A short while later, GK changes her mind and decides not to do the test.

(26) Liz:	<i>Ek wens ek kan vi mevrou wat te doen sê wat te doen ma ek kan nie dis nou mevrou se besluit. Nou bietjie daaroor dink en weer inkom?</i>	I wish I could tell ma'am what to do what to do but I can't now it's ma'am's decision. Now do you want to think about it a bit about that and come in again?
GK:	<i>Ek sal 'n bietjie dink eeste.</i>	I'll first think a bit.

However, by the time GK has her post-consultation interview (which happened immediately after the consultation,) she has again changed her mind and reverted back to her initial decision - to opt for an amniocentesis.

The final example of the need for “intellectual outsourcing” (Entwistle and others, 2008) which again, might be more a need for emotional than intellectual support, occurred in MF’s consultation. This patient was again quite obviously in distress. She was caught in an unhappy marriage where she still lived with her husband, but they slept in separate rooms. She was having an affair with a married man who, when he first learned she was pregnant, advised her to have an abortion. She was desperate for somebody to discuss the issue with, but not sure where to turn. The following exchange shows her first reaction to the news that a decision was needed that day.

(27)	Rachel:	<i>Die ding is mevrou jy’s nou oorie negentien weke uhm so [laughs] tyd raak ’n bietjie min</i>	The thing is, ma’am, you’re now more than twenty weeks uhm so [laughs] time is running out
------	----------------	---	--

Clearly distressed by this, MF asks if she is able to get advice from her partner.

(28)	MF:	<i>Kan ekie eintlik vi hom phone om te luisterie?</i>	Can’t I actually phone him to hear?
	Rachel:	<i>Ja seker! Gaan jy dit nou doen?</i>	Yes sure! Are you going to do it now?
	MF:	<i>Ja</i>	Yes
	Rachel:	<i>Vanoggend? Jy bedoel [unclear]</i>	This morning? You mean [unclear]
	MF:	<i>[unclear]Ja ja [unclear] go luiste</i>	[unclear] Yes yes [unclear] go listen
	Rachel:	<i>Alright. Okay so sal ons jou kans gee om te gaan bel?</i>	Alright. Okay so shall we give you a chance to phone?
	MF:	<i>Mmm</i>	Mmm

As in the case of NN, the interview was interrupted so that MF could go and phone her partner for advice. Finding no support there, she then phoned a work colleague. The following excerpt occurred at the beginning of the resumption of her consultation, after she had asked for time to speak to her partner.

(29) MF:	<i>Ek moet decide daaroo want hy vra mos vi my [unclear] toe sê ek vi hom is 1 uit 'n honderd mos en soe an.</i>	I must decide about that because he then asks me [unclear] then I told him it's one out of a hundred and so forth.
Rachel:	<i>Ja</i>	Yes
MF:	<i>Ma ek het nou 'n aner meisie 'n guardtjie by die werk gevra toe sê sy is eintlik iets goed ek moet dit dingesse, ek gan it ma doen.</i>	But I asked another lady a guard at work then she said it's actually something good I must, I am going to do it.

These excerpts illustrate the enormity of the decision and the difficulty the patients have in making a quick decision. Hospital ethnographers describe hospitals as places of liminality – associated with rites of passage like birth and death (Long, Hunter & van, 2008). The decision these patients are asked to make must be the epitome of liminality – with each decision the patient stands on the threshold of having a baby who may be intellectually disabled and need care all his/her life or a “normal” child – with all the joys and heartache that entails. In finding out which of the two is their lot, they then run the risk of losing the baby through a miscarriage. To make decisions like this without any prior warning or time to consider is a cruel burden – and the issue of *Need for time* must be addressed by the service providers at every level in the chain of referral.

CHAPTER 5

5.1 Summary of findings

Sarangi and Candlin (2003) have stated that in order to provide analysis of the *language of risk* that is both adequate and useful, there are three angles to be tackled equating to the *what*, *why* and *how* of the discourse as I have discussed them.

Considering, in the first instance, *what* is communicated to patients, this research has shown how different lexemes pertaining to risk are used with either different meanings or different connotations of meaning. Also, although the number of lexemes from the patients was too small for statistical analysis to be meaningful, this research raises the possibility that there is discordance between the counsellors' use of some of the terms versus the patients' use (cf Levin, 2006a).

Considering *why* risk communication occurs in the manner it does, I looked at different layers of context which played a role (cf McCormick, 2009). At the first level, the Immediate Context, a blatant gap in service provision was to the isiXhosa-speaking patients. None of the counsellors was able to speak isiXhosa and getting an interpreter to help was difficult. In addition the wide variation in language background and educational background of the patients adds to the challenge of the counsellors' job.

Secondly, at an Institutional level, there needs to be an awareness that terms such as *needle* may carry a difference in meaning between everyday usage of the word versus institutional usage. One element of the consultation that did not seem standardised and/or well understood was the explanation of chromosomes. Alternative everyday examples and/or visual representations should be sought which are applicable to the diverse linguistic and educational backgrounds of the women seen (see later recommendations for suggested alternative.)

Thirdly, at a Socio-economic level, the counsellors are challenged by working within a resource-challenged public health sector. The provision of care along the chain of referral was shown to be extremely problematic. Very few patients had a clear or accurate idea about why they had been referred to the Pregnancy counselling clinic – the notable exception being the patient who had been referred from the private sector. The counsellors also need to be challenged on some of their negative assumptions about interpreters (such as interpreters causing delay). In fact it was the *lack* of interpreters which caused delay in this research.

The Historical context explains how the different language acquisition patterns for Blacks, Coloureds and Whites has resulted in variation within South African English. However, although this variation is certainly

present, it does not lead to miscommunication – provided the counsellors are also speakers of South African English.

The non-material context of the clinic showed ideology at both a societal and individual level. At a societal level English is still the default setting for the consultations and by not actively changing this, if we are to believe Fairclough (2001) then the Pregnancy Counselling Clinic is supporting the ideology of English dominance and this needs to be challenged. At an individual level, the dominant ideology for each of the patients was around their need for clear facts and reassurance about their babies. Feedback obtained during the post-consultation interview showed that all 12 patients were happy with the service they received.

Concerning *how* risk was demonstrated to the patients, this research demonstrates how verbal, numerical and pictorial elements were used. The difference between an individual's perception of risk as an experiential one versus the health practitioner's perception of risk as an analytic one was evident in this research, but was also recognised as such by the counsellors and largely dealt with appropriately. Where it proved difficult was if the patient's "risk of knowing" (Sarangi, 2002) was perceived as outweighing everything else.

This research has also explained factors that affect *how* patients make a decision. Previous research has looked at factors relating to the patient (like individual values and beliefs) (Holmes-Rovner and others, 1999) and factors relating to the health practitioner's communication of risk (like framing of risk) but this research looked at factors in the context of the clinic which impacted on the patients' decision-making. Significant factors included misconceptions and/or lack of information about their reason for attendance - which needs to be addressed by the referring centre. Another significant factor was the need to involve others in the decision. Generally this need was recognised by the counsellors but they showed ambivalence about whether the patients' partner should be present or not. By far the majority of patients, however, wished to have their partners present and in some instances, consultations were delayed whilst a partner was telephoned or brought in.

The final factor shown to be significant in decision-making was the need for more time to weigh everything up before being rushed into a decision. Often this factor arose because of problems in the chain of referral. For example, the lack of information pre-conception (at Family Planning clinics), advanced gestation at first pregnancy booking visit, lack of information provided by referring centres, and late presentation to the Pregnancy Counselling Clinic. A strict adherence to clinic protocol appeared to be rated more highly than individual heartache by the counsellors and resulted in some patients (such as NN and her husband) having to make a decision when they did not feel ready to do so.

5.2 Recommendations

South Africa presents multiple challenges to health care practitioners and health care providers, challenges that occur at multiple levels within the delivery of service. When considering health care offered to women and children, UNICEF (United Nations Children's Fund) has concluded that "The continents of Africa and Asia present the largest global challenges to the survival of children and women" (UNICEF, 2009 p. 23). Despite the resource constraints under which the clinic operates, if we look at the patient satisfaction statements obtained in the post-consultation interview then twelve out of twelve patients (100%) were happy with the service – a staggering statistic! Although this is encouraging and cause for praise, the object of research is to look with a critical eye. Thus there are changes that could be made to optimise the care the patients receive, even within the challenging South African situation.

At a lexical level, given the diversity of interpretation to the word *risk*, counsellors should consider starting off with a definition of what they mean when they use the word *risk*. They could also make explicit to patients the difference between the individual's "perceived risk" and the clinicians "determined risk" (Beck, 1992). From a clinician's point of view *risk* could be defined as 'the mathematically calculated possibility that something unpleasant will happen'. An individual's definition would tend towards including 'the uncertain dangers of a test' or 'the uncertain possibility of having a child Down Syndrome'.

At a conceptual level, an alternative analogy to explain the difference between a chromosome and a gene could, for example, be a necklace made of beads. The chromosome is the necklace and the individual beads are the individual genes.

For the challenge of tackling the ideology of English dominance a symbolic greeting in isiXhosa from the counsellors to the isiXhosa-speaking patients could go a long way. When asking the Black patients about language preference, *yes/no* questions should be avoided, even in the positive, and the patient should be offered the choice of a professional interpreter immediately (cf Deumert & Mabandla, 2008). The counsellors need to recognise that patients may fear losing their consultation slot or be otherwise disadvantaged by requesting an interpreter. Alternative appointment arrangements (such as booked slots) could be considered.

Since PGWC holds the purse strings for the clinic's facilities clinic staff could also apply pressure to GSH to insist that signage in the hospital be given in the three major languages of the Western Cape. The local and national government should also be urged to provide the necessary funding for interpreters. Money should be invested in having a permanent professional interpreter on site or a counsellor competent in isiXhosa.

The counsellors need to be more aware of patients' needs for intellectual outsourcing and emotional support in making these difficult decisions. They should offer a more open encouragement for patients to have the opportunity to bring spouses to the consultation. Moreover, issues such as the referral system need to be assessed and addressed so that patients can have the opportunity to have time to weigh up their options before being rushed into decisions that will resonate into their future.

Finally, to allow one's service to be put under the microscope for analysis takes courage. The Genetics Department and the Pregnancy counselling clinic showed this courage in allowing my research to take place and in already implementing some changes whilst planning others for the future. I am indebted to everyone at the Clinic for their assistance and hope that these findings can be used to offer these patients an even better service.

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APPENDICES

Appendix 1 – Counsellor Questionnaire

What is your age?

How many years have you been working as a counsellor?

What is your educational background?

What language are you most comfortable in?

What other languages do you speak?

Do you tend to follow a set structure in the consultations and if so, can you describe that structure?

What is your experience of / feelings about group sessions?

How do you manage to explain the notion of risk to the patients?

What factors do you think influence the women's decision whether to have an amniocentesis or not?

What are the difficulties you experience in your job as a counsellor?

How do you deal with a patient whose cultural belief is very different from a western medical belief?

How do you deal with language difficulties?

Have you got any ideas for improving the service in the future?

Any other thoughts?

Appendix 2 - Questionnaire for patients post consultation

Name _____

Age _____

How far is this pregnancy _____

Other children _____

Language most comfortable in _____

Other languages spoken _____

Education _____

Current employment _____

Prior information on reason given for coming to this clinic

Prior knowledge on Down's _____

Language of consultation _____

Group or individual session _____

Impression of the counsellor _____

Key facts learned _____

Any information that was completely new?

Partner present

YES

NO

Would you have liked him to be here YES NO

Are you going ahead with amniocentesis? YES NO

Why or why not? _____

Your understanding of risks of amniocentesis? _____

Beliefs about TOP _____

Seen the information leaflet? YES NO

Written info more helpful before coming to clinic or to take home after session to discuss with partner / family? BEFORE TO TAKE HOME

Areas / concepts that were difficult to understand

Was the language of the consultation helpful?

Any ideas on ways of improving the service offered

OTHER NOTES:

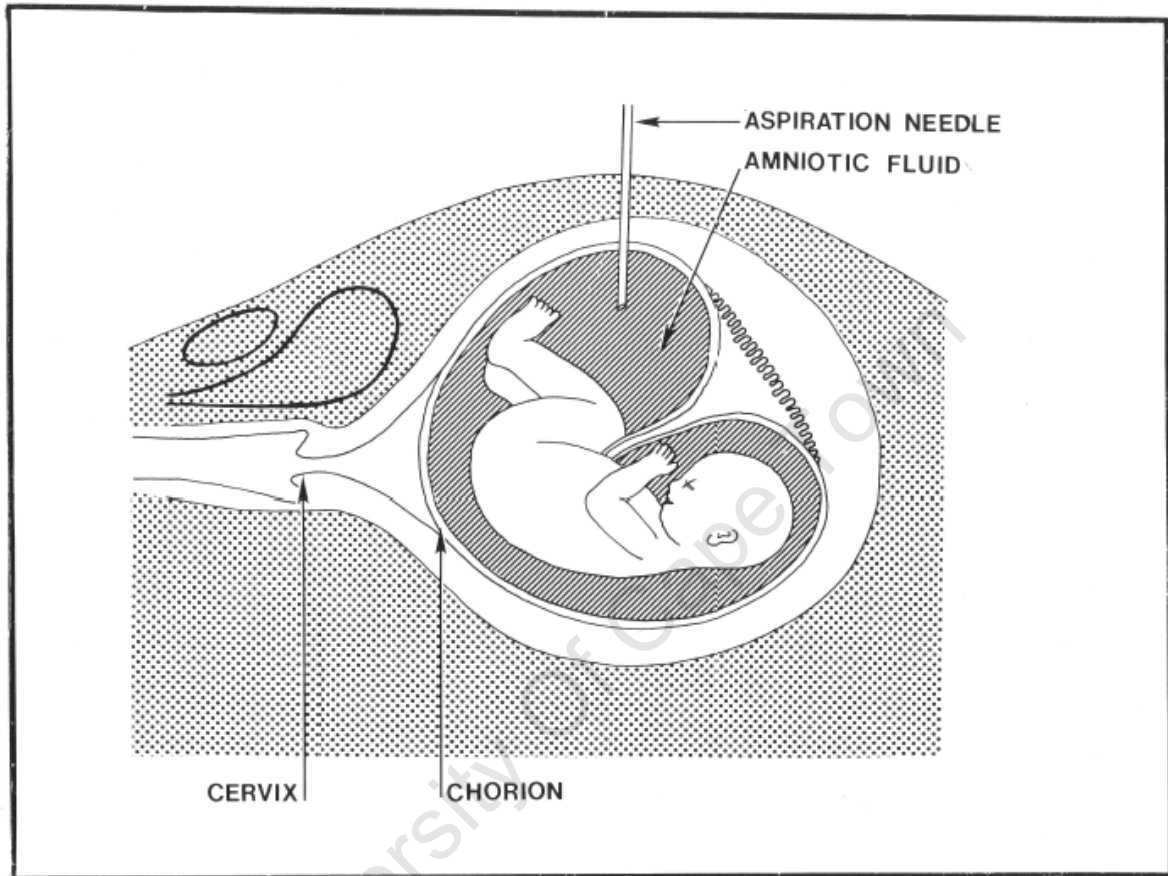
Women's feelings

Direct quotes.

Appendix 3 – Consultation Duration

PATIENT	DURATION OF CONSULTATION
ED	30 mins 44 secs
GK	31 mins 23 secs
NM	38 mins 59 secs
MF	36 mins 27 secs
ST	22 mins 35 secs
NB	36 mins 00 secs
NN	52 mins 31 secs
LN	43 mins 00 secs
ZR	35 mins 37 secs
VD	41 mins 19 secs
IA	48 mins 34 secs
Grp English	22 mins 43 secs
Grp Afrikaans	35 mins 56 secs
<u>AVERAGE</u>	<u>36 mins 36 secs</u>

Appendix 4 – Diagram illustrating amniocentesis procedure



AMNIOCENTESIS

Appendix 5 – Table and Graph used by Gail

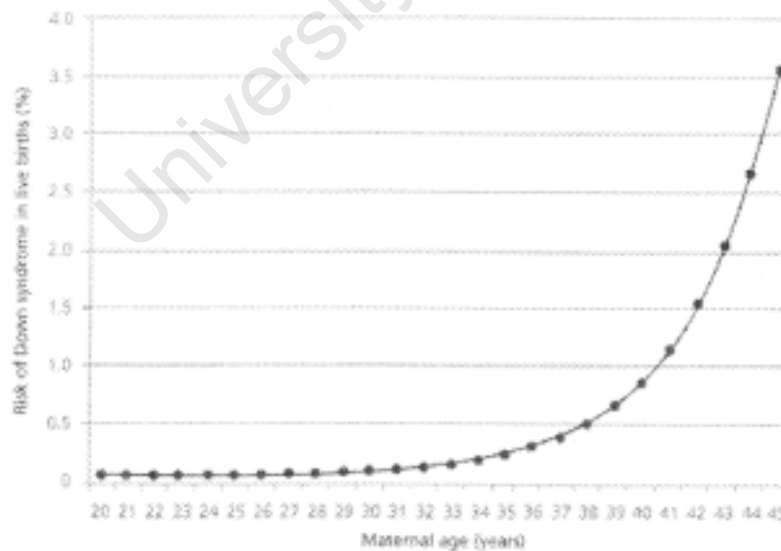
RISK OF DOWN SYNDROME BY MATERNAL AGE

DIV HUMAN GENETICS UCT PCC GSH

Figures rounded off for counselling purposes.

Updated May 2005 Ref: Morris et al. J Med Screen 2002;9:2-6

<u>MATERNAL AGE</u>	<u>RISK, 1 in</u>	<u>%</u>
20	1500	0.06
30	900	0.1
35	400	0.25
36	300	0.33
37	240	0.4
38	190	0.5
39	150	0.7
40	110	0.9
41	85	1.1
42	65	1.5
43	50	2
44	35	3
45	25	4
46	20	5



Patients who have had a previous Down baby (trisomy) have the following risk of recurrence.
 Ref: Gartner, Sutherland: Chromosome abnormalities and genetic counselling. 2nd edition.

Appendix 6 – Table used by Liz and Rachel

UNIVERSITY OF CAPE TOWN



Division of Human Genetics

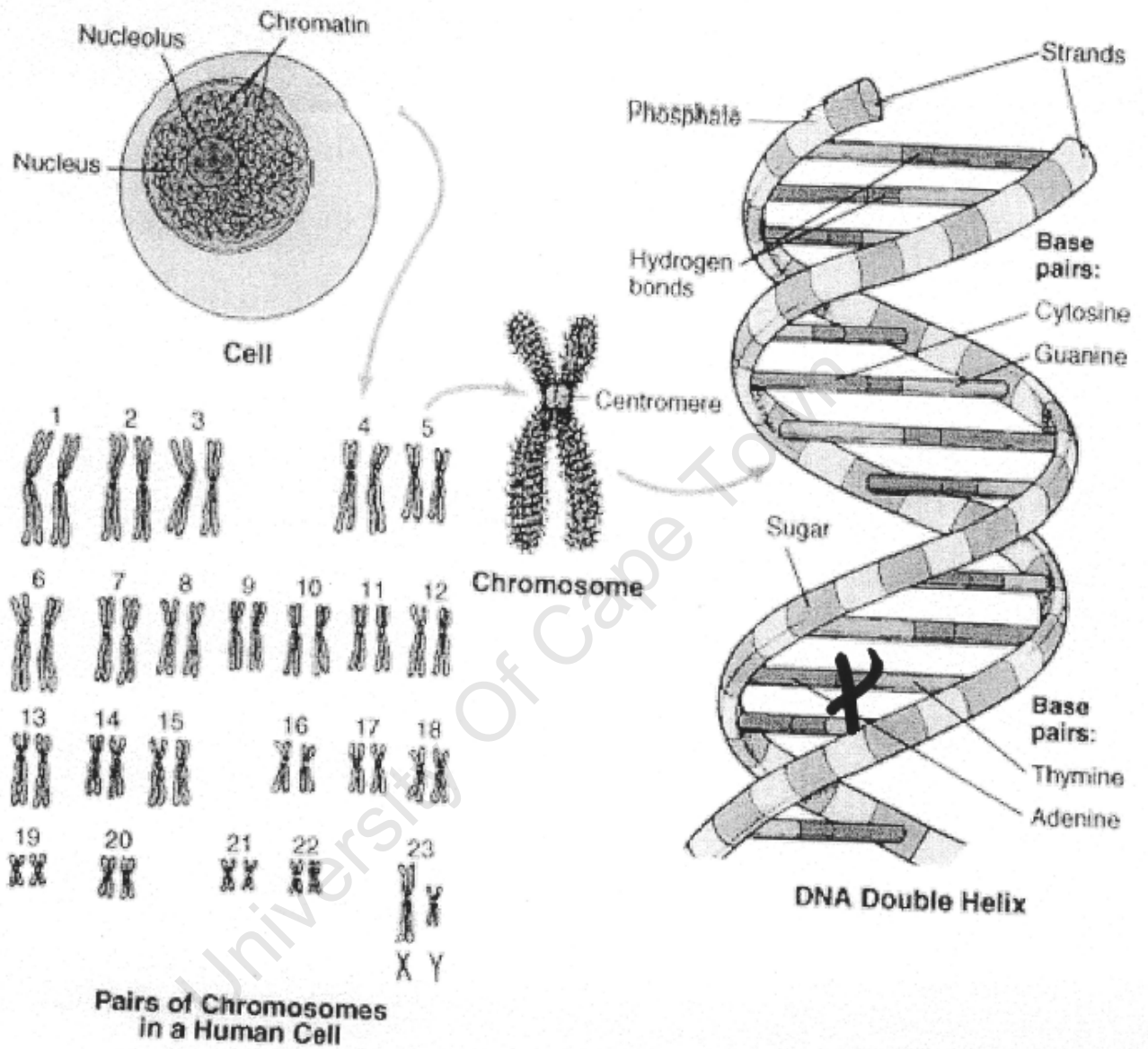
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RISK OF DOWN SYNDROME BY MATERNAL AGE

Figures rounded off for counselling purposes.
Updated May 2005. Ref: Morris et al. J Med Screen 2002;9:2-6

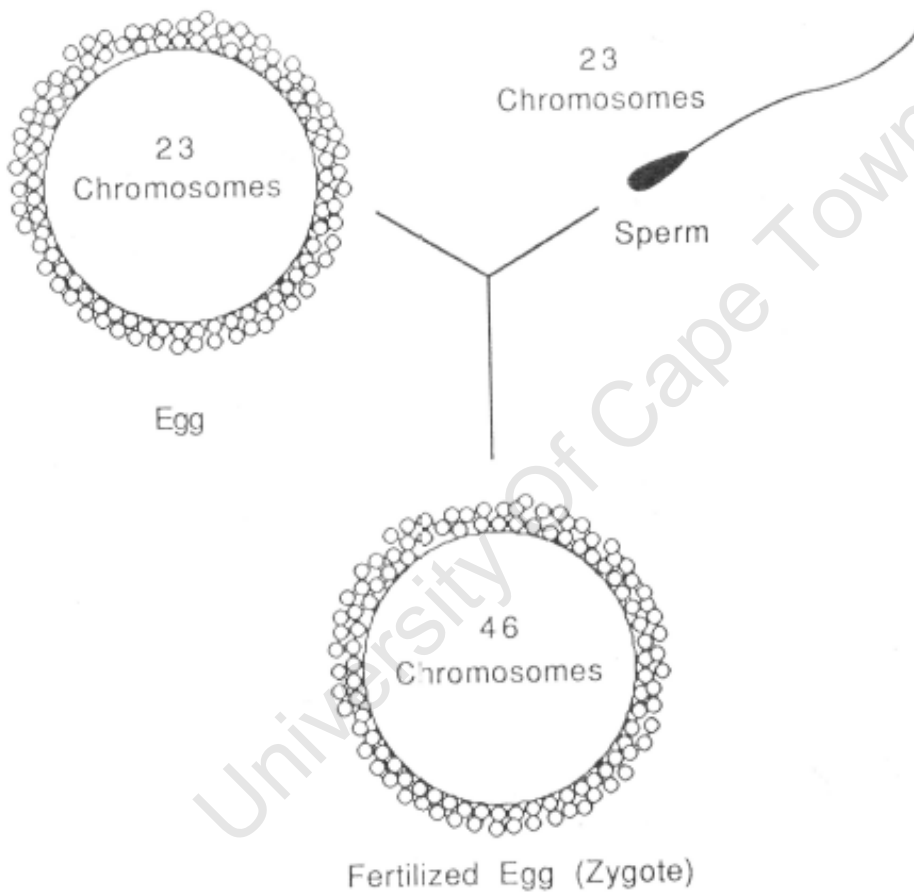
<u>MATERNAL AGE</u>	<u>RISK, 1 in</u>
20	1500
30	900
35	400
36	300
37	240
38	190
39	150
40	110
41	85
42	65
43	50
44	35
45	25
46	20

Appendix 7 – Diagram of a chromosome



Appendix 8 – Diagram showing how chromosomes are inherited

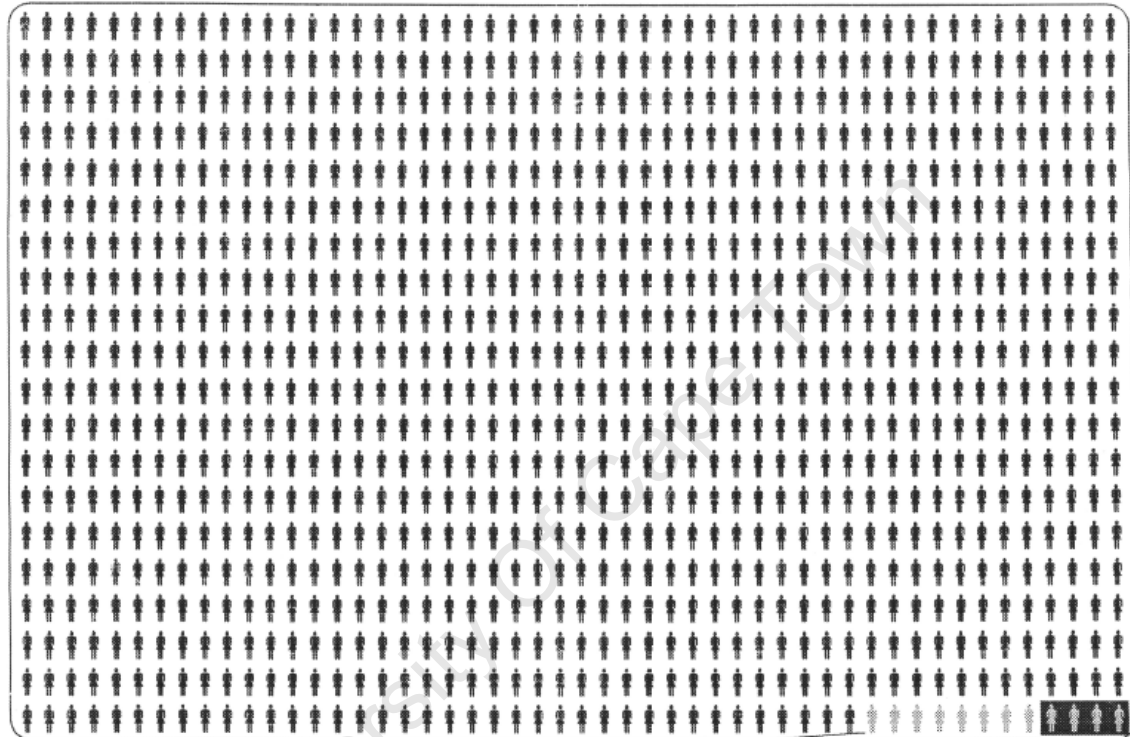
FERTILIZATION



Appendix 9 – Illustration of 1000 people

The Paling Palette of Adult Women

One Thousand People-Pictures to Help You See Your Relative Likelihood



Odds for 39 year old woman of producing a child with Down Syndrome or other chromosome abnormality (12 out of 1000)

Odds of a woman having a miscarriage as a result of amniocentesis (4 out of 1,000)

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Appendix 10 – Results of grading of RISK and RISIKO

GRP INTERVIEW (AFRIKAANS)	GRADING
Okay? So unfortunately dis nou die risk vi die toets.	-2
en ons gesels oor die die risiko van swangerskap	-2
praat oor die risiko op julle ouderdom en die toets	-2
Daar is 'n risiko met die toets	-2
julle dit hoor dat daar is 'n risiko vir die kinnere	-2
om net vi julle te veduidelik wat die risiko is	-2
because sommige mummies weet niks van die risiko	-2
en wat is die risiko?	-2
GROUP INTERVIEW ENGLISH	
But as we get older so the risk goes up.	-3
what is the risk for each age group	-3
let's offer it to those who are at a higher risk	-3
it's a small risk for a young lady	-3
if I look in my book (gets it) to see what the risk is as we get older	-3
when you're 20 the risk is one out of fifteen hundred	-3
This is the risk of Down's Syndrome	-3
so the risk would be one out of whatever	-3
by the time you're 46 – if you're expecting a baby then, the risk is one out of twenty.	-3
we measure thickness in the neck – that can say to women put you in a higher risk than your age	-3
or lower risk than your age	-3
even for women who have then had their risk changed by that early scan	-3
We need to tell everybody who takes the test there's a one percent risk of a miscarriage, if you take the test	-3
INTERVIEW NB	
Gail: So there is risk of it happening	-2
but there are also risks	-1
from 20 – 45 the risk of down syndrome is never zero	-3
you see that's a small risk	-3
everyone has the same risk	-3
because of the risk they want to have the test	-2
the same risk in a different way	-3
– so - .5% or 1 in 190 risk at your age	-3
So there is 1% risk of having a miscarriage	-3
because there is risks and benefits	-2
did you know about the risk of the test beforehand	-2
to keep the risk low okay	-3
about the miscarriage risk	-2
to keep that risk of miscarriage as low as possible	-2

to keep the risk as low as possible	-2
P: It is risk of down syndrome	
– the risks and limitations of this procedure	-2
GK INTERVIEW	
kan jou increase risk	-2
die vi die risk vi die miskraam	-2
Grieta: Ek gan ma 'n kans vat ek gan ma die risk vat. Ek salit ma los.	
Interviewer: Die risiko vir die baba	-3
Interviewer: Die risiko vi om nie 'n baba van Down sindroom te kry is baie méér	-3
oor die risiko of of op daai nomme	-3
ED INTERVIEW	
because of the risk of transmitting the HIV	-2
there is a risk the baby will be exposed	-2
and there's risk that the baby will get the virus	-2
we increase the risk of transmitting the virus	-2
has put you at a low risk okay?	-3
in fact I think I know uhm [unclear] of risk that	-2
then it increases the RISK, IT'S ALSO	-3
we've seen now what their risk is	-3
that can actually refine the risk	-3
So that's one way of adjusting the risk .	-3
it reduces the risk	-3
You can't take away risk	-1
Mr ED: But but tell me one thing say for example there is a risk	-1
The miscarriage risk is one in a hundred chances	-3
there's a risk of one of those tests	-2
Liz: Okay the risk of the the test, how do you view that,	-2
how do you view that as a small risk	-3
are you happy to take that risk	-2
are you prepared to take that risk .	-2
Liz: The risk of [unclear] uhm losing the baby because having that amniocenteses	-2
ED: I'm not comfortable with the the risk .	-1
I'm not comfortable with the the risk at my age, the idea	-2
ED: Because the the low low Down risk uh blood results, I'm not comfortable with that at all.	-3
If the results said no risk	-3
more concerned risk of miscarriage	-2
The risks and limitations of the procedure	-2
The risks of having the actual procedure	-2
MF INTERVIEW	
Okay daar is die risk vir iemand van thirty seven	-2
En uhm uhm wat ek probeer kan jy onthou wat was die risk om 'n [unclear] op jou ouderdom te [unclear] Down sindroom?	-3

So wat is die **risk** op jou ouderdom kan jy onthou? -3
En kan jy onthou wat is die **risk** vir 'n miskraam as 'n mens die toets
vat? -3

ZR INTERVIEW

there is the **risk** of a miscarriage. -2
And we give that **risk** as one out of a hundred. -3
is your **risk** at your age -3
we've spoken about a **risk** for having a miscarriage -2
how high is your **risk** at your age -3
any woman is at **risk** for having -2
ZR: [Yes.] So any pregnancy you've got the **risk** -1
so the **risk** for having a baby with Down's Syndrome -2
what is the **risk** as you get higher -3
This chart gives you the **risk** of Down's Syndrome -3
her **risk** is one out of one thousand five hundred -3
sound like a high **risk**, -3
a low risk -3
I know I'm turning 40 and there is a **risk** I'm taking. -1
can you remember what **risk** I gave you for a 39 year -3
And the **risk** for having a miscarriage -3

VD INTERVIEW

VD: due to my age I'm 44 and that's going to be a **risk** just now. -1
And the **risk** for Down Syndrome -2
We're going to talk about those **risks** -2
how does that affect the **risk** in general -2
the **risks** involved with the test -2
So you can see that the **risk** is quite low the chance is quite low -3
You've all got the same **risk**. -3
I want you to remember that the **risk** at your age -3
So I want you to remember that **risk** based on your age -3
So we've said your **risk** At your age is one in .35. -3
And the **risk** is for a Down's Syndrome -2
How do you feel about the miscarriage **risk**. -2
So there is a **risk** of a miscarriage -2
there's already an increased **risk** -3
so the **risk** has increased since your last baby -3
there is a 3 percent **risk** but that means there's a 97 percent chance
that the baby's going to be fine. -3

ST INTERVIEW

do you remember what **risk** when I went in my book we gave you for
your age? -3
do you remember what the risk **was** that we said -3
the **risks** and the limitations of this procedure -2
So that's the **risks** -2
small **risk** of one OUT OF A HUNDRED -3

uhm small risk of infection -3

NN INTERVIEW

and I could say to Mrs Ngoyi the risk for when you're 40 years old -3

so this is the risk, for Down's Syndrome -3

then we say the risk is one out of a hundred and ten -3

the risk was one out of a hundred and five . -3

small risk of a miscarriage. -3

your risk at 40 years is one out of a hundred and ten? -3

NM INTERVIEW

if we . look at this chart, it gives the risk, for Down's Syndrome -3

When the mother is 20 years old, the risk is one in one thousand five hundred -3

the risk in one out of twenty -3

For anybody who takes this test, There is a small chance, small risk, for a miscarriage. -3

And we say that the risk is usually one out of a hundred. -3

But because you have had 3 miscarriages already, we would say your risk is higher than that. -3

The risks or the limitations of this procedure have been explained to me by me, Sr, OK. -2

Now, the risks, -2

I've talked about that one out of a hundred risk of having a miscarriage, or one out of fifty in your case, um. -3

So what was the risk I gave you of having a baby with Down's Syndrome at your age -3

the risk for the miscarriage – was what? -3

NM: If you take the test, there's a risk of miscarriage -2

LN – LIZ

So it's more or less the same risk for you for having a baby with Down's Syndrome. -3

The risk is the same. -3

IA INTERVIEW

wat is die kaanse – wat is die risk dat jy miskien 'n kind kry met die downsyndrome -2

maar dis net daai risk van 'n miskramp daar is -2

daar is altyd 'n risk vir 'n miskramp -2

En kan mevrou onthou wat was die risk vir 'n miskram as 'n mens die toets wat? -3

GRP AFRIKAANS

en ons praat net oor die risiko as 'n mens dan ouer as 37 is – -2

Appendix 11 – Results of grading of CHANCE, KANS and MOONTLIKHEID

GRP INTERVIEW (AFRIKAANS)	GRADING
wat is my <u>kans</u> om Down syndrome babatjie	-2
Op forty-three is die <u>kans</u> een uit vyftig	-3
as jy ouer raak is die <u>kans</u> dat jy kan babatjie met Down syndrome	-3
daar is 'n <u>kans</u> en as die chromosome normaal is ons kan vi julle sê die babatjie sal nie Dowsindroom hê nie	2
'n <u>kans</u> vat nie	-1
So ek sal die <u>kans</u> vat.	-1
as 'n mammie HIV positive is is daar <u>kans</u> dat die kieme	-2
as die mammie nou positive is is daar <u>kans</u> vir die baba nou	-2
daar uhm meer <u>kans</u> dat die kiem kan ook gaan na die babatjie	-2
Patient: Die suster het gesê omdat ek veertig is is is daar 'n <u>kans</u> dat ek 'n Down sindroom baba kry	-2
GROUP INTERVIEW ENGLISH	
And you could say the <u>chances</u> are that one of them out of one thousand five hundred will have a baby with Down's Syndrome.	-3
So there's still a much bigger <u>chance</u> that the baby will be fine	-3
Patient: [Is there any <u>chance</u> that there] are any signs or how	
GAIL - NB	
there is an increased <u>chance</u>	-2
but the <u>chance</u> of a bay with down syndrome	-3
the <u>chance</u> of it happening gets higher	0
do you understand when I say <u>CHANCE</u> :	-3
but the <u>chance</u> of it happening is smaller	-3
the <u>chance</u> stays small	-3
the <u>chance</u> gets bigger	-3
the <u>chance</u> at your age	-3
the <u>chance</u> is 1 in 190	-3
.5 percent <u>chance</u>	3
there is 99.5% <u>chance</u> that the baby is healthy	-2
there is a <u>chance</u> of it happening	-2
And the <u>chance</u> of the miscarriage	-2
GK INTERVIEW	
is daar uhm meer as 'n <u>kans</u> dat die foutjie is in die familie	-2
Daar is daar is uhm uh meer <u>kans</u> dat familieledede van die familie	-2
is die <u>kans</u> om 'n babatjie met Down sindroom te kry	-2
So hoe voel mevrou oor oor daai daai <u>kans</u> ?	-2
ons dit uhh kyk na één <u>kans</u> uit honderd-en-tien	-3

honder-en-nege <u>kanse</u> uit honderd-en-tien dat dit sal nie 'n baba	3
daar's 'n baie groter <u>kans</u> dat die babatjie sal nie Down sindroom kry nie	3
Daar's bai e meer <u>kans</u> Down sindroom	-3
GK: Ek salit ma vedag [laughs]doen ek vat ma die <u>kans</u> .	-1
En is jy heeltemal tevrede om om die <u>kans</u> te vat	-2
GK: Ek gan ma 'n <u>kans</u> vat ek gan ma die risk vat. Ek salit ma los.	-1
 ED INTERVIEW	
Okay [unclear] oor die <u>kanse</u> Down sindroom	-2
Okay, kan jy daai uh nommer onthou wat die <u>kans</u> is wat [unclear]	-3
jy is uh hoe skraler word die <u>kanse</u> .	-3
 MF INTERVIEW	
MF: But ek sien nie <u>kans</u> omit te stopie.	0
ek sien nie <u>kansie</u> ek wil nie gaan nie. (but I don't see it fit I don't want to.)	0
Rachel: En dink jy dis 'n hoë kans	-3
of 'n lae kans of wat dink jy?	-3
MF: Sieke 'n lae <u>kans</u>	-3
En wat dink jy wil jy 'n <u>kans</u> hê om hieroor te dink of	-2
MF: Ma staan jy nou 'n kans om daai baby te veloo?	-2
Daar is 'n een uit 'n honderd <u>kans</u> .	-3
sal ons jou <u>kans</u> gee om te gaan bel?	0
En enige <u>kans</u> dat jy en hy miskien bloedfamilie is	-1
 ZR INTERVIEW	
Any <u>chance</u> you and your husband could be related	-1
Yes. (laughs) so you doesn't know what your <u>chances</u> is?	-1
Well, we say your <u>chances</u> are one out of a hundred. OK?	-3
 VD INTERVIEW	
So we're saying there is an increased <u>chance</u> of having a child with Down's Syndrome as one gets older?	-3
what is the <u>chance</u> according to your age	-3
even when you're 20 the <u>chance</u> isn't zero	-3
But the <u>chance</u> of having it does increase with age	-3
the <u>chance</u> is quite low	-3
The <u>chance</u> of having a baby with Down 's syndrome is one in 35	-3
So 3 percent <u>chance</u>	-3
which means there's a 97 percent <u>chance</u> that the baby is not going to have Down's Syndrome.	3
a high <u>chance</u> for diabetes	-3
there's a 97 percent <u>chance</u> that the baby's going to be fine.	3
VD: Um. . if the test needs to be done there's a bigger <u>chance</u> .	-2
1 percent <u>chance</u>	-3
 ST INTERVIEW	
any <u>chance</u> you and your husband could be related	-1

Ladies chances are one of you out of thirty-five will have a baby with Down syndrome. Thirty-four will be fine -3

NN INTERVIEW

Any chance that you and your husband come from the same clan -1

there any chance that you . and him are cousins -1

There is a small chance for having a baby with Down's Syndrome. -3

We're just saying there is a chance children that look like this? -2

So the chance is greater. -3

So it's a small chance. -3

There is a small chance for a miscarriage -3

NM INTERVIEW

But as we get older, so the chance is greater for a baby like that. -3

chance you and your partner could be related -1

But as we get older, the chance goes up, -3

the chance gets bigger -3

So that's a small chance. -2

I need to look at my book ,what is the chance -3

The chances are one of you will have a baby with Down's Syndrome -3

There is a small chance, small **risk**, for a miscarriage. -3

LN INTERVIEW

Any chance that you and your boyfriend are from the same family? -1

there's always the chance that the baby can be put together in a way that there's a mistake -1

there is a higher chance thaT older mommies -2

there is a higher chance to have a baby that's got a condition that these children have got. -3

Now we know that when you get older, there is a bigger chance of having a baby like this -3

But we know that as you get older, there is a bigger chance. -3

there's a bigger chance than if you were 20 years old -3

your chances are to have a baby like this with Downs Syndrome -2

So do you think that's a big chance, or not so big? -3

You still think it's a big chance? -3

there is a there's a chance that the needle can cause a miscarriage -2

So, if you did want the test, it's the same chance. -3

You've got the same chance of having a baby with Down's Syndrome as, -3

And that you don't want to take a chance to have the test -1

If a mom is HIV positive, there's a chance that the baby can also get it -2

it can increase the baby's chance of being exposed to that virus. -3

GRP AFRIKAANS

En ons se daai <u>kans</u> is een uit 100	-3
maar as ons ouer raak end dis veraal van ons vroumense dan is die <u>kaanse</u> al hoer	-3
wat is die <u>kaanse</u> – wat is die risk dat jy miskien ‘n kind kry met die downsyndrome	-2
en as jy ouer raak dan gaan die <u>kaanse</u> al hoer	-3
– <u>kaanse</u> is date een van julle uit 1500 kan die kind kry met die	-3
so ‘n klein <u>kaansie</u> as jy jonk is	-3
as sy 20 jaar oud is dan is die <u>kaanse</u> net 1 uit	-3
so dis nogal hoer <u>kaans</u>	-3
– so is dit ‘n groter <u>kaans</u> wat jy geweet het	3
as ‘n mens die toets wat daar is ‘n <u>kaans</u> van ‘n miskramp	-2
id die <u>kaanse</u> een uit 20 onthou jy?	-3
En dan ek wil net vra die kind se pa enige <u>kaans</u> dat jy en hy miskien ‘n bloed familie is	-1
– het enige lets wat ons in hospital doen daar is altyd ‘n <u>moontlikheid</u> dat ons ‘n bietjie daar kieme is	-2
Dis nie <u>ontmoontlik</u> nie maar dis baie – nie iets wat dikwels gebeur nie –	-2
so it’s very very unlikely – maar ek moet net vir mevrou vaarsku dis ‘n <u>moontlikheid</u>	-2

Appendix 12 – Results of lexeme analysis

	RISK	CHANCE	DANGER	POSSIBI- LITY	RISIKO	KANS	MOONT- LIKHEID
<i>IA</i>							
<i>RACHEL</i>	4			2	1	12	2
<i>LIZ</i>					5	9	1
<i>GK</i>					1	2	
<i>MF</i>						4	
<i>RACHEL</i>	4					6	1
<i>ED</i>	4						
<i>LIZ</i>	22	2				3	
<i>MR ED</i>	1			1			
<i>ST</i>							
<i>RACHEL</i>	6	2					
<i>VD</i>	1	1					
<i>GAIL</i>	15	12					
<i>ZR</i>	2	1		2			
<i>RACHEL</i>	14	2					
<i>LN</i>							
<i>LIZ</i>	2	19					
<i>NM</i>	1						
<i>RACHEL</i>	11	9					
<i>NN</i>							
<i>MR N</i>			7	1			
<i>RACHEL</i>	6	7	4				
<i>NB</i>	1						
<i>GAIL</i>	17	13					
<i>RACHEL</i>	15	2		3			
<i>GROUP ENGLISH</i>		1					
<i>LIZ</i>	1	1			7	11	
<i>GRP AFRIKAANS</i>						1	
COUNSELLOR TOTAL	117	69	4	5	13	31	4
PATIENT TOTAL	10	3	7	4	1	7	0
GRAND TOTAL	127	72	11	9	14	38	4