

**UNDERSTANDING DECISION-MAKING REGARDING  
PRENATAL DIAGNOSTIC TESTING FOR DOWN SYNDROME  
AND TERMINATION OF PREGNANCY:  
AN INTERPRETIVE PHENOMENOLOGICAL STUDY**

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March 2018

## DECLARATION

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## ABSTRACT

Pregnant women or couples who screen high risk for a baby with Down syndrome (DS) are faced with having to make life changing decisions. Firstly, they need to decide whether they want prenatal diagnostic testing to confirm whether the baby has DS or not. If this diagnosis is confirmed, they have the added burden of deciding between a termination of pregnancy (TOP) and giving birth to a baby with DS. The pregnant women and couples often need to make these decisions while feeling emotionally distressed and overloaded by information. This may cause them to make decisions they regret, which may have a long-term negative impact on their psychological well-being and daily lives. Therefore, the current study aimed at gaining a deeper understanding of how women/couples experience their decision-making process around the option of prenatal diagnosis (PND) for DS and TOP, in order to improve their satisfaction with the decisions they make. This study particularly focused on the experiences of women/couples who attend the prenatal clinic at a public sector hospital, Tygerberg Hospital, in Cape Town, South Africa (SA).

The study was conducted using a qualitative interpretive phenomenological approach. A total of 27 women and six couples were recruited using purposive sampling. These participants were selected and grouped according to the decisions they made, in order to investigate the decision-making process and impact of each decision. The four groups were: those participants who declined PND, who accepted PND, who declined TOP and who accepted TOP. In-depth interviews were conducted to collect the data. These interviews were conducted at different intervals during and after the outcome of the pregnancy. The interviews were audio-recorded and transcribed. Thematic analysis was used to derive meaning from the data.

The findings of the study highlights the complexity of the decision-making processes regarding PND for DS and TOP. The women/couples reported several factors influencing their decision-making processes including their perceived severity of DS, interpersonal relationships, procedure related risks, risk perception, perceived benefit of procedure, family structure, religious values and moral beliefs. It was noted that those women/couples who made decisions which were not in line with their religious beliefs and moral values experienced the most ambivalence and feelings of regret. Each decision was found to have a major impact on the women's/couples' psychological wellbeing, interpersonal relationships and daily lives. Therefore, this study also illustrated the additional support these women/couples require, in order to cope with the anxiety caused by their high risk status of DS and their decisions regarding PND and TOP.

This study is the first of its kind in SA and will enhance the understanding of the experiences and decision-making processes of women and couples who attend the prenatal clinics within this context. The findings of the current study was integrated into a practice guideline specific to the SA context in order to improve the provision of genetic counselling to better assist women and couples in their decision-making processes regarding PND for DS and TOP.

## OPSOMMING

Swanger vroue en paartjies, wat 'n hoë risiko het vir 'n baba met Down sindroom (DS), moet lewensveranderende besluite neem. Eerstens moet hulle besluit of hulle voorgeboorte diagnostiese toetse (VDT) wil ondergaan om te bevestig of hulle baba DS het of nie. As hierdie toetse die diagnose bevestig, moet hulle kies tussen 'n terminasie van swangerskap (TVS) of om geboorte te skenk aan 'n baba met DS. Die swanger vroue/paartjies moet dikwels hierdie besluite neem terwyl hulle emosionele angste ervaar en oorlaai word met inligting. Dit kan veroorsaak dat hulle besluite neem waaroor hulle later spyt voel en wat 'n langtermyn negatiewe impak op hulle sielkundige welsyn en daaglikse lewens het. Daarom was die doel van die huidige studie om 'n beter begrip te kry van hierdie vroue/paartjies se ervarings en besluitnemingsprosesse rondom die opsie van VDT vir DS en TVS, en sodoende hul tevredenheid met die besluite wat hulle neem, te verbeter. Hierdie studie het spesifiek gefokus op die ervarings van vroue/paartjies wat die voorgeboorte kliniek by 'n staatshospitaal, Tygerberg Hospitaal, in Kaapstad, Suid-Afrika (SA) bywoon.

Die studie is uitgevoer met behulp van 'n kwalitatiewe interpretatiewe fenomenologiese benadering. Altesaam 27 vroue en ses paartjies is gewerf vir deelname, deur middel van doelgerigte steekproefneming. Hierdie deelnemers is gekies en gegroepeer volgens die besluite wat hulle geneem het, om die besluitnemingsproses en die impak van elke besluit te ondersoek. Die vier groepe was: die deelnemers wat VDT geweier het, wat VDT ondergaan het, wat TVS geweier het en TVS aanvaar het. In-diepte onderhoude is gevoer om die data te versamel. Hierdie onderhoude is uitgevoer op verskillende tydsdure tydens en na die uitkoms van die swangerskap. Oudio-opnames is van die onderhoude gemaak. Hierdie opnames is getranskribeer en tematiese analise is toegepas om afleidings van die data te maak.

Die bevindinge beklemtoon die kompleksiteit van die besluitnemingsprosesse rakende VDT vir DS en TVS. Die vroue/paartjies het verskeie faktore genoem wat hul besluitnemingsprosesse beïnvloed, insluitend hul waargenome erns van DS, interpersoonlike verhoudings, prosedureverwante risiko's, risiko-persepsie, waargeneemde voordeel van prosedure, familie struktuur, godsdienstige waardes en morele oortuigings. Daar is opgemerk dat die vroue/paartjies wat besluite geneem het, wat nie in lyn was met hulle godsdienstige oortuigings en morele waardes nie, die meeste gevoelens van onsekerheid en spyt beleef het. Elke besluit het ook 'n groot impak op die vrouens/paartjies se sielkundige welsyn, interpersoonlike verhoudings en daaglikse lewens gehad. Hierdie studie het dus ook

geïllustreer dat hierdie vroue/paartjies addisionele ondersteuning nodig om aan te pas met hulle hoë risiko-status van DS, asook die besluite wat hulle rakende VDT en TVS gemaak het. Hierdie studie was die eerste van sy soort in SA en sal die begrip verbeter van die ervarings en besluitnemingsprosesse van vroue/paartjies, wat die voorgeboorte klinieke binne hierdie konteks bywoon. Die bevindinge is geïntegreer in 'n praktyk riglyn wat spesifiek om ten einde die voorsiening van genetiese berading, om vroue en paartjies te ondersteun in hul besluitnemingsprosesse rakende PND vir DS en TOP, in die SA konteks te verbeter.

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## LIST OF ABBREVIATIONS

|               |  |
|---------------|--|
| <b>AMA:</b>   | Advanced maternal age                      |
| <b>ARSA:</b>  | Aberrant right subclavian artery           |
| <b>AVSD:</b>  | Atrio-ventricular septal defect            |
| <b>BSc:</b>   | Bachelor of Science                        |
| <b>CPT:</b>   | Cape Town                                  |
| <b>CVS:</b>   | Chorionic villus sampling                  |
| <b>DNA:</b>   | Deoxyribonucleic acid                      |
| <b>DS:</b>    | Down syndrome                              |
| <b>DST:</b>   | Department of Science and Technology       |
| <b>EIF:</b>   | Echogenic intracardiac focus               |
| <b>EU:</b>    | Expected Utility                           |
| <b>F:</b>     | Female                                     |
| <b>FA:</b>    | Fetal anomaly                              |
| <b>FISH:</b>  | Fluorescent <i>in situ</i> hybridisation   |
| <b>FMF:</b>   | Fetal Medicine Foundation                  |
| <b>G:</b>     | Gravida                                    |
| <b>HBM:</b>   | Health Belief Model                        |
| <b>HCG:</b>   | Human chorionic gonadotropin               |
| <b>HCP:</b>   | Health Care Professional                   |
| <b>HIV:</b>   | Human immunodeficiency virus               |
| <b>HPCSA:</b> | Health Professions Council of South Africa |
| <b>IVF:</b>   | <i>In vitro</i> Fertilisation              |
| <b>M:</b>     | Male                                       |
| <b>NB:</b>    | Nasal bone                                 |
| <b>NIPT:</b>  | Non-invasive prenatal testing              |
| <b>NRF:</b>   | National Research Foundation               |
| <b>NT:</b>    | Nuchal translucency                        |

|                |   |
|----------------|---|
| <b>P:</b>      | Para  |
| <b>P(n):</b>   | Participant number  |
| <b>PAPP-A:</b> | Pregnancy associated plasma protein A   |
| <b>PCR:</b>    | Polymerase chain reaction   |
| <b>PhD:</b>    | Doctor of philosophy  |
| <b>PND:</b>    | Prenatal diagnosis  |
| <b>PNS:</b>    | Prenatal screening  |
| <b>RE:</b>     | Regarding   |
| <b>SA:</b>     | South Africa  |
| <b>SANPAD:</b> | The South African/Netherlands Research Programme on Alternatives in Development |
| <b>T1:</b>     | First trimester   |
| <b>T2:</b>     | Second trimester  |
| <b>TBH:</b>    | Tygerberg Hospital  |
| <b>TG:</b>     | Topic guide   |
| <b>TOP:</b>    | Termination of pregnancy  |
| <b>TPB:</b>    | Theory of Planned Behaviour   |
| <b>TRA:</b>    | Theory of Reasoned Action   |
| <b>UK:</b>     | United Kingdom  |
| <b>US:</b>     | United States (of America)  |
| <b>USA:</b>    | United States of America  |
| <b>VSD:</b>    | Ventricular septal defect   |
| <b>WC:</b>     | Western Cape  |

## LIST OF TERMS

|  |   |
|--|---|
| <b>Antiretroviral treatment:</b>         | Medicine used to treat HIV. This medication is used to slow down the rate which the HIV makes copies of itself in the patient's body and therefore leads to a reduction in the viral load.  |
| <b>Aberrant right subclavian artery:</b> | Rare anatomical variant of the origin of the right subclavian artery which supplies blood to the right side of the upper body.  |
| <b>Amniocentesis:</b>                    | A procedure in which a sample of the amniotic fluid is taken by inserting a needle into the uterus, to test for fetal abnormalities in the fetus.   |
| <b>Atrio-ventricular septal defect:</b>  | A heart defect characterised by holes in the area of the septum separating both the upper and lower chambers of the right and left side of the heart.                                       |
| <b>Biochemical tests:</b>                | Tests which test the level of certain hormones in the women during pregnancy in order to determine the risk of certain conditions in the fetus, like Down syndrome or a neural tube defect. |
| <b>Brachycephaly:</b>                    | The shape of the back of an individual's head is more rounded and flattened in comparison to most individuals in the general population.  |
| <b>Chorionic villus sampling:</b>        | A procedure in which a tissue sample is taken from the placenta, in order to test for abnormalities in the fetus.   |
| <b>Chromosomal abnormalities:</b>        | An incorrect number or structural variant of the chromosomes which carry an individual's genetic information.   |
| <b>Clinodactyly:</b>                     | Curving of the fifth finger toward the fourth finger.   |

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|---|--|
| <b>Cordocentesis:</b>                             | A procedure in which blood is taken from the fetal umbilical cord to test for fetal abnormalities.   |
| <b>Congenital anomalies:</b>                      | Structural or functional anomalies that occur during intrauterine life and can be detected during the pregnancy, at birth or later on in life. These anomalies are also commonly referred to as birth defects.                       |
| <b>Cystic hygroma:</b>                            | Abnormal growths (fluid-filled sacs) that usually occur on a baby's neck or head. This is most often caused by blockages in the lymphatic system (a network of organs and tissues which help remove toxins and waste from the body). |
| <b>Duodenal atresia:</b>                          | A condition in which the first part of the small bowel (the duodenum) has not developed properly and therefore cannot allow the passage of stomach contents through the bowel.   |
| <b>Echogenic intracardiac foci:</b>               | A focal spot within the heart of the fetus, that is similar to the brightness of the bone, on an ultrasound scan.  |
| <b>Femur:</b>                                     | The bone in the human leg extending from the pelvis to the knee also known as the thighbone.   |
| <b>Fetal anomalies:</b>                           | Deviations in the expected normal structural development of the fetus.   |
| <b>Fetomaternal haemorrhage:</b>                  | The entry of fetal blood into the mother's bloodstream before or during delivery.  |
| <b>Fluorescence <i>in situ</i> hybridisation:</b> | A genetic test which uses a fluorescent technology to visualise the genetic material in a person's cell. This test is used to visualise specific genes or chromosomes under the microscope.  |

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|--------------------------------|---|
| <b>Gravida:</b>                | A term used to describe the total number of confirmed pregnancies that a women has had, regardless of the outcome.  |
| <b>Hirschprung's disease:</b>  | An abnormality in which certain nerve fibres are absent in segments of the bowel resulting in severe bowel obstruction.   |
| <b>Humerus:</b>                | The bone of the upper arm or forelimb extending from the shoulder to the elbow. Plural: humeri.   |
| <b>Hydrops fetalis:</b>        | A serious fetal condition defined as abnormal accumulation of fluid in two or more fetal compartments, including the ascites, pericardial effusion, and skin oedema.    |
| <b>Hyperechogenic bowel:</b>   | The appearance of the fetal bowel as brighter than expected during antenatal ultrasound imaging.  |
| <b>Hypoplasia:</b>             | Underdevelopment or incomplete development of a tissue or organ.  |
| <b>Hypoplastic nasal bone:</b> | The ultrasonographic observation where the fetal nasal bone appears smaller than expected for the gestational age at the time of examination.                           |
| <b><i>In utero:</i></b>        | In a woman's uterus or before birth.  |
| <b>Karyotyping:</b>            | A laboratory test to study an individual's number of chromosomes as well as their structure.  |
| <b>Long bones:</b>             | A term used to refer to both an individual's humerus and femur.   |
| <b>Malformations:</b>          | Abnormally formed parts of the body.  |
| <b>Mifepristone:</b>           | A synthetic steroid that inhibits the action of progesterone. It is given orally in early pregnancy to induce labour as part of the termination of pregnancy procedure. |

|                                      |  |
|--------------------------------------|--|
| <b>Misoprostol:</b>                  | Medication used in conjunction with mifepristone to induce labour as part of the termination of pregnancy procedure.   |
| <b>Mosaicism:</b>                    | A condition in which tissues of genetically different types occur in the same organism.  |
| <b>Nuchal oedema:</b>                | A term used to describe collection of fluid at the back of the fetus' neck. It can be thought of as a less severe form of cystic hygroma.  |
| <b>Nuchal translucency:</b>          | A term used to refer to the translucent fluid filled space behind the neck of the fetus.   |
| <b>Para:</b>                         | A term used to refer to parity, which is defined as the number of births a woman has had after a viable gestational age, including live births and stillbirths.                                      |
| <b>Polyhydramnios:</b>               | The presence of excess amniotic fluid in the uterus.   |
| <b>Pyelectasis:</b>                  | Enlargement of the part of the kidney that collects the urine (the renal pelvis).  |
| <b>Quantitative fluorescent PCR:</b> | A genetic test in which DNA markers on chromosomes are used to pick up variation in the number of an individual's chromosomes.   |
| <b>Sandal gap:</b>                   | A widely spaced gap between the first toe (the big toe) and the second toe.  |
| <b>Soft-markers:</b>                 | Soft-markers are anatomical variants seen in fetuses during an ultrasound scan, which are not classified as malformations, but increases the risk for certain genetic syndromes, like Down syndrome. |
| <b>Talipes:</b>                      | A congenital deformity where the foot is twisted inwards and the person seems to be walking on their ankle. This is commonly referred to as a club foot.   |

|                                   |   |
|-----------------------------------|---|
| <b>Trisomy:</b>                   | A condition in which a person has an extra copy (three copies in total) of a particular chromosome.   |
| <b>Ventricular septal defect:</b> | A heart condition where there is a hole in the septal wall dividing the left and right upper chambers (ventricles) of the heart.                  |
| <b>Ventriculomegaly:</b>          | A brain condition which occurs when the lateral ventricles become dilated.  |
| <b>WhatsApp Messenger:</b>        | A cross-platform instant messaging application that allows smartphone cell phone users to exchange text, image video and audio messages for free. |

# CHAPTER 1: INTRODUCTION

## 1.1. BACKGROUND

The overall purpose of this study was to gain a deeper understanding of women or couples' decision-making processes regarding prenatal diagnostic (PND) testing for Down syndrome (DS) and termination of pregnancy (TOP) within the unique context of the Western Cape (WC) province in South Africa (SA). What makes this setting unique is that SA is a country rich in ethnic, cultural and religious diversity, but severely resource constrained with a large percentage of the population being classified as financially underprivileged. All of these factors have been previously reported as impacting decision-making within the prenatal setting (Todd *et al.*, 2010; Choi, Van Riper and Thoyre, 2012).

Worldwide, DS is the most common chromosomal condition causing intellectual disability with an incidence of between 1 in 650 to 1000 live births (Pivetti and Melotti, 2013). Evidence has suggested that the live birth incidence of DS in SA is high and the birth prevalence in the WC has been estimated as 1 in 670 (Molteno *et al.*, 1997). A condition like DS, which leads to a significant intellectual disability and ongoing general health care over a potentially long life, places a significant financial and psychosocial burden on families. Even more so in a resource constrained country like SA.

All pregnant couples are at risk of having a baby with DS regardless of age, lifestyle and socioeconomic status. Prenatal testing policies have been developed in most countries, including SA, in order to detect DS prenatally (Bryant, Green and Hewison, 2005). There are two main aspects to these prenatal testing services: prenatal screening and prenatal diagnosis (PND) (Sooben, 2010).

Prenatal screening strategies are used to determine the risk of the fetus having DS and usually entail one or a combination of the following: maternal age, maternal serum screening, non-invasive prenatal testing and ultrasound scanning to look for congenital anomalies or soft markers for DS (Smith and Visootsak, 2013). However, due to constraints on public health care resources in SA, risk calculation for DS is mainly based on maternal age and findings on ultrasound scans, most often performed in the 2<sup>nd</sup> trimester of pregnancy (Geerts, 2008; Urban *et al.*, 2011). Statistically women of advanced maternal age (AMA), over 35 years, have a higher chance to have a fetus with DS than younger women (Bittles *et al.*, 2007). Women

above a specific calculated risk are sent for genetic counselling and offered the option of PND (Saller and Canick, 2008).

PND of fetal chromosomal abnormalities, including DS, have been offered in SA since 1971 (Jenkins and Kromberg, 1976). Genetic counselling clinics were established in the early 1970's and genetic services are currently available in all the major cities with outreach services to surrounding rural areas (Jenkins, 1990; Todd *et al.*, 2010). In the WC, there are two major prenatal genetic counselling and testing services based at two public sector tertiary hospitals in Cape Town (CPT): Groote Schuur Hospital and Tygerberg Hospital (TBH). The SA National Health policy states that free PND should be part of the standard package of care offered to women who are at an increased risk for DS (Urban *et al.* 2011). If a prenatal diagnosis of DS is confirmed, TOP is offered (Wilson *et al.*, 2013).

TOP is defined as the premature ending of a pregnancy by any means (Aiken and Brockelsby, 2013). The SA Choice on Termination of Pregnancy Act of 1996 states that a pregnancy may be terminated at any stage when two medical practitioners, or one medical practitioner and a registered midwife believe that the continued pregnancy would result in a severely handicapped child (Ndjapa-Ndamkou, Govender and Moodley, 2013). Currently for DS, the limit for TOP is set before 24 weeks as the fetus is believed to be viable after this gestation (Govender and Moodley, 2013). This process usually entails the induction of labour with a combination of mifepristone and misoprostol medication (Kapp *et al.*, 2007). The final decision of whether to opt for TOP lies with the woman and her partner and a study conducted in SA has shown that 69% of women who receive a prenatal diagnosis of DS will opt for this procedure (Todd *et al.*, 2010).

## **1.2. STUDY RATIONALE AND SIGNIFICANCE**

The advancement of technology within the prenatal setting has had a major impact on how women or couples experience their pregnancy. Conventionally, pregnancy is seen as a happy and positive experience in the lives of many women and their partners. Once they have accepted and adjusted to the pregnancy, they imagine their future child and prepare for their role as parents (Leifer, 1998). Having the technology to tell couples that they are at a high risk for DS has changed this positive experience to one that is anxiety provoking for many women or couples as they are now faced with having to make unexpected life and death decisions regarding their unborn child (Heyman *et al.*, 2006).

Firstly they need to make a decision regarding PND, which has been described in the literature as a profoundly stressful event which can have devastating effects on the emotional wellbeing of the women or couples. Secondly they need to decide about whether they will continue the pregnancy if the fetus is affected (Singer, 2004; Leuthner and Jones, 2007). Decision-making regarding TOP can have even more profound psychological and social consequences on the health of the women and couples. These consequences include grief, guilt, feeling genetically inferior, low self-esteem, doubt about rightness of decision and feeling moral and social pressure from others due to fear of judgment (Kersting *et al.*, 2005; Korenromp *et al.*, 2009; Asplin *et al.*, 2013).

Decision-making within the prenatal setting is complex and several factors are believed to influence women's decisions (Choi, Van Riper and Thoyre, 2012). These decisions are full of emotion. Self-reflection and many societal, familial, medical and interpersonal factors play an influential role (Anderson, 2007; Lawson and Pierson, 2010). These decisions are pivotal in a pregnancy and the couples need to face the consequences this might have on their lives and their family (Carroll *et al.*, 2012). These decisions are also time sensitive as PND and TOP can only be offered up until a specific gestation as decided by the clinicians and permitted by the law. These time constraints only allow a short period in which women or couples have to make these complex and emotionally charged decisions (Marteau and Dormandy, 2001; Durand *et al.*, 2009). As they need to make these decisions while feeling overloaded with information and emotionally distressed, there have been reports of women regretting the decisions at a later stage, especially regarding TOP (Durand *et al.*, 2009). These women were often conflicted if their decision was in disagreement with their own personal and moral beliefs as well as with their partners' decisions (Korenromp *et al.*, 2009).

As a genetic counsellor assisting women and couples with making decisions regarding PND for DS and TOP for more than 8 years, I have witnessed, first-hand, the devastating effects inadequate decision-making can have on these couples and their families. I have seen how couples become and remain anxious for the remainder of the pregnancy even after a negative PND test result. The anxiety of being at high risk for DS becomes so overwhelming at times, that some couples who opted against TOP, reported regretting their decision as they were unable to enjoy the remainder of their pregnancy. There have also been couples who felt regret after having a TOP for DS.

The studies done previously have mainly focused on describing women or couples' attitudes towards and identifying the key factors that influence decisions regarding PND (Reid *et al.*, 2009; Seror and Ville, 2009; Brajenović-Milić *et al.*, 2010; Choi, Van Riper and Thoyre, 2012).

However, hardly any of these studies made use of qualitative methods to provide an in-depth understanding of how these key factors interact with each other and how the decision-making processes in the prenatal setting are experienced. Even less is known about women's decisions regarding TOP after a positive diagnosis of DS and the impact this had on their emotional wellbeing and daily lives (Choi, Van Riper and Thoyre, 2012; Asplin *et al.*, 2014).

Furthermore, to my knowledge there have been no qualitative studies investigating how pregnant women or couples experience the decision-making process regarding PND for DS and TOP within a SA context. The lack of SA studies makes it difficult for the health care professionals (HCPs) to anticipate the psychosocial issues these women and their families might encounter. If the HCPs are not aware of the possible negative impact then the proper support cannot be offered to limit this (Brajenović-Milić *et al.*, 2010). Without further investigations to gain an understanding of the experiences of these women and couples it is impossible to improve the services offered.

From my personal experiences working in a prenatal genetic counselling clinic and after researching the available literature on this topic, I have identified the need for conducting a study to gain a greater understanding of these decision-making processes. The value in gaining a unique in-depth understanding of the lived experiences of these women and their partners, and the process of navigating decisions, are valuable for professionals working in this setting as this will lead to better provision of decision support within a holistic context, while acknowledging the multiple challenges for couples and their families (Muller and Cameron, 2015). This in turn will lead to increased patient satisfaction with regards to their decisions which will limit the negative impact of these decisions on the patients' emotional wellbeing and daily lives. Therefore, the current study is aimed at filling this gap in knowledge by investigating the experiences of women or couples who attend the prenatal clinic at a SA public sector hospital, TBH in CPT.

### **1.3. THE SOUTH AFRICAN CONTEXT**

The present study was conducted in the SA context which is vastly different from the developed countries in which most of the previous qualitative studies investigating the decision-making processes within the prenatal setting were conducted.

SA is home to about 55 million people, with the vast majority of 80.7% being Black African, 8.7% are Coloured, 8.1% are White and the remaining 2.5% are Indian or Asian. The ethnic stratification in the WC province differs in comparison to the other provinces as the majority,

47.5%, of the population are Coloured, 35.7% are Black African, 16% are White and the very small remaining 0.8% are Indian or Asian. SA has 11 official languages with the three most spoken household languages in the WC being Afrikaans (46.6%), Xhosa (31%) and English (19.6%). Most (78%) South Africans affiliate themselves with Christianity. Others either have no religious affiliation (11.98%), belong to Traditional African religions (4.41%) or to other smaller religious groups including Islam, Hinduism and Judaism (Statistics SA, 2016).

About 87.4% of the SA population has some form of formal education, of which about half have completed their secondary education (Grade 12 certificates). Only 4.6% of individuals will go on to seek some form of Tertiary education. About 12.6% of the population has no formal education. There is a high unemployment rate of 27.7% and on average the annual household income is about R29 400 (Statistics SA, 2016). Therefore, due to financial constraints the majority of the SA population live in lower socioeconomic areas and make use of the public sector health care facilities. Statistics SA (2016) reported that only 23.2% of households could afford having at least one member on a private medical-aid.

The public health care services in SA have been severely affected by the country's troubled past of apartheid, gender-inequality and violence. Even though the national public health care services, were transformed into a more comprehensive and integrated service post-apartheid, failure in the leadership and weak management of funds have lead to the inadequate implementation of what are often good policies (Coovadia *et al.*, 2009). The health and well-being of most of SA's population remains plagued by the additional burden of infectious and noncommunicable diseases (specifically HIV), persisting social disparities, and inadequate human resources to provide efficient health care to the growing population. Some pivotal facets of primary health care are not in place due to financial constraints and the substantial human resources crisis SA is facing (Mayosi and Benatar, 2014).

Within the SA context, it is important to be aware of the above-mentioned challenges when trying to improve the health care services. It has been suggested that in order to improve the health care services it is important to firstly address the social issues which lie outside the health system. As a large proportion of the population is affected by poverty, health is predominantly affected by a lack of access to basic requirements for life like clean water, adequate nutrition and effective sanitation, reasonable housing conditions, access to vaccinations and good schooling (Coovadia *et al.*, 2009; Mayosi and Benatar, 2014). These factors in addition to cultural and language barriers all lead to the impediment of adequate health care services (Penn and Watermeyer, 2012).

SA does not have the adequate number of trained health care professionals to meet the needs of its population (Coovardia and Mayosi article). SA is also facing a major HIV epidemic which has contributed to these lack of resources (Coovardia).

The unique SA context adds to the significance of the current study as it investigated how these above-mentioned challenges influenced the prenatal care SA women or couples received as well as their decisions regarding PND for DS and TOP.

#### **1.4. CHAPTER OUTLINE OF DISSERTATION**

This dissertation comprises of six chapters in total and a brief overview of each is provided below in order to help the reader navigate through this document.

This chapter, Chapter 1, introduces the study, provides the rationale for conducting the study and the significance thereof. It also gives a broad overview of the SA context in which the study was conducted. This chapter is concluded by an overview of all the chapters in the dissertation.

Chapter 2 and 3 presents the literature review. Chapter 2 focused on describing the available literature on PND and TOP. This chapter also provides literature on the women or couples' reported experiences with regards to these procedures. Lastly an outline of the prenatal genetic counselling session and a description of the counsellor's role is given. Chapter 3 provides detailed information on decision-making theories within the health setting in general as well as proposed models and theories within the prenatal setting. The results of the previous empirical studies investigating the women and/or couples' decision-making processes within the prenatal setting is also presented. Chapter 3 is concluded by a summary of all the decision-making factors believed to play a role in making a decision regarding PND for DS and TOP.

Chapter 4 is the methodology chapter and presents the research aim, objectives and research question. This chapter provides a detailed description of the qualitative research methodology use as well as an explanation for why this was the method of choice. This is followed by a description of the philosophical underpinnings of an interpretive phenomenological approach and how this was used to conduct the current study. The sampling strategy, data collection and analysis methods are also discussed in detail. This chapter is concluded by the researchers' declaration of self as well as the challenges faced while conducting the study.

Chapter 5 presents the findings of the current study. The three major themes which arose from the data were being at high risk for DS, decision-making and experiences regarding PND testing and decision-making and experiences regarding TOP. These major themes and their subthemes are discussed in detail in Chapter 5.

Chapter 6 provides a discussion of the results of this study in comparison to the findings of previous studies. The findings are also compared to the existing proposed decision-making models within the prenatal setting. A summary of the self-reported decision-making factors are given and have been used to develop a guideline. This guideline is aimed at guiding HCPs offering decisional support to women and couples within the SA context. Recommendations are listed on how to improve the decisional support and aftercare offered in the prenatal clinics. The study strengths and limitations are discussed. Lastly the chapter presents the final conclusions of the study.

## CHAPTER 2: PRENATAL TESTING AND TERMINATION OF PREGNANCY

### 2.1. INTRODUCTION

In order to gain an understanding of the decision-making process regarding PND for DS and TOP, it is important to first understand what each of these procedures entail and how it impacts on the women and/ or couples. Therefore, in this chapter, detailed information about these procedures and the impact of each will be provided. In addition, information about the prenatal genetic counselling session and the role of the counsellor will be presented.

The information was obtained by doing a literature search on PubMed, Google Scholar, ScienceDirect, EBSCOhost, SA ePublications and Sabinet. The following search terms were used: "Down syndrome parent experiences" "prenatal genetic testing", "prenatal testing Down syndrome", "experience prenatal testing", "qualitative study prenatal testing", "termination of pregnancy Down syndrome", "experience termination of pregnancy Down syndrome", "Down syndrome parent experiences", "experience continuing pregnancy prenatal diagnosis Down syndrome" and "prenatal genetic counselling".

### 2.2. PRENATAL TESTING STRATEGIES

As briefly mentioned in the background section of Chapter 1, prenatal testing strategies consist out of two components i.e. prenatal screening tests (PNS) and prenatal diagnostic tests (PND). These two testing strategies will be discussed in further detail in the sections below as well as how having these tests impacts on the women and her partner's pregnancy experience.

#### 2.2.1. Prenatal Screening Tests

Screening tests are non-invasive testing procedures that hold no risk for fetal loss. They do not provide a definitive diagnosis, but risk assessment information is useful when having to make a decision to undergo an invasive prenatal diagnostic test (Wilson *et al.*, 2013).

Table 2.1 provides information on the prenatal screening tests for DS that are currently being offered in SA (Geerts, 2014). It should be added that maternal age is also an important component in risk assessment for DS, and an age above a certain threshold (37 years in the public sector hospitals in CPT) is used as the initial screening method. Currently maternal age is factored into the risk results generated by the other screening methods as listed in Table 2.1. It is important to note that biochemical tests and non-invasive prenatal testing (PNT) are

not being routinely offered in the public sector hospitals due to cost constraints. Specifically at TBH, where the current study was conducted, prenatal screening strategies are limited to maternal age and ultrasound-based methods.

**Table 2.1: Description of different screening tests offered in SA, in ascending order of cost per screening test (Geerts, 2014 – modified)**

| Test                | Description  | Gestational age window                                  |
|---------------------|--|---|
| Fetal anatomy scan  | Mid-trimester scan with general practitioner or obstetrician   | 18-23 weeks   |
| Biochemical test T2 | Triple test on maternal blood  | 14-20 weeks (ideal 16)                                  |
| Biochemical test T1 | PAPP-A and free beta HCG on maternal blood   | 8-14 weeks (ideal 9)                                    |
| Simple NT scan      | Ultrasound scan with NT measurement by FMF accredited operator   | 11-13 weeks (ideal 12)                                  |
| Genetic sonogram    | Detailed ultrasound scan by expert, specifically for DS risk assessment                                  | 16-23 weeks   |
| Extended NT scan    | NT scan with additional markers (nasal bone, tricuspid valve, ductus venosus) by FMF accredited operator | 11-14 weeks (ideal 12)                                  |
| Early combined test | Extended NT scan and biochemical test (usually T1)   | Ideal: Biochemical test at 9 weeks and scan at 12 weeks |
| NIPT                | Cell-free fetal DNA in maternal blood  | From 10 weeks onwards                                   |

T1: first trimester, T2: second trimester, NT: nuchal translucency, FMF: Fetal Medicine foundation, NIPT: non-invasive prenatal testing

At TBH screening tests are offered according to the Western Cape Ultrasound Policy (2012). This policy suggests ultrasound screening recommendations based on maternal age at the time of conception. Women who are younger than 37 years of age are offered a routine fetal anatomy scan in primary care by a community ultrasonographer between 18 to 23 weeks. Depending on gestational age at presentation, women between the ages of 37 and 39 years are offered an 11 to 14 week NT scan or an 18 to 23 week genetic sonogram. This is typically conducted at a tertiary level, but may occur in primary care clinics subject to the availability of an appropriately skilled sonographer. All women older than 40 years are referred to a tertiary hospital for an 11-14 week NT scan and a 16 to 18 week fetal anatomy scan or genetic sonogram. As the NT scan and genetic sonogram are the two screening methods most often used at TBH, these ultrasound scans will be discussed in further detail.

#### **a) Nuchal Translucency Scan**

The NT scan is performed during the first trimester between 11 weeks and 13 weeks and 6 days gestation. NT is the fluid filled space behind the neck of the fetus. During this scan this space is measured. An increased NT measurement is the single most powerful marker for DS

during the first trimester (Unterscheider and Malone, 2011). It has a detection rate of 70-80% with a false positive rate of 5% (Snijders *et al.*, 1998).

### **b) Fetal Anatomy Scan and Genetic Sonogram**

The fetal anatomy scan is a systematic assessment of the fetus for common major fetal anomalies. This typically takes place between 18 and 23 weeks of pregnancy. The genetic sonogram is an adaptation of the fetal anatomy scan in which the fetus is also assessed for the presence of second trimester soft-markers associated with DS.

The major congenital anomalies associated with DS include cardiac defects (atrio-ventricular septal defect (AVSD) and ventricular septal defect (VSD), duodenal atresia, cystic hygroma and hydrops fetalis (Unterscheider and Malone, 2011). Nicolaides *et al.* (1992) have shown that fetuses that have more than one congenital anomaly are more likely to have chromosomal abnormalities. With one anomaly, the risk of chromosomal abnormality is 2%, it rises to 11% with two, to 66% with five and up to 92% with eight malformations.

Soft-markers are anatomical variants seen in approximately 15% of normal fetuses and are not classified as malformations or anomalies. They are however associated with an increased risk for genetic conditions, such as DS (Odibo and Ghidini, 2014; Reddy *et al.*, 2014). The presence of soft-markers is not diagnostic and is only used to adjust the risk of having a fetus with an aneuploidy (Acharya *et al.*, 2013).

Soft-markers vary in the degree of association with DS and therefore it has become practice to estimate the degree of association as a likelihood ratio by which the age-related risk is altered. The likelihood ratio when multiple soft-markers are detected significantly increases when compared to seeing the same marker in isolation (Acharya *et al.*, 2013). Markers that are more frequently associated with DS are hypoplasia or absence of the nasal bone (NB), thickened nuchal fold, shortened long bones, pyelectasis, hyperechogenic bowel, echogenic intracardiac foci (EIF), abberant right subclavian artery (ARSA) and mild ventriculomegaly (Nicolaides *et al.*, 1992; Kalelioglu, 2007; Geipel *et al.*, 2010; Sooklim and Manotaya, 2010; Towner *et al.*, 2010; Agathokleous *et al.*, 2013). A short description and the management implications of each of these markers are provided in table 2.2.

**Table 2.2: Description and management of soft markers most often associated with DS (Nicolaides et al., 1992; Kalelioglu, 2007; Geipel et al., 2010; Sooklim and Manotaya, 2010; Towner et al., 2010; Agathokleous et al., 2013).**

| Soft-marker                      | Description   | Possible cause  | Management  |
|----------------------------------|---|---|---|
| Hypoplastic or absent nasal bone | Nasal bone measurement below the 2.5th or 5th percentile for gestational age or not seen.   | Familial facial features<br>Chromosomal abnormality   | None  |
| Thickened nuchal fold            | Measurement made from outside of occipital bone to the skin edge. Thickened when equals or exceeds 6mm at 15-20 weeks   | Chromosomal abnormality<br>Congenital cardiac defect<br>Congenital intrauterine infection   | Two week follow-up assessment to assess whether progressive. If non-progressive no further follow-up needed.  |
| Short long bones                 | When femur or humerus length measurement is below the 5th centile for gestational age   | Familial short stature<br>Chromosomal abnormality<br>Skeletal dysplasia<br>Growth abnormality   | Follow-up assessment in third trimester to assess fetal growth.   |
| Renal pyelectasis                | Anteroposterior diameter of the renal pelvis of 4mm before 28 weeks and 7mm after 32 weeks gestation. When measurement is more than 10mm and/or calyche dilatation is present the term hydronephrosis is used.  | Chromosomal abnormality<br>Uretropelvic obstruction   | Follow-up assessment at 32 weeks to rule out persistent or progressive pyelectasis as well as significant hydronephrosis. Postnatal follow-up in significant hydronephrosis as may lead to renal complications. |
| Hyperechogenic bowel             | Bowel is as bright as or brighter than the surrounding bone.  | Chromosomal abnormality<br>Cystic fibrosis<br>Congenital intrauterine infections<br>Intrauterine growth restriction<br>Swallowing of intra-amniotic blood | Treat infection if due to infection. Follow-up assessment of fetal growth at 32 weeks.  |
| Echogenic intracardiac foci      | Focal spot within the heart that is similar to the brightness of the bone.  | Microcalcification<br>DS (if other markers also seen)   | None  |
| Abberant right subclavian artery | Occurs in the setting of a left-sided aortic arch where the last branch of the aortic arch is the right subclavian artery, instead of being the left subclavian artery. The right subclavian artery then crosses behind the trachea and oesophagus in order to reach the right subclavian region. | Normal variation<br>Chromosomal abnormality   | None  |
| Mild ventriculomegaly            | Width of the cerebral ventricles between 10 and 15mm.   | Chromosomal abnormality<br>Single gene disorders<br>Developmental brain abnormalities<br>Congenital intrauterine infections                               | Follow-up assessment to rule out progression. Neonatal assessment to rule out neurodevelopmental delay which occurs in 10% of isolated cases.   |

### 2.2.2. Prenatal Diagnostic Tests

Typically, PND tests are offered only to women who meet a predetermined level of risk based on screening tests. This is done for two reasons: the greater cost and the slight increased risk of miscarriage associated with diagnostic versus screening tests. Until the introduction of NIPT, screening programmes have typically and rather arbitrarily been designed to offer PND to the 5% of women at highest risk of DS. Since the risk threshold applied is around 1 in 200-300, it is evident that the majority of this 5%, should they choose PND, would test negative for DS (and therefore have a false positive screening test result). The exact false positive rate varies with the screening method used, for example a mathematical model of combined first trimester biochemical testing and ultrasound found that it would detect one case of DS for 29 positive screen results. This means that 28 out of these 29 individuals received a false positive result. On the contrary, since even the best screening tests have an imperfect detection rate, some cases of DS will be missed by screening (false negative screening test result) (Spencer, 2001).

Internationally, maternal age remains an important screening method and PND tests are usually offered to women of AMA, over 35 years, as statistically their age places them at a higher risk for DS than younger women (Kuppermann *et al.*, 2000; Bittles *et al.*, 2007). Additionally, PND is offered to young women who screen high risk for DS on any of the screening tests (Wapner *et al.*, 2003).

In the WC public health care sector, PND is offered to all women above the age of 40 years as their risk for DS significantly increases at this age and is estimated to be at least 1 in 100 (1%). PND is also offered to all women who screen high risk (1 in 100) for DS during first trimester NT-risk assessment. During the second trimester, women aged between 37 and 40 will only be offered PND if a fetal anomaly (FA) or at least one marker for DS is detected on their ultrasound scan. Women younger than 37 are offered PND only in the instances where multiple markers for DS or a significant FA is detected which places them at high risk for aneuploidy (Geerts, 2012).

PND allows for a definitive diagnosis of DS and currently three procedures are available to collect samples for genetic diagnostic tests. These procedures are called chorionic villus sampling (CVS), amniocentesis and cordocentesis (Wilson *et al.*, 2013). Each of these procedures carries a risk of miscarriage over and above the gestation-related risk of miscarriage. In women who are HIV positive, it also carries a small risk of transmitting the virus to the fetus. This risk has been reported to be as high as 3% and as low as less than 1% if the mother is on antiretroviral treatment (Maiques *et al.*, 2003; Somigliana *et al.*, 2005).

The samples obtained from the above-mentioned procedures are used for chromosomal analysis by karyotyping, which takes about two weeks to do or one week in the case of cordocentesis. If there is a time limitation, a reliable result may be generated within 3 days by using rapid interphase fluorescence *in situ* hybridisation (FISH) or quantitative fluorescent PCR (de Jong *et al.*, 2011; Wilson *et al.*, 2013). If either a full or partial triplication of chromosome 21 is found, a diagnosis of DS is confirmed (Bittles *et al.*, 2007).

A brief explanation of each of the PND procedures will follow. Also Figure 2.1 (p.14) provides an illustration of the CVS and amniocentesis procedures as these are the two procedures most often performed.

### **a) Chorionic Villus Sampling**

During the first trimester between 10 and 13 weeks and 6 days of gestation, the CVS is performed. This procedure involves an ultrasound guided transabdominal aspiration of the chorionic villi from the placenta (Wapner, 2005).

The CVS procedure is limited by the less than 1% chance for mosaicism. Mosaicism occurs when some of the cells studied show an abnormality, while others appear to be normal. The procedure is also limited by the less than 1% chance for maternal contamination, where the cells studied are from the mother and not the fetus (Ledbetter *et al.*, 1992). The estimated risk of miscarriage after this procedure is between 0.5 and 1% (Jackson *et al.*, 1992). At TBH, a miscarriage risk of 1% is presented to the patients.

However, the major benefit of CVS is that it allows for genetic diagnosis in the first trimester, which decreases maternal anxiety and provides the option of a safer, less traumatic first-trimester TOP in the event of an abnormal result (Heckerling, Verp and Hadro, 1994).

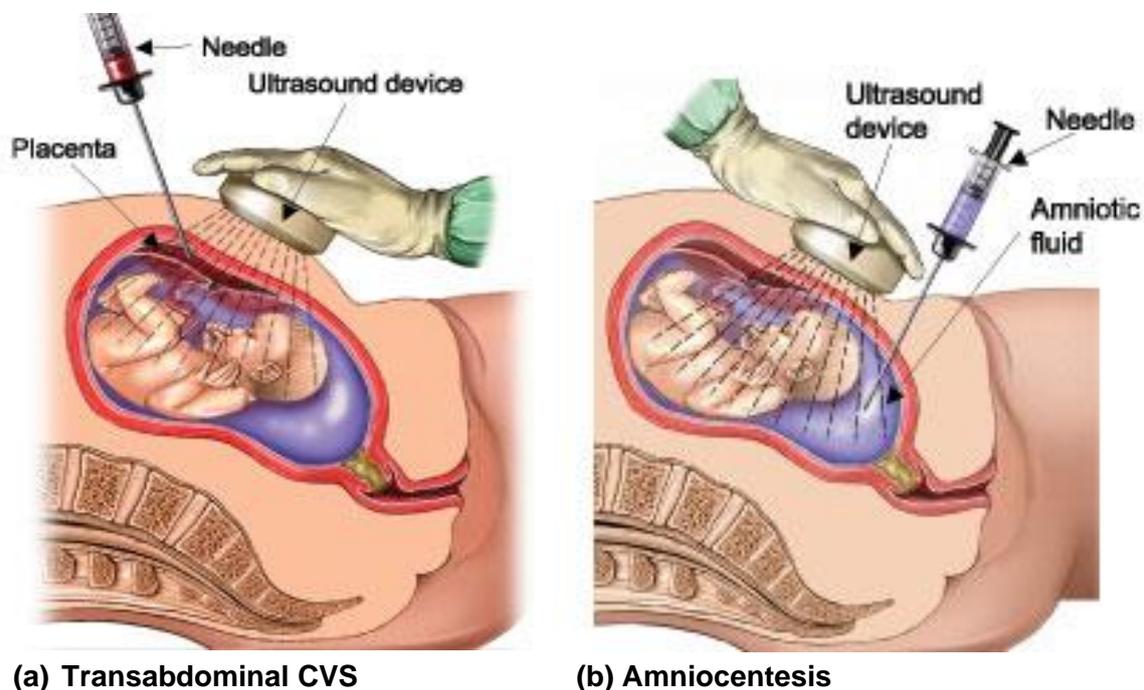
### **b) Amniocentesis**

After 15 weeks of gestation the amniocentesis is the preferred test. This procedure entails ultrasound guided transabdominal removal of amniotic fluid by needle (Harper, 2004). The accuracy for detection of fetal chromosomal abnormalities by amniocentesis is higher than CVS as it does not carry the risk of placental mosaicism or maternal contamination (Wilson *et al.*, 2013).

The miscarriage risk post amniocentesis procedure is variable and depends on each specific centre. The risk that is most often quoted in the literature is 0.5%. However, this figure is dependent on the centre where the procedure is being performed and can be as high as 1%

and as low as 0.1% (Wilson *et al.* 2013). At TBH, the miscarriage risk is quoted as 1%. In comparison to CVS, amniocentesis has a lower risk of miscarriage post procedure (Heckerling, Verp and Hadro, 1994).

The major limitation of amniocentesis is that it can only be performed later in the pregnancy, which leads to an undesired second-trimester TOP with a risk of maternal morbidity. The delay in genetic diagnosis also leads to increased maternal anxiety and diminished maternal-fetal bonding as many women only allow bonding to occur once they know their fetus is healthy (Heckerling, Verp and Hadro, 1994).



**Figure 2. 1: Illustration of transabdominal CVS and amniocentesis procedures (<http://www3.betterhealth.vic.gov.au>)**

### **c) Cordocentesis**

Cordocentesis is usually performed from 20 weeks of gestation. This procedure entails sampling fetal blood from the umbilical cord and is performed by inserting a needle through the maternal abdominal wall under ultrasonographic monitoring. This procedure is only performed for the purposes of PND for DS in cases where CVS and amniocentesis are not feasible or an urgent test result is required (Tongprasert, 2007).

Procedure-related miscarriage is a major complication of cordocentesis. An overall fetal loss risk of 1.4% has been reported if performed before 28 weeks gestation (Ghidini *et al.*, 1993).

This procedure is also the more difficult to perform in comparison to the CVS and amniocentesis and may lead to serious complications like fetomaternal haemorrhage if performed by an inexperienced practitioner (Nicolini *et al.*, 1988).

### **2.2.3. Impact of Prenatal Testing on Pregnancy Experience**

The advancement of technology within the prenatal setting has had a major impact on how the couples experience their pregnancy. Pregnancy is usually seen as a happy and positive experience in the lives of many woman and couples (Leifer, 1998). Having the technology to tell couples that they are at a high risk for DS has changed this positive experience to one that is anxiety provoking for many (Heyman *et al.*, 2006).

Studies have shown varied reactions towards high risk screening test results. Some women treat their screening results as a positive diagnosis in order to be better prepared for an actual positive diagnostic test result (Rothman, 1994; Heyman *et al.*, 2006). It has also been indicated that a false positive screening test or a delay in the diagnostic test results can lead to considerable stress and mental burden and even rejection of the pregnancy (Moyer *et al.*, 1999; Heyman *et al.*, 2006; Aune and Möller, 2012).

Tercyak *et al.* (2001) investigated the psychological status of 129 women who attended an urban women's health clinic in the USA. Their findings suggested that women who undergo prenatal counselling and testing are prone to experience distress and anxiety. These findings were supported by Hunt, De Voogd and Castañeda (2005) who interviewed 40 women from three prenatal genetic speciality clinics in the USA. They added that a confirmed high risk after having a positive screening test, can be even more distressing and devastating. Sommerseth and Sundby (2010) interviewed Norwegian women after the detection of soft-markers on a second trimester ultrasound scan and added that even though these women felt overpowered by emotions they still maintained a sense of hope that the baby will be normal while awaiting the outcome of the pregnancy or PND results.

Those women who decide to have PND have the added stress of fear of having a miscarriage, worry about the health of the fetus and having to decide what they will do if the result comes back positive for an abnormality (Kenen, A. C. Smith, *et al.*, 2000). Burke and Kolker (1993) who conducted in-depth interviews with 24 women who underwent invasive PND found that women had raised anxiety levels over the possibility of having to terminate. An interesting finding from this study was that the women who went for a CVS were less anxious than those who went for an amniocentesis as they seemed less bonded to the fetus as the gestation of their testing were earlier. This phenomenon was supported by Tursinawati *et al.* (2015) who

conducted a quantitative study to investigate the psychological responses amongst 70 women undergoing PND in Singapore

Even though anxiety is raised pre-test, in the majority of cases the prenatal test is negative, which leads to relief and reassurance in many couples which promotes pregnancy adaptation (Phipps *et al.*, 1986). Pregnancy-related anxiety, depression, and somatic symptoms have been shown to decrease post prenatal test (Marteau *et al.*, 1992; Lou *et al.*, 2015). However, there have been reports of residual feelings of anxiety (Baillie *et al.*, 2000).

This finding was emphasised by a qualitative study conducted in the UK by Heyman *et al.*, (2006) who found that some women find it difficult to disengage from higher risk status even after the diagnostic test has ruled out a chromosomal abnormality. Furthermore, Åhman, Runestam and Sarkadi (2010) reported that the women in their study experienced it difficult to become attached to a possibly abnormal child, even after they had received negative test results. This relates to a phenomenon called a “tentative pregnancy” which was introduced with the introduction of prenatal testing. Rothman (1994) defined this as delayed investment in the pregnancy or not experiencing the pregnancy as real until test results are normal, the consideration of TOP subsidies and feeling reassured the baby will be normal.

## **2.3. TERMINATION OF PREGNANCY**

If PND confirms a diagnosis of DS in the fetus, those couples who are less than 24 weeks pregnant are offered the option of TOP. In SA, the legal offer of TOP for fetal anomalies is governed by the Choice on Termination of Pregnancy Act of 1996, which states that TOP after the 20<sup>th</sup> week of pregnancy is permitted if a medical practitioner, after consultation with another medical practitioner or a registered midwife, believes that the pregnancy would result in a severe malformation of the fetus if continued. This legislation’s stratification of indications for TOP by gestation is not linked to the timing of fetal viability and it also does not clarify what is meant by “severe malformations”. The Tygerberg Fetal Medicine policy therefore accepts TOP for DS up to 24 weeks, which is commonly accepted as a threshold for viability.

### **2.3.1. TOP Procedure**

The TOP procedure involves the expulsion of the fetus before viability. A distinction is made between surgical and medical TOP (Kelly *et al.*, 2010).

Surgical TOP up to 15 weeks of gestation entails dilatation of the cervical canal and vacuum aspiration of the uterus (Robinson, 2014). After 15 weeks of gestation dilatation and evacuation of the uterus is needed (Kelly *et al.*, 2010).

Medical TOP is usually performed after 12 weeks of gestation and entails an induced labour process. This procedure is performed by giving the women an initial dose of mifepristone in the hospital and then sending them home. They are then re-admitted to hospital 36 to 48 hours later to receive 3 hourly misoprostol until the fetus is delivered (Andersson, Christensson and Gemzell-Danielsson, 2014). The median interval from misoprostol induction to delivery is 5 to 6 hours (Hamoda *et al.*, 2005). A nurse usually assists the women in the delivery process. Paracetamol and non-steroid anti-inflammatory drugs are commonly used for pain relief (Andersson, Christensson and Gemzell-Danielsson, 2014).

The method used to perform TOP depends on the gestational age. In SA, the women who find out about the diagnosis of DS during their first trimester after the CVS result are usually offered the option between surgical or medical TOP. Those women who find out in the second trimester after the amniocentesis have to go through the medical TOP process (Robinson, 2014).

The labour process during the medical TOP is shorter in comparison to natural labour, but not less painful and still involves similar complications. The pain experienced has been described as similar to menstrual pain, pain from previous labour or miscarriage (Andersson, Christensson and Gemzell-Danielsson, 2014). The biggest difference is that this is an emotionally difficult process as it results in the birth of a stillborn baby and the patient does not experience the joy that she will during the birth of a live and healthy baby (Hodgson *et al.*, 2016).

### **2.3.2. Impact of Having TOP**

When couples choose to terminate a pregnancy due to a diagnosed FA like DS, this loss is associated with a greater psychological morbidity than a TOP for non-fetal indications (Hodgson *et al.*, 2016). Women who undergo a TOP of a wanted pregnancy experience deep emotions such as sadness, anger, guilt and grief that is associated with any other bereavement. Their grief process is believed to be complicated due to their role in the decision to TOP (Statham, Solomou and Chitty, 2000).

McCoyd (2007) interviewed 30 American women undergoing a TOP and reported these women describing an initial period of shock and numbness shortly after receiving the diagnosis

of a FA. This initial period played a protective role for days or weeks until the TOP procedure was done and extended up to two to three weeks after the procedure. However, the majority of the women described experiencing intense grief once this period was over.

A questionnaire study conducted in the Netherlands by Korenromp *et al.* (2009) found that this intense grief lasted for a considerable period afterwards. The majority of their participants still presented with serious problems including symptoms of post-traumatic stress disorder and depression, four months after termination. A review by Sandelowski and Barroso (2005) found that many studies in the literature reported couples still reliving the trauma of the TOP event up to ten years after the process. A qualitative study conducted in the USA by Maguire *et al.* (2015) described that certain triggers caused their previously subsiding grief to re-intensify. These triggers were certain anniversary dates like the date of TOP or the due date.

Apart from the long-lasting grief that many couples experience, studies have reported that couples may also struggle with feelings of ambivalence, guilt, shame and regret (Rillstone and Hutchinson, 2001; Robinson, 2014). The couples may wonder if they rather should have continued the pregnancy and managed with raising a child with a disability.

The feelings of guilt and shame amongst the couple who have a TOP is believed to be exacerbated by the social stigma that having a TOP is immoral and unacceptable (France *et al.*, 2013). A review by Robinson (2014) found that for this reason many couples reported feeling hesitant to disclose this information with their family and friends as they feared being condemned for their actions by those who do not approve. This led to social isolation as the couples kept their experiences secret. This also diminished their support system (Thachuk, 2007; France *et al.*, 2013).

Robinson (2014) also found that in many of the studies included in their review, the couples preferred stating they had had a miscarriage as this offered them support from others without being judged or feeling guilty for having to make the decision to end the pregnancy. McCoyd (2007) commented that this support received when not disclosing the full truth was often ill-gotten and the women reported not feeling effectively supported. Studies have indicated that women who disclose their decision to have a TOP to their social network, often encountered less disapproval than expected and allowed them to gain the necessary support to overcome their loss (Sandelowski and Barroso, 2005; McCoyd, 2007; France *et al.*, 2013). France *et al.* (2013) conducted a qualitative study in the UK and reported that even though there were positive aspects to full disclosure, in some instances the couples' fears became a reality and they did not get the anticipated support and empathy. They were faced with disapproval from

people or the people not knowing how to deal with the news, which in turn lead to social withdrawal.

In some instances the couples chose non-disclosure in order to protect others from the emotional impact. In the study by France *et al.* (2013) the couples reported not wanting to tell their grandparents as they felt the shock may cause a deterioration in their health. They were also hesitant when telling their other children as they did not want to burden or upset them. The majority of the participants did disclose this information by using selective language like there was something wrong, the baby had gone to heaven or had been born too soon and died.

The choice of having a TOP also impacted on future reproductive choices of the couples. Fisher (2008) reported that women are often anxious to recover physically as they would like to try and conceive again in order to replace their grief with the joy of a healthy baby. In contrast a study conducted in SA by Ndjapa-Ndamkou, Govender and Moodley (2013) that many of the women were cautious when planning future pregnancies as they feared having another child with a disability. Previous studies have reported that women experienced anxiety during a new pregnancy after having a FA diagnosed in a previous pregnancy (Rillstone and Hutchinson, 2001; Lafarge, Mitchell and Fox, 2013).

In the long run the couples did not regret their decision to have a TOP. With time, the negative emotions experienced improved and they were able to cope with their loss by employing various coping strategies (Kersting *et al.*, 2005; Fisher, 2008; Robinson, 2014).

### **2.3.3. Coping After TOP**

Previous studies have shown that women or couples who have had a TOP, use different coping strategies to deal with the trauma of this event (Carver and Connor-Smith, 2009; Lafarge, Mitchell and Fox, 2013). Coping strategies entail identifying psychological or physical resources to reduce the magnitude of the subsequent impact on an individual when facing a stressful and traumatic event (Lafarge, Mitchell and Fox, 2013).

The strategies used are determined by individual factors such as personality, previous experience, values and beliefs, as well as situational factors such as type of stressor and timing of the event (Lafarge, Mitchell and Fox, 2013). As this is such an individualised process women in similar situations employ different coping strategies. The coping strategies reported within the context of this study include acknowledging and remembrance of the baby,

validation of decision to TOP, avoidance, social isolation, support from others and focusing on the future.

Lafarge, Mitchel and Fox (2013) conducted a survey study amongst UK women who had a TOP for fetal indications, to investigate the coping strategies they used. Lafarge, Mitchel and Fox (2013) found that support was the main coping strategy used in women undergoing a TOP for FA. Support during and after the TOP process have been reported as essential with coping and to promote the long-term wellbeing of couples who have undergone this process for fetal-indications. Studies have identified the woman's partner as the main source of support. Support from HCPs, family members and friends were also deemed as important (Lafarge, Mitchell and Fox, 2013; Andersson, Christensson and Gemzell-Danielsson, 2014). The women who are not supported by their partners, family or friends, post-termination, experience increased morbidity (Statham, Solomou and Chitty, 2000).

Additionally, Lafarge, Mitchel and Fox (2013) found that the women used acknowledgement of their baby to cope with their loss after having a TOP. They acknowledged their baby by spending time with their stillborn after delivery. They found this comforting as it allowed them the opportunity to bond with their baby and to check for any resemblance to family members (and themselves) and to see the baby's anomaly. A Swedish study by Andersson, Christensson and Gemzell-Danielsson (2014) added that the women also viewed this opportunity as a way to say goodbye and to get rid of any fantasies that the baby is still alive. In contrast, some studies have found that women who chose to see the stillborn found it more difficult to adjust than those women who chose not to see the stillborn (Statham, Solomou and Chitty, 2000; Lafarge, Mitchell and Fox, 2013).

Another form of acknowledgement described by Lafarge, Mitchel and Fox (2013) was the process of giving the baby an identity by naming the baby, taking photos and showing these photos to other people. These photos were also used as a way of remembering the baby. An additional key element to remembrance was speaking about the baby with their partners, friends and family. Andersson, Christensson and Gamzell-Danielsson (2014) found that speaking about their baby was helpful as it allowed them the opportunity to process their memories and experiences after TOP.

Makenzius *et al.* (2012) reported that women who spoke about their TOP experience also wanted to receive some understanding and affirmation as part of their adjustment. Studies have shown that women who receive validation of their decision from others seemed to cope

better as this reduced possible feelings of ambivalence and regret (Jones *et al.*, 1984; Maguire *et al.*, 2015; Hodgson *et al.*, 2016).

Lafarge, Mitchel and Fox (2013) reported avoidance and self-distraction as methods of coping amongst the women they had interviewed. This was defined as strategies to avoid thinking about the trauma or to dissociate themselves from their reality. Activities of self-distraction included watching television, reading, going for long walks, focusing on their children, going away or moving house. These coping strategies were initially seen as helpful, but if used for a prolonged period it seemed to hamper the grieving process as they were pushing aside their emotions. Lafarge, Mitchel and Fox (2013) also added that women felt focusing on the future helpful in coping with their loss. They felt getting back into their normal life-work routine was helpful as it helped them gain a sense of normality. They felt this normality was linked to finding closure and essential to the healing process.

Even though women have various coping mechanisms they can employ to adapt to the trauma of having a TOP, the adaptation process is not always successful. Korenromp *et al.* (2009) identified predictors for long-lasting maladjustment in those women who seemed to take longer to adjust after the trauma. The strongest predictor for persistent disturbances was an initial high level of distress, not only due to the diagnosis of a FA but also due to other life stressors. Other predictors included low self-efficacy, high level of doubt during decision-making, lack of partner support, being religious and advanced gestational age.

#### **2.3.4. Impact of Declining TOP**

The couples who decide against TOP after receiving a diagnosis of a congenital condition, like DS, still go through a grieving process. Studies have described these couples as mourning the loss of the healthy and perfect child they expected to have (Fanos and Mackintosh, 2000; Lalor, Begley and Galavan, 2009).

Hedrick (2005) interviewed American mothers who continued the pregnancy after receiving a prenatal diagnosis of a nonlethal congenital abnormality, including DS. These women described experiencing feelings of shock, anger and guilt once they heard the diagnosis. They also described grieving the loss of their perfect baby. The coping mechanisms used to deal with this grief included support from family and friends, spiritual beliefs and staying busy.

Hedrick (2005) described that despite the diagnosis leading to grief, the women still appreciated this knowledge. They felt that knowing about the condition during the pregnancy allowed them time to learn more about the complications related to the diagnosis in order to

make logistical and emotional preparations for the arrival of the baby. In contrast, the women also described the waiting period for the arrival of the baby as worrying as they kept wondering how severely their baby would be affected and whether they would be able to cope with raising the baby. This study also supports previous qualitative studies examining the experience of high-risk pregnancy who found that the uncertainty of the outcome negatively affected the pregnancy experience (Stainton, McNeil and Harvey, 1992; McCain and Deatrck, 1994).

Studies have shown that the knowledge of a fetal abnormality did not prevent the development of prenatal attachment (Kemp and Page, 1987; Mercer *et al.*, 1988). This was further explained by the study conducted by Hedrick (2005). The participants stated that even though they knew the baby would be a lifelong commitment and would not be perfect, they still accepted and loved the baby nonetheless. They also described becoming more attached to the baby as the pregnancy progressed.

An Australian study by Hickerton *et al.* (2012) investigated the impact of their decision to continue the pregnancy on the couples' relationship as well as the relationship of the wider family. The participants reported that it did place stress on their relationship, however despite this they were still able to support each other which strengthened their relationships. In contrast there has been reports of couples in similar situations where it had caused a bigger divide and some couples eventually splitting up (Rothman, 1994; Fanos and Mackintosh, 2000).

Hickerton *et al.* (2011) also found that support from friends and family was valued together with support groups and other families in the same situation. If initially their choice to continue the pregnancy was not supported by all the individuals in their social network, they had a negative impact on the parents' experience. This meant that they not only had to deal with their own prior attitudes towards disability, but also the views and attitudes of others.

## **2.4. RAISING A BABY WITH DOWN SYNDROME**

Once the women or couples, who either decline PND testing or TOP, give birth to a baby with DS, they are faced with the unique challenges associated with raising a child with this condition (Van Riper, Ryff and Pridham, 1992; Marder and Dennis, 1997).

Children with DS may present with a variety of developmental and health problems. All individuals with DS have a developmental delay and an intellectual disability. Therefore, they typically have to attend schools who cater for children with special educational needs. They

are also more likely to develop behavioural problems in childhood, including attention deficit hyperactivity disorder, disorders on the autism spectrum, attention seeking behaviour, aggression, stubbornness and impulsivity (Dykens *et al.*, 2002). In contrast they may have some positive behavioural characteristics including being affectionate, outgoing, good-natured and sociable (Myers and Pueschel, 1991).

The health problems that are more common in babies with DS, include a variety of medical conditions and congenital malformations. Multiple systems are affected, including the cardiac, digestive, endocrine, musculoskeletal, respiratory and urinary tract systems. Cardiac defects are the most common associated anomalies and occur in approximately 50% of babies with DS (Malec *et al.*, 1999). In these babies, the more complicated cardiac defects are the leading cause of death during the first two years of life. These complicated cardiac defects require surgical correction and the preference is to perform this before 6 months of age in order to enhance survival. Gastrointestinal malformations like duodenal atresia (10%), Hirschsprung disease (1-3%) and gastrointestinal reflux disease are common. Chronic constipation, abdominal pain, indigestion and diarrhoea are common symptoms experienced by these children (Agarwal Gupta and Kabra, 2014). Additionally, individuals with DS are prone to thyroid dysfunction, especially hypothyroidism which occurs in about 15% of individuals. Approximately 75% of children with DS will experience auditory problems of which chronic otitis media and hearing loss are the most common. Eye problems are also common in about 60% of children with DS. Lastly, obstructive sleep apnea occurs in about 50-79% of individuals with DS (Bull and the Committee of Genetics, 2011).

Not only do children with DS present with more health complications, as described above, but they are also more prone to catching illnesses like colds and flu. This means that these children often require regular visits to the hospital (Agarwal Gupta and Kabra, 2014). A SA study conducted by Scott (2011) indicated that mothers reported these constant hospital visits as the most unpleasant aspect of raising their child with DS. They found organising transport to the hospital problematic and were stressed as they feared losing their child due to an illness.

Overall, the increased care demands of a child with DS, including daily responsibilities like transportation, dressing, feeding and other basic needs, have been reported to cause higher levels of stress in the families raising these children (Hodapp and Urbano, 2007; Skotko, Levine and Goldstein, 2011; Norton *et al.*, 2016). It has also been reported that these families have adjustment difficulties as the parents and families have to adapt their lifestyle to cater for the unique needs of their child. Often these families have to restrict their daily work and social activities (Povee *et al.*, 2012; Norton *et al.*, 2016). This may have an adverse effect on the

main caregiver, usually the mother's, employment. Often the caregivers either have to reduce their working hours or quit their jobs. The additional needs of their child with DS and their loss of employment adds a financial strain on the family (Brannan and Heflinger, 2006; Worcester *et al.*, 2008; Resch *et al.*, 2010).

Having a child with DS is a lifelong commitment as they will remain dependent on their parents and families (Skotko, Levine and Goldstein, 2011). Parents are often concerned about their child's future relationships and whether they will be accepted by society. They are worried about their job opportunities as an adult due to the limited opportunities available. Individuals with DS can mostly only work in community-supported employment where appropriate supervision is offered (Bull and the Committee of Genetics, 2011; Skotko, Levine and Goldstein, 2011). Adults with DS have an increased risk of developing psychological problems (like depression), premature aging and Alzheimer disease (Bull and the Committee of Genetics, 2011).

Raising a child with DS may also place a burden on the marital relationship and a slightly increased divorce rate has been reported amongst these couples (Hodapp and Urbano, 2007; Skotko, Levine and Goldstein, 2011). The reason for these couples splitting up is usually due to neglect of a partner, or due to the excessive devotion of the other partner to the child with DS. The couples' other children are also believed to be negatively impacted and studies have often reported a feeling of neglect amongst these children (Sari, Baser and Turan, 2006). In contrast, other studies have found that a sibling with DS has had a positive impact as they were taught to be kind and empathetic towards others with disabilities (Cuskelly and Gunn, 2006; Skotko and Levine, 2006).

Studies specifically focusing on parents raising a child with DS, have found that this experience is not always seen as negative as these children are able to interact socially and have a caring and gentle personality. Additionally, some report parents raising a child with a disability see this as giving meaning and purpose to their lives (Hodapp *et al.*, 2001). An American study by Skotko, Levine and Goldstein (2011) found that despite the challenges faced with raising a baby with DS, the couples still reported loving and accepting their children. They described laughter, joy and celebration as part of their family experience and that they learned to be more tolerant, kind and accepting. The SA women participating in the study by Scott (2011) also experienced raising a child with DS positively.

Furthermore, positive family adaptation has been reported amongst families who receive adequate social support for themselves and their children. The sources of social support

include support from friends, the community, religious groups, parent support groups and HCPs (Ross and Deverell, 2010). Some parents have reported that support groups were their most significant source of emotional and practical support. They found the practical tips and advice from other parents with an older or similar aged child with DS invaluable (Buckley, 2002).

## 2.5. PRENATAL GENETIC COUNSELLING

When couples are at a high risk of having a baby with DS they are referred for genetic counselling (Weil, 2000). The National Society of Genetic counsellors in the USA provides the following comprehensive definition of genetic counselling:

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

- *Interpretation of family and medical histories to assess the chance of disease occurrence and recurrence.*
- *Education about inheritance, testing, management, prevention, resources and research.*
- *Counselling to promote informed choices and adaptation to the risk or condition”* (Resta *et al.*, 2006, p77).

Prenatal genetic counselling usually entails an initial pre-test (PND) counselling session, followed by a post-test counselling session. During the initial prenatal genetic counselling session the genetic counsellor gathers detailed information about the family and obstetric history of the women or couples. The counsellor then uses this information in combination with their screening test results to explain their personalised risk for DS. Detailed standardised information on DS is provided and special attention is given to providing a neutral view, in other words not giving an overly negative or positive explanation about what this condition entails. The women or couples are then presented with information on further PND testing options and the option of TOP if a diagnosis of DS is confirmed (Weil, 2000; Hunt, De Voogd and Castañeda, 2005). Currently, at TBH, the patients watch an informational video explaining DS and PND prior to their initial session with the genetic counsellor.

The role of the genetic counsellor during the initial session, prior to PND, is to clarify what the information they have already been presented with, what they know, what is unclear, what information will be added if PND is done, the risks to the baby and the implications if PND is declined. This session is not only intended to provide patients with technical information, but

for the counsellor to provide emotional support and assistance in making the decision regarding further management of the pregnancy (Hunt, De Voogd and Castañeda, 2005). The shock and anxiety caused by the high risk DS screening test result has been reported to interfere with the decision-making process as the patient is unable to process the provided information while experiencing these extreme emotions. Here the counsellor plays an integral role in containing the anxiety so that the women or couples are able to absorb the information in order to make an informed decision (Evans, 2006; Hodgson *et al.*, 2010).

At TBH, the PND results are usually available within one to two weeks after the procedure has been performed. In the event of a negative diagnostic result for DS, this result is delivered and discussed over the telephone. In comparison, in the event of a positive diagnostic result for DS, face-to-face post-test counselling is offered. The patients who test positive for DS, are contacted telephonically to schedule a counselling appointment. As far as possible the pre- and post-test genetic counselling is provided by the same HCP. As the delivery of PND results are time-sensitive, exceptions are made when the HCP is on annual leave. The aim of the post-test counselling session is to deliver the test result, provide further information on DS and the effect this will have on the future life of the unborn child (Evans, 2006). During this session the role of the counsellor will also be to explore how the women or couples feel about disability and TOP. The counsellor will provide detailed information on what the TOP process will entail if they decide to go ahead with this option. The outcome of continuing the pregnancy will also be discussed. Once again the counsellor will emphasize the importance of individual choice and ensure enough time is given to the patients to process the information in order to make an informed decision (Hodgson *et al.*, 2010).

If the women or couples decide to have a TOP, the counsellor offers bereavement support during and after the procedure and often needs to refer the women or couples to psychiatric or social services for added support. If PND or TOP is declined, the counsellor makes sure a proper management plan is put in place. The counsellor makes referrals to the appropriate specialists for management of the remainder of the pregnancy and to offer postnatal support. In the instances where the woman gives birth to a baby with DS, the counsellor provides further information on appropriate healthcare and resources of social support like parent support groups (Skirton *et al.*, 2014).

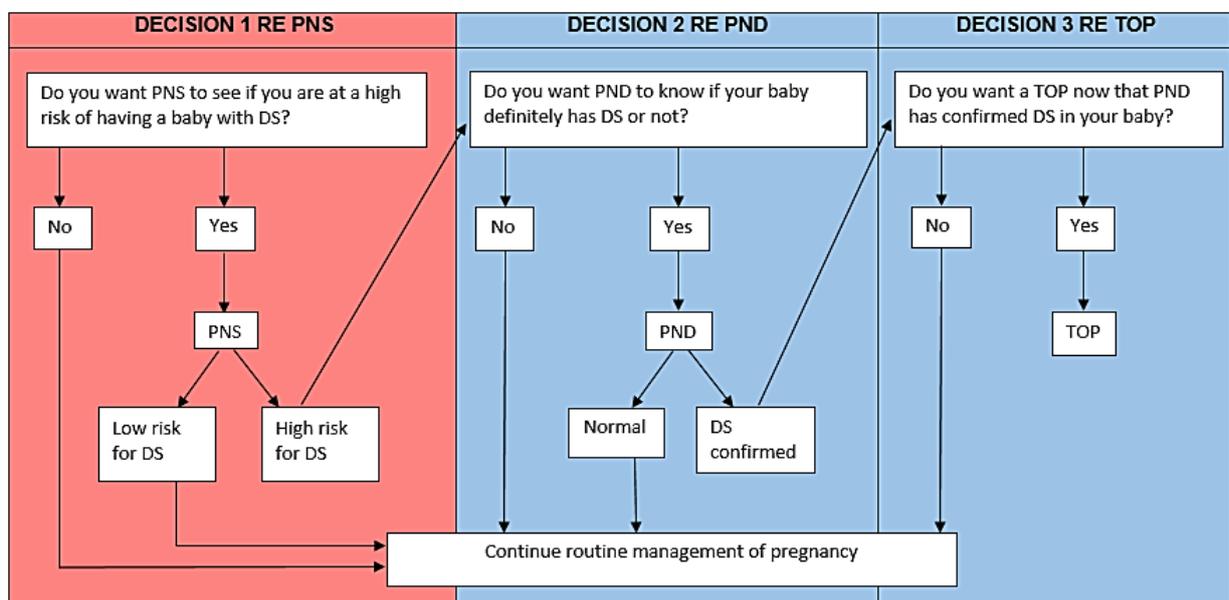
It is recommended that genetic counselling should be provided by certified genetic counselling specialists as a high level of skill is required to assist women and couples in their decision-making processes under these highly emotional circumstances. The counsellor needs to be able to tolerate the degree of distress without becoming professionally mechanistic, over-

involved, overwhelmed or too helpful. The counsellors need to show compassion and empathy while offering non-directive counselling in order to promote autonomous informed decision-making (Evans, 2006). In most countries it is not always possible to offer genetic counselling by certified genetic counsellors due to the paucity of these specialists. Often these services are provided by other HCPs not specifically trained in genetic counselling, such as physicians, nurses and social workers (Michie, Marteau and Bobrow, 1997; Elwyn, Gray and Clarke, 2000; Hunt, De Voogd and Castañeda, 2005). Fortunately at TBH, the women and/or couples are mostly counselled by certified genetic counselling specialists i.e. a genetic counsellor or medical geneticist.

## CHAPTER 3: PROCESS AND EXPERIENCE OF DECISION-MAKING

### 3.1. INTRODUCTION

The information presented in Chapter 2 identified three possible major decisions that pregnant women and their partners are faced with. The first being making a decision regarding PNS. If PNS indicates a high risk for DS, they are faced with the second decision related to whether they want PND or not. If this test diagnoses DS in their fetus, it gives rise to the third decision which is deciding whether to have a TOP or continue with the pregnancy. This decision-making process is illustrated in Figure 3.1 (p.28).



**Figure 3.1: Illustration of three major decision-making processes in the prenatal setting**

As decision-making within the prenatal setting is complex, a number of theories and models have been put forward to describe the decision-making processes within this context (Anderson, 2007; Van den Berg *et al.*, 2008; Muller and Cameron, 2015). The various decision-making theories and models will be discussed in this chapter. Findings from previous studies investigating women and their partners' experiences making a decision in the prenatal context and the different factors that influence their decisions will also be presented. As the current study focused on decision 2 and 3 as illustrated in Figure 3.1 (p.28), literature on these two processes will be highlighted.

To obtain the information presented, a literature search was done on the same databases listed in Chapter 2. The search terms used were "decision-making theories health decisions",

“decision-making prenatal testing”, “decision-making termination of pregnancy”, “experiences decision-making prenatal testing”, “experiences decision-making prenatal testing Down syndrome”, “experiences decision-making termination of pregnancy Down syndrome”, “decision-making factors prenatal testing” and “decision-making factors termination of pregnancy”.

## **3.2. DECISION-MAKING THEORIES AND MODELS**

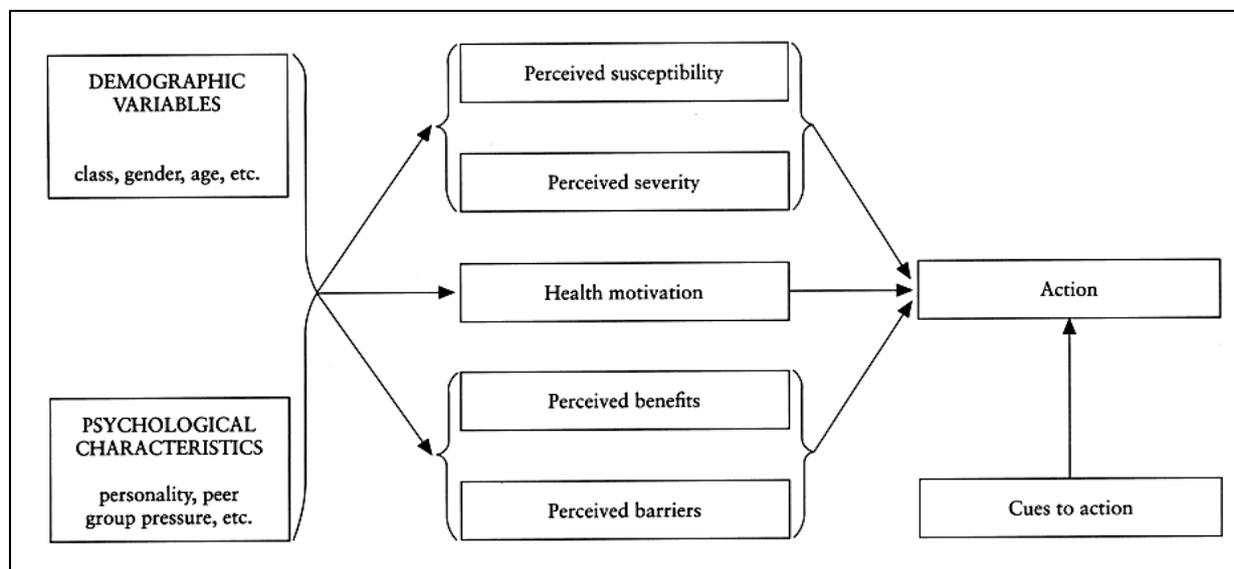
The majority of the studies investigating decision-making within the health care setting were guided by the health belief model (HBM), theory of planned behaviour (TPB) and rational choice models (Heckerling, Verp and Hadro, 1994; Van den Berg *et al.*, 2008; Lawson and Pierson, 2010; Muller and Cameron, 2016).

### **3.2.1. Health Belief Model**

The health belief model (HBM) has been the most influential attitude theory of why individuals practice certain health behaviours (Taylor, 2006). Beliefs are enduring individual characteristics which shape behaviour and can be acquired through socialisations. A person's beliefs are mainly dependent on a combination of demographic variables (e.g. age and ethnicity) and psychological characteristics (e.g. personality and peer group pressures). Beliefs are modifiable and can differentiate between individuals with the same background. The relationship between health beliefs and behaviours were initially conceptualised in terms of Lewin's (1951) expectancy-value model. This model proposed that events believed to be likely were positively or negatively evaluated by an individual. In particular health behaviour was shaped by the following key beliefs: the likelihood of experiencing a health problem, the severity of the consequences of that problem and the perceived benefits of a health behaviour in combination with its potential costs. This model was later developed into the HBM by Rosenstock (1974).

The HBM explains that whether a person practices a particular health behaviour can be understood by knowing two factors: threat perception and behavioural evaluation (Hochbaum, 1958; Rosenstock, 1974). Threat perception refers to two beliefs i.e. whether a person perceives a personal vulnerability to a particular illness or health problem and the person's beliefs about the severity of the consequences of the illness (are they serious or not). Behavioural evaluation also has two distinct set of beliefs, those concerning the benefits or efficacy of a recommended health behaviour and those concerning the costs of, or barrier to, enacting the behaviour (Conner and Norman, 2005; Taylor, 2006). This model also proposed that certain cues to action can activate the health behaviour when appropriate beliefs are held.

These “cues” included a diverse range of triggers including individual perceptions of systems, social influence and health education campaigns. Finally an individual’s general health motivation or readiness to be concerned about health matters was included in later versions of the model by Becker *et al.* (1977) as illustrated in Figure 3.2 (p.30).



**Figure 3.2: The Health Belief Model (Abraham and Sheeran, 2005)**

Weinstein (1988) further elaborated on how an individual perceives susceptibility and identified three stages in this process. The first involving the individual’s awareness that the threat exists. The second determining how dangerous the threat is and how many people are likely to be affected. The last being personalising the threat. It is only in this final stage that the individual acknowledges personal susceptibility which is likely to lead to action. Increased social awareness of a particular condition will have a direct impact on the person’s perceived susceptibility. Perceived severity involves both medical severity (pain, complications, etc.) and psychosocial severity (the extent to which the illness might interfere with valued social roles). Here an individual’s past experiences with the condition plays a major role on the perception of severity (Abraham and Sheeran, 2005). The perceived benefit construct entails both medical and psychosocial benefits of engaging in a certain health behaviour. The perceived barriers construct comprises of practical barriers to performing the behaviour (e.g. time, financial cost, availability, transport, waiting time) as well as psychological barriers (e.g. pain, embarrassment, change in lifestyle, threat to well-being, self-efficacy, lack of social skills). Mattson (1999) added to the cues to action construct by including all persuasive experiences including interpersonal communication, exposure to mass media and internal responses to threat. Health motivation includes perceived control over health and health status, health value and intention (Chen and Land, 1986).

In the context of this study, the action (health behaviour) refers to the individual having PND for DS and/or TOP. According to this model, an individual who believes they are at a significant risk of having a baby with DS and that DS is a severe condition, will undergo PND if they have the following two beliefs: (1) they are confident that this test will provide them with a definite answer and (2) the information this test will provide outweighs the cost of the test (miscarriage risk). Additionally, if they believe that having a TOP is an effective method of dealing with the threat, they are more likely to opt for PND in order to obtain the information about the need to have a TOP.

Even though six constructs of this model were identified, it did not offer clear guidelines on how to operationalise the links between perceived susceptibility, severity and overall threat perceptions. Similarly, although it was suggested that perceived benefits were weighted against perceived barriers, no formula for creating an overall behavioural evaluation measure was developed (Abraham and Sheeran, 2005). Furthermore the constructs as defined by this HBM have been found to be overly simplistic and therefore in order to properly explain health behaviour, other theories and models were developed like the theory of reasoned action (TRA) and TPB (Conner and Norman, 2005).

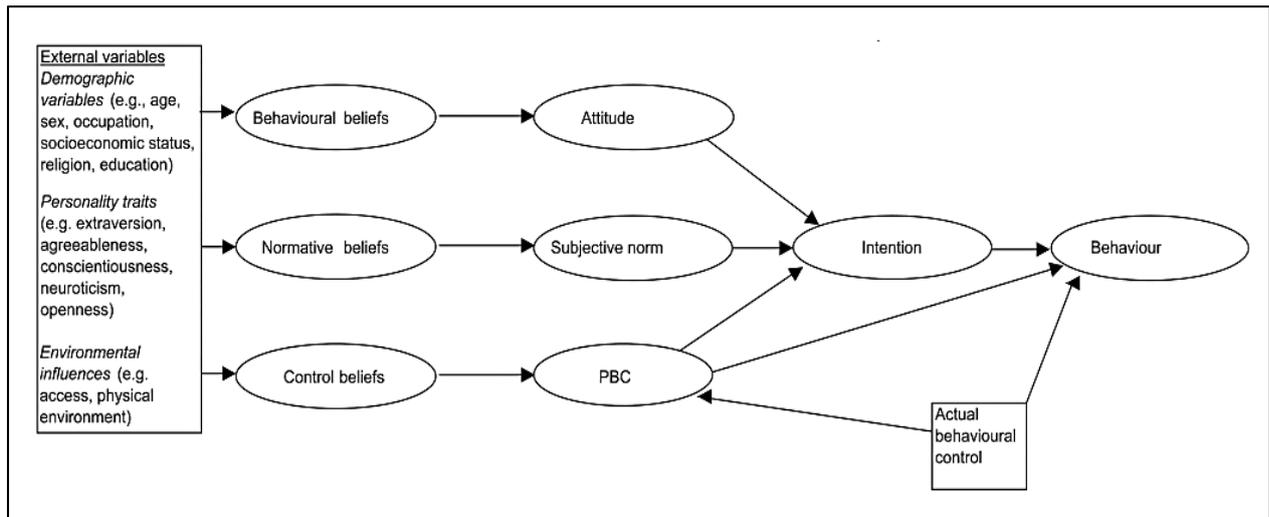
### **3.2.2. Theory of Planned Behaviour**

The TPB is an extension of the TRA, which are both deliberative processing models that imply that people's attitudes are formed after careful consideration of available information. These models attempt to link an individual's health beliefs to the individual's behaviour (Ajzen and Madden, 1986). TRA suggests that the cause of volitional behaviour is one's behavioural intention to engage in that behaviour. Behavioural intention is seen as a person's motivation to apply effort to perform a specific behaviour. TRA identifies two factors influencing intention, namely the individual's attitudes towards the action as well as subjective norm. Attitudes towards the action are based on the person's beliefs about the likely outcomes of the action and evaluations of those outcomes. Subjective norms are what the person believes others think that person should do (normative beliefs) and the motivation to comply with those normative references. It is however important to note that TRA restricts itself to the prediction of volitional behaviours and does not include behaviours requiring skills, resources or opportunities that are not freely available. The TPB broadens the scope of the TRA beyond these behaviours (Conner and Norman, 2005).

Therefore, according to the TPB, a health behaviour is the direct result of a behavioural intention which is made up of three components: attitudes toward the specific action, subjective norms regarding the action, and perceived behavioral control (PBC). TPB builds on

the concepts introduced by TRA. Attitude is seen as the individual's perception of the behaviour either being favourable or unfavourable. These attitudes are determined by the individual's demographic variables, personality traits as well as environmental influences (Ajzen and Fishbein, 1980). Subjective norms are assumed to assess the social pressures individuals feel to perform or not perform a particular behaviour from significant others. Significant others are seen as individuals or groups whose preferences about a person's behaviour is important to him or her (Taylor, 2006). These significant others may include an individual's partner, family members, friends, social group and religious group. Here it is also important to consider the individual's motivation to comply with the specific wishes of the referent on the issue. TPB added perceptions of control over performance of the behaviour as an additional factor (Ajzen, 1991). PBC is an individual's need to feel that he or she is capable of performing the action contemplated and that the action undertaken will have the intended effect (Taylor, 2006). PBC is determined by the perceived presence or absence of necessary resources and opportunities to facilitate or inhibit the performance of the behaviour. Certain internal and external control factors have been identified to play a role in an individual's PBC. The internal factors include information, personal deficiencies, skills, abilities and emotions. The external factors include available opportunities, dependence on others and barriers. The TPB is illustrated in Figure 3.3 (p.33).

Within the prenatal setting the specific health behaviour would be prenatal testing or TOP. According to this theory an individual is more likely to undergo these procedures if they have a favourable attitude towards these procedures, if they perceive their significant others as wanting them to have the test and if they believe that they are capable of coping with undergoing testing and the risks and anxieties associated with this procedure. They will also be more likely to undergo testing if they felt capable of making the decision to have a TOP and be capable of living with the consequences of having this procedure.



**Figure 3.3: The Theory of Planned Behaviour (Connor and Sparks, 2005)**

### 3.2.3. Rational Choice Models

Rational choice models state that people make logical decisions by weighing up the various options and outcomes and then choosing the course of action that they believe has the maximum benefit with minimum risk (Janis and Gentry, 1984).

The expected utility (EU) model is one of the major decision-making under risk theories (Tversky and Kahneman, 1981). This model is based on a set of axioms which provide criteria for the rationality of choice. An axiom is a term used to refer to the “general truths” which everyone in society accepts to be true. The choices of an individual who conforms to the axioms can be described in terms of the utilities of various outcomes for that individual. The utility of a risky prospect is equal to the expected utility of its outcomes, obtained by weighting the utility of each possible outcome by its probability. When faced with a choice, a rational decision-maker will prefer the prospect that offers the highest expected utility (Tversky and Kahneman, 1981).

The EU model was later identified as too simplistic and led to the development of the prospect theory. This theory is restricted for use in making decisions where numerical probabilities and quantitative outcomes are stated. In prospect theory, outcomes are expressed as positive or negative deviations (gains or losses) from a neutral reference outcome, which is assigned a value of zero. This model also proposes that the displeasure of loss is much greater than the pleasure experienced from gain of the same amount. Therefore, the same loss holds a greater weight than if this was gained. Both models are weighted by the subjective experiences of each individual. Individuals place different weights on each outcome based on how they perceive the risks they are presented with (Tversky and Kahneman, 1981).

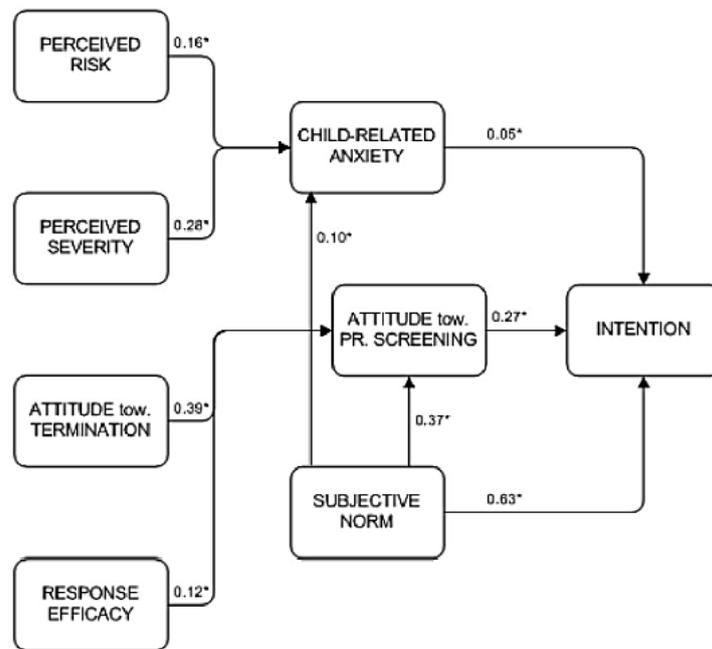
In the prenatal setting, the rational choice models assume that women and/or couples will weigh up the relative risks (risk of DS and PND procedure related risks), burdens and benefits of various courses of action to make a rational decision (Weil, 2000). According to the prospect theory, if the women or couples perceive having a TOP as a greater loss than having a baby with DS, they will be more inclined to opt against PND and TOP.

### **3.3. STUDIES PROPOSING DECISION-MAKING MODELS WITHIN PRENATAL SETTING**

Even though the HBM, TPB and rational choice models have identified valuable components, studies have shown that these models by themselves are too overly simplistic to address decision-making in the prenatal context. Decisions in this context are complex as they are not purely rational and full of self-reflection and many societal, familial, medical and interpersonal factors play an influential role. Therefore, further elaboration on these models are needed in order to incorporate these additional factors (Anderson, 2007; Lawson and Pierson, 2010).

Van den Berg *et al.* (2008) aimed at addressing some of these aspects with their Hypothesized prenatal screening behaviour model (Figure 3.4, p.35). According to this model, one's attitude towards prenatal screening is directly influenced by perceived risk of having a child with DS, perceived severity of DS, attitude towards termination and response efficacy (perceived accuracy of test) which will in turn have an indirect effect on prenatal screening intention.

They used two of the three factors identified by the TPB. The first being one's attitude towards the procedure and the second subjective norm. Here subjective norm is defined as the perceived social pressure from key people in the individual's environment to engage or not to engage in the behaviour. In other words if an individual has both a positive attitude and a positive subjective norm it will increase their intention to undergo prenatal screening (Ajzen, 1991; Conner and Sparks, 1995). They did not make use of the third factor, perceived behavioural control, as this is a measure of the ability to perform a specific behaviour regularly. They felt that this factor is irrelevant in this context as prenatal testing is usually a one-time decision and the procedure is performed by a practitioner and not the individual making the decision (Van den Berg *et al.*, 2008).



**Figure 3. 4: Hypothesised prenatal screening behaviour model of Van den Berg *et al.* (2008) \*indicates statistically significant path coefficients ( $p < .05$ )**

Van den Berg *et al.* (2008) added two additional factors to the TPB: perceived risk and perceived severity. These assumptions are based on the HBM, EU model and expectancy-value model that one's attitude toward a behaviour is based on your beliefs about the probability of certain outcomes (perceived risk of having a child with DS) and the evaluations of these outcomes (perceived severity of DS) (Ajzen, 1991; Eagly and Chaiken, 1993). In other words if an individual's perceived risk and severity is low, then they are likely to decline prenatal testing.

An individual's risk perception is highly subjective and influenced by cognitive processes and emotional factors. Three cognitive processes have been identified by Tversky and Kahneman (1974, 1981) namely anchoring, availability and outlook on life. Anchoring occurs when the individual has a prior belief regarding the magnitude of the risk which serves as a framework when interpreting the new risk figures. Therefore, individuals who have previously been told that they are at high risk of DS, but then gave birth to a healthy child, will perceive the risk to be low if they find themselves in a similar situation in a subsequent pregnancy. Availability relates to how easily examples of the potential outcomes can be brought to mind. Those individuals who are familiar with DS and have met individuals with this condition are believed to have a higher risk perception. Another variable is the extent to which individuals have a pessimistic vs optimistic outlook of themselves, their families and their previous life events. Pessimism will increase the risk perception, where optimism will decrease it (Weil, 2000).

Emotional factors are heightened levels of anxiety, sadness and stress which limits the individual's ability to understand risk information (Evans, 2006).

Additionally, the intention to undergo prenatal screening is influenced by child-related anxiety. This assumption is based on the risk-as-feelings hypothesis that states that individuals' responses to risky situations are influenced by their emotions such as worry, fear and anxiety (Loewenstein *et al.*, 2001). Child-related anxiety is directly influenced by perceived risk, perceived severity of DS and subjective norm. In this scenario it is believed that a pregnant woman who feels anxious about the health of her baby will accept prenatal testing (Van den Berg *et al.*, 2008).

Van den Berg *et al.* (2008) also drew on the EU model to add response efficacy which refers to the individuals' perception of the accuracy of the test result. If they felt the test was accurate, making it useful, they were more inclined to opt for testing. Lastly they added attitude towards TOP as an important factor regarding PNS. If individuals had ethical objections against TOP they were less likely to undergo PNS.

As this model was mainly proposed to account for decision-making regarding PNS, there are some factors that need to be added when exploring decision-making regarding PND. A proposed model by Muller and Cameron (2015) incorporated some of these psychological and clinical factors. As decision-making regarding PND is much less straight-forward due to the procedure-related risks as discussed in Chapter 2, this proposed model accounted for decisional conflict rather than an actual intention or behaviour. Decisional conflict is defined as uncertainty about which course of action to take when having to choose amongst options that all involve either a level of risk, regret or challenges the individual's personal life values (LeBlanc *et al.*, 2009).

Muller and Cameron (2015) also incorporated perceived efficacy, child related anxiety, perceived severity of condition and subjective norm into their model as described by Van den Berg *et al.* (2008). They further elaborated on subjective norm by including interpersonal dynamics. These interpersonal dynamics entailed interactions with their doctors and their partners. They seemed to be motivated to pick the option that was most in line with their partners' preference and what they perceived their doctor's preferences to be, in order to maintain harmonious relationships.

Additionally, they included perceived benefits from normal results as proposed by the EU model. If the individual felt that having PND would provide reassurance about the health of the

fetus, they were more likely to opt for this procedure. If they were uncertain about the benefit from a normal result this enhanced decisional conflict. They also used the common-sense model of health behaviour and added condition coherence as an important decision-making factor. This refers to how well a couple have been able to gain an understanding of the genetic condition (DS) and the cause thereof. Couples who had a high condition coherence, experienced less decisional conflict.

Lastly Muller and Cameron (2015) added parity as a factor influencing decisional-conflict when making a decision regarding PND. This was seen as an important factor as PND carries a risk of miscarriage. Individuals who were childless were much more conflicted as they did not want to risk having a miscarriage post procedure. They also seemed conflicted about having a TOP for a child with a disability as they had no live born children.

As studies have shown that women and their partners' decisions are influenced by their interpersonal relationships and social environment, it is important to include a systems perspective model. This perspective allows for further elaboration on the notion of subjective norms proposed by Van den Berg *et al.* (2008) and Muller and Cameron (2015). The impact of different systems on the decision-making processes within the prenatal setting was emphasized by Lawson and Pierson (2010). They argue that the pregnant woman makes a decision within the context of her interpersonal relationships (with her partner, fetus and physician) that are embedded within larger societal contexts (social, legal and medical norms). This belief is supported by Anderson (2007) who developed a conceptual model of decision-making regarding prenatal genetic testing.

Anderson (2007) concluded that each individual has their own personal style of thinking and they find meaning through interactions with others, themselves and their environment. Anderson (2007) adds that many of these personal styles of thinking relates to an individual's ethical, moral and religious beliefs. The personal styles of thinking may include analytical, practical hypothetical, ethical, moral, judgmental, scary and reflective thinking.

Analytical thinking refers to looking for a basic analytical standard, mathematical criterion or a rule to apply when making a decision. This way of thinking reduces a risk figure to a rational cognitive concept that can be manipulated by shifting the frame of reference from "good" to "bad". This way of thinking has been described to be used more often by men than women (Anderson, 2007).

Hypothetical thinking is “something you do as you wait for life to unfold” (Anderson, 2007, p.16). The person uses logic to devise imagined scenarios to allow the person to explore different points of views and outcomes in an attempt to think about the consequences. This way of thinking allows a person to examine their personal values, beliefs, priorities, strengths and weaknesses, and real or imagined limitations in the context of everyday life and society. It is used to visualise new possible ways of living life and to come to terms with what is most important and valuable about living one’s own life, or the value of becoming a parent (Anderson, 2007).

Practical thinking is similar to hypothetical thinking as the individual uses conclusions drawn from the imagined scenarios along with hope and signs to give meaning and direction to actions that need to be taken. Hope is motivated by personal virtues such as courage, perseverance, a positive attitude and moral integrity. It is practiced through prayer, faith, belief in God, inspiration or feeling connected to a higher spirit or life force. Signs are either physical or spiritual and are used to reconcile fear and anxiety. Physical signs can be feeling the baby kick or subtle physical feelings or changes that indicate forewarnings of well-being or ill-health. Spiritual signs happen in direct response to prayer, having faith, trusting and crossing fingers. For example a person receiving a good PND result after prayer (Anderson, 2007).

Ethical thinking refers to ethical uncertainty as well as ethical certainty. Ethical uncertainty is when a person is not 100% sure what to do about making a moral choice. This is often described as a place or point when a person gets to a “*fork in the road*” (Anderson, 2007, p.16). In contrast, ethical certainty is when a person knows with 100% certainty what they personally think should be done. There is no choice at all as ethically there is only one acceptable option and outcome. This is based on the person’s moral beliefs and does not change from one situation to the next. This is usually experienced by couples who know that TOP is not an option for them or those couples who feel that they will be unable to raise a disabled child (Anderson, 2007).

Moral thinking is based on moral uncertainty and moral sensing and arises from an internal source. Moral uncertainty involves focusing on an inner conversation about “*what is good for human beings now and in the future, why and under what conditions*” (Anderson, 2007, p17). Moral sensing is when a person, while doing soul searching, reaches a point where they experience a feeling of comfort and an inner sense of knowing what is good and what is not (Anderson, 2007).

Judgmental thinking is the process of placing judgments on the information presented in order to make a decision. This also refers to the individual's perception of the judgments of the HCPs and society regarding the use of PND and DS. The judgmental thinking of others might have an impact on the individual's own thinking and might persuade them to make a decision more in line with others' convictions rather than their own (Anderson, 2007).

Scary thinking is an emotional response rather than a reasoned action. It is rooted in the biological and psychological response to stressful situations. This way of thinking runs the risk of individuals making premature decisions, just to resolve unpleasant feelings. This also relates to individuals accepting PND in order to try and reduce their level of anxiety experienced after hearing about their high risk of DS (Anderson, 2007).

Reflective thinking is a process of deep thinking in order to understand one's own self-context and who one is as a person and what is important to one-self. By engaging in deep thinking a person can take into account the whole picture, including emotions, facts, gut feelings, intuitions and personal and past experiences when making a decision (Anderson, 2007).

### **3.4. STUDIES INVESTIGATING DECISION-MAKING IN PRENATAL SETTING**

A number of previous studies have been conducted to investigate couples' experiences regarding decision-making within the prenatal setting as well as the factors playing a role in their decision. The factors identified in these studies are in line with the factors believed to play a role in decision-making as proposed by the models discussed in the previous section. The findings of these studies will be summarised in this section.

#### **3.4.1. Patient Experience of Decision-Making Process**

Previous studies investigating the experiences of women and couples who need to decide whether to undergo prenatal testing for DS and possible TOP, have illustrated the complexity of feelings they experience (Moyer *et al.*, 1999; Hunt, De Voogd and Castañeda, 2005; Chevalier Sapp *et al.*, 2010). As the tests carry a 1% risk of miscarriage and there are no prenatal treatments for DS, this is widely recognized as a morally controversial decision. The benefits of the knowledge the test can provide must be weighed against considerations such as the acceptability of TOP and attitudes about disability (Hunt, De Voogd and Castañeda, 2005).

Moyer *et al.* (1999) conducted focus group discussions with pregnant women in the US and found that these women were confronted with both the positive and negative aspects of testing

when having to make their decision. The positive aspects were giving them a choice, control, and reassurance while the negative aspects were interference, lack of choice and anxiety. The women felt the tests were interfering with the natural process of pregnancy and medicalising the process by causing you to think about negative things that could occur.

These findings were supported by Chevalier Sapp *et al.* (2010) who conducted a qualitative study amongst 34 women attending a private prenatal testing center in the US. This study once again emphasised the ambivalence women feel when having to make this decision. The women were conflicted about their need for this information in order to prepare for the arrival of a child with special needs or having the option of TOP and taking the risk of possibly having a miscarriage after the procedure.

Those couples who decided to have PND are faced with making an even more challenging decision about TOP if the test indicates their baby has DS. Studies have found that women and their partners often report this experience as challenging and intensely distressful (Statham, Solomou and Chitty, 2000; Hunt, De Voogd and Castañeda, 2005; Lalor, Begley and Galavan, 2009). These couples are forced to make a choice between two options, neither one giving them the desired outcome of a healthy child. The woman must choose between the identity of being a mother of a disabled child or becoming a bereaved mother (McCoyd, 2007).

McCoyd (2007) conducted interviews with 30 American women faced with having to make a decision regarding TOP. The women reported struggling making this decision while feeling isolated, frightened and confused by their feelings. This decision is confusing as they desire the pregnancy and bond with the fetus, only to decide against their desires when opting to have a TOP when a FA, like DS, is discovered.

A qualitative study by Gaille (2016) reported similar findings amongst French couples who described the decision regarding TOP as a terrible ordeal as they had to choose between two solutions, neither of which is desirable. The very nature of this decision gives rise to painfully ambivalent feelings and the couples described eventually choosing the lesser of the two evils.

#### **3.4.2. Factors Influencing PND Decision**

A vast number of studies have been conducted to identify factors that influence the pregnant women or couples' decisions regarding PND. These influences include various personal characteristics as well as psychological and socioeconomic factors (Åhman, Runestam and Sarkadi, 2010).

Firstly, evidence has suggested that the decision-making process regarding PND is influenced by the way in which prenatal testing information is presented (Michie, Smith and Marteau, 1999). There is evidence that HCPs give minimal information regarding FA scans and prenatal tests are presented as routine, rather than one requiring a decision. It has been proposed by Porter and Macintyre (1984) that women tend to opt for prenatal testing as they perceive that what has been offered to them by the HCP must ultimately be the best option, especially if the HCP speaks authoritatively. Wessels, Koole and Penn (2014) conducted a SA study investigating the genetic counselling interactions with women of AMA who attended a public sector hospital in Johannesburg. They reported that the invitation from the counsellors to undergo PND was not neutral and both the counsellors and women appeared to treat the offer of PND as one which should be accepted.

Furthermore, how the risk information is presented to the couple by the HCP offering them counselling, influences their decision regarding PND. According to studies, to be told that “*you have a one in 20 chance of having a child with DS*”, sounds higher than “*you have a 19 out of 20 chance that your child does not have DS.*” A risk assessment often carries a positive or negative message and this can possibly influence the choices (Michie, Smith and Marteau, 1999).

Also, how the couples perceive and understand this risk is influenced by the high stress situation they find themselves in and the added pressure of having to make a decision within potentially severe time constraints. Their emotional state significantly decreases their ability to process complex probabilistic information and numerical data in order to understand the risks associated with PND (e.g. risk of miscarriage and risk for DS) (Booth and Siegler, 2006; Beilock and DeCaro, 2007; Durand *et al.*, 2009). For this reason it has been reported that many couples reduce the figures to a binary all or nothing approach (i.e. the baby either has DS or does not have DS) in order to simplify things for themselves (Lipman-Hand and Fraser, 1979; West and Bramwell, 2006). In some instances this can cause major anxiety due to the uncertainty that is caused by screening tests as these women who screen high risk might spend the rest of their pregnancy believing something is wrong, while the ones who receive a negative screening test might be falsely reassured (West and Bramwell, 2006).

Durand *et al.* (2009) did a qualitative study to investigate the reasons why British women undergo amniocentesis or not. They found that one of the major reasons for undergoing testing was due to the anxiety caused by the uncertainty of the screening tests. They felt they would be unable to cope with the stress of not knowing whether the baby had DS for the remainder of the pregnancy. An Italian questionnaire study by Pivetti and Melotti (2013) and a Swedish

interview study by Ternby *et al.* (2016) supported this finding as the majority of their participants underwent testing in order to relieve them from the anxiety caused by the uncertainty.

Studies have also indicated that couples who fear the risks and discomfort associated with PND are most likely to decline testing. Cederholm, Axelsson and Sjöden (1999) conducted a questionnaire study amongst Swedish pregnant women and found that these women mainly declined PND as they feared post-test miscarriage, the pain of the procedure, fetal injury as well as the outcome of the test. An Australian study Tsianakas and Liamputtong (2002) by supported that women declined testing as they were concerned about the well-being of their fetuses. Durand *et al.* (2009) conducted interviews with British women who also reported declining PND due to the miscarriage risk. This was especially true for the participants who had a history of miscarriage, struggled to fall pregnant or fell pregnant through *in vitro* fertilisation (IVF).

Kuppermann *et al.* (2000) reported that American women who felt that having a child with DS would be worse than a procedure-related miscarriage opted to have PND. Furthermore, research conducted in Hong Kong by Yau and Zayts (2014) found that women who had constructed DS negatively and as undesirable, opted for PND in order to have a TOP if the fetus tested positive. The women also accounted for their decision to undergo PND by stating that they were minding the interest of their future child by protecting them from suffering.

Wanting a TOP if a problem was found was also reported as a major motivation to undergo PND amongst the participants interviewed by Durand *et al.* (2009). These couples felt strongly about ending the pregnancy as they felt they would be incapable or unwilling to look after a child with a disability. They were not only concerned about the impact on themselves, but also the impact it might have on their other children. Interestingly, not all of the women in this study accepted testing in order to have a TOP in the case of a diagnosis of an abnormality, but did so in order to prepare themselves for the birth of a baby with a disability. Ekelin *et al.* (2017) reported similar findings amongst the Swedish couples they interviewed who felt that despite not wanting a TOP in the case of a positive result for an abnormality, they still wanted to have PND in order to gain more information about their unborn child's condition and in order to prepare for the arrival of their baby by putting all the necessary support in place to cater for their baby's needs post-delivery.

In contrast, studies have reported the opposite to be true, and that the majority of couples who would not consider TOP, declined testing. For this reason they see having a test as pointless

as it holds no medical benefit for the pregnant women or unborn child (Pivetti and Melotti, 2013). This notion is further explained by studies completed by Markens, Browner and Press (1999) and Liamputtong Rice and Naksook (1999) amongst American and Thai women respectively. They indicated that the women felt that even if their fetuses were abnormal they should have a chance in life and that they would find ways to take care of their children. Therefore, they declined PND as they felt there was nothing they could or would do if the child had a condition. Also they did not want to go through the emotional distress that a positive result could cause.

The Australian women interviewed by Tsianakas and Liamputtong (2002) reported that their religious views influenced their decision-making regarding PND. The women felt that Islam encourages everything that is of importance for the well-being of an individual. Prenatal screening was seen as important as it provides information on the well-being of the unborn child. However, perceptions regarding PND, including amniocentesis, vary, as this is associated with a risk of miscarriage and inflicting potential harm. If the mother perceived a risk to the baby, she avoided the procedure. Their religion also gave rise to a negative view regarding TOP. This finding was supported by the findings of Yau and Zayts (2014). The Swedish women interviewed by Ternby *et al.* (2016) supported that the concern for miscarriage post-procedure was their major reason for declining PND.

Liamputtong Rice and Naksook (1999) also reported the notion of acceptance of a procedure due to the normalisation and routinisation of prenatal testing. Women act according to the societal norms as they want to be recognised as a normal mother. In their Australian society it is assumed and expected that women should undergo prenatal testing in order to ensure that the child is healthy and normal. Therefore, these women feel obligated to go so that they are not made to feel irresponsible if the baby is born with an abnormality. If a woman did not follow the advice of the HCP and harm resulted from this decision, then it is perceived to be the fault of the mother. Therefore, the woman who declines prenatal testing, and there is a negative outcome for the baby, would feel a heavier societal burden.

The literature indicates that women who have to decide about prenatal testing, value the input of important referents such as their partners, family members and HCPs before making their final decision (Markens, Browner and Press, 1999; Marteau and Dormandy, 2001; García, Timmermans and van Leeuwen, 2008; Van den Berg *et al.*, 2008; Chevalier Sapp *et al.*, 2010; Pivetti and Melotti, 2013). These women are more likely to opt for the decision which most of her referents agree with. Studies have shown that the most important referent is the woman's partner (Kenen *et al.*, 2000; Åhman, Lindgren and Sarkadi, 2012).

Kenen *et al.* (2000) investigated American men's views on decision-making regarding PND. They found that the decision was seen as a joint decision made by both the women and their partners. When they were in agreement, they approached the decision as a couple, but with the women's opinions carrying more weight. When there was disagreement, they would gain more information and have another discussion. If there was still disagreement they would then decide in favour of the partner who felt the strongest about the issue. A Swedish study by Åhman, Lindgren and Sarkadi (2012) also emphasised the engagement of the male partners in the decision making process regarding PND and how the women also took their thoughts and experiences into consideration.

Within the African cultures the influences of the community are seen as specifically important and draws on the principle of "communal autonomy." This principle refers to the individual making a decision within the context of the community traditions and customs from where this individual derives his/her existence. Individuals from strong African cultures therefore do not make decisions based on their own views, but need to discuss the options with the community or family as decision making is a group effort. This decision is seen to impact on the community or family as a unit (Jegede, 2009).

Furthermore socioeconomic circumstances are also believed to play a role in decision-making. Yau and Zayts (2014) reported that women whose socioeconomic circumstances were constrained opted for PND and TOP. Pilnick and Zayts (2012) investigated the motivations for either having prenatal testing or not amongst pregnant women from Hong Kong. They raised work as a rationale for not having testing, or being unable to undergo testing at the preferred time. They stated that socioeconomic factors (e.g. being a single parent) as a rationale for testing as they would be unable to manage raising a child with DS. Rahaman *et al.* (2012) found that Egyptian women living in urban areas were more knowledgeable and accepting toward prenatal testing procedures than women living in rural areas. They attributed this finding to the belief that the women in urban areas having a higher educational level and better availability of medical services.

A factor influencing the decision regarding PND that is specific to the SA context is the HIV status of the women. A study conducted by Bee *et al.* (2013) reported that HIV status played a significant role and that the women who were HIV positive were less likely to opt for PND due to the risk of transferring the virus to the fetus.

Lastly, a study conducted in the USA by Kuppermann *et al.* (2006) found a difference in factors influencing decision-making for PND for DS between women aged older and women aged younger than 35 years. The factors viewed as important for making a decision by women who were younger than 35 years were listed as their beliefs about modern medicine's interference with pregnancy, inclination to opt for TOP if fetus had DS, access to care and how directive the counselling was that they had received. Women, who were older than 35 years were influenced by the testing information, distrust of health care system, accepting God's will, having a fatalistic attitude toward DS and the procedure-related miscarriage. As this was a questionnaire study, no further explanations were offered for these discrepancies between the two age groups.

### **3.4.3. Factors Influencing TOP Decision**

Making the decision of whether to have a TOP or to continue with the pregnancy after a prenatal diagnosis of DS has been described in the literature as complex and dependent on many factors. Often the decision of whether the women or couples would be prepared to TOP for DS, precedes the decision to have PND, therefore many of these factors overlap with the factors reported to have an influence on the uptake of PND (Schechtman *et al.*, 2002; Zlotogora, 2002; Rauch *et al.*, 2005).

In the majority of the studies, the women reported their partner's opinion as essential when having to make a decision regarding TOP (Korenromp *et al.*, 2007; Andersson, Christensson and Gemzell-Danielsson, 2014; Gaille, 2016). Korenromp *et al.* (2007) conducted a questionnaire study amongst Dutch women who received a prenatal diagnosis of DS and they reported that their partners mostly influenced their decision. The women felt making a shared decision with their partners were desirable. Those women who were in disagreement with their partners felt much more conflicted than those women who made a decision in harmony with their partners. These findings were similar to the findings reported by Gaille (2016) who interviewed French couples and those reported amongst Swedish couples by Andersson, Christensson and Gemzell-Danielsson (2014). Gaille (2016) went on to describe that the couples often identified the women as taking the leading role in the decision-making process, even though consensus and shared decision-making was important. Andersson, Christensson and Gemzell-Danielsson (2014) further explains that the reasons why the couples felt the women should take the leading role, was that it was the women who would be physically and socially implicated. The women would have to go through the TOP procedure and then have to explain to her social circles why she is not pregnant anymore. In most settings the women

will also be the main caregiver of the child with special needs, and therefore carry the heaviest burden if they were to continue with the pregnancy.

A review study by Choi, Van Riper and Thoyre (2012) indicated that the most influential TOP decision-making factor was the couples' attitudes towards individuals with a disabling condition like DS. As mentioned in the previous section, the couples who had more negative attitudes towards individuals with disability (including DS) were more likely to choose TOP than those who had a more positive attitudes (Bell and Stoneman, 2000; Lawson, 2006; Bryant, Green and Hewison, 2010). Previous contact with individuals with DS and the degree of personal comfort in those interactions were also associated with decision-making regarding TOP. Those participants who had a good relationship with individuals with DS were less likely to consider TOP than those with poor relationship and interaction (Bell and Stoneman, 2000; Lawson, 2006).

A study conducted by Ahmed *et al.* (2008) indicated that the most important factor in decision-making about TOP was the perception of the quality of the life of the child. In particular, whether the child would be enduring physical or emotional suffering. Those women who felt the child would suffer were more likely to TOP, not only due to the suffering of the child but also due to the immense distress the death of a child would cause the parents. This was supported by Korenromp *et al.* (2007) and Reed, Berrier and Reed (2017) as the women in their studies, reported that their motivations to opt for TOP were predominantly based on the perceived quality of life of their child. They considered the abnormality too severe and that the burden of care for the child would be too heavy on themselves and their families. These women further reported concerns about who would care for the child after their death which was similar to the concerns reported by the study from Gaille (2016). The participants interviewed by Gaille (2016) further described their concerns related to the inability of the child to have a social life and the prospect of a medicalized life. They were concerned about the children's ability to live an independent life, love a partner, have children and be able to work. The participants justified their decision to TOP as being one made in the name of love and the moral responsibility to not give birth to a life of suffering as this would be a harmful and egotistical decision.

Gaille (2016) indicated that another primary reason to opt for TOP, reported by the participants, was related to personal and family stability. This refers to the perceived capacity of the parents and the family to raise the child with a disability while continuing with their usual daily lives. If they felt that it would be too much of a burden and have too much of an impact on their daily lives they would opt for a TOP. This finding is supported by Roberts, Stough and

Parrish (2002) and Korenromp *et al.* (2007). In contrast, studies have reported that if the couple felt they would be able to raise a child with DS and that they had support from their friends and family, they were less likely to opt for TOP (Choi, Van Riper and Thoyre, 2012; Pivetti and Melotti, 2013).

The women interviewed by Gaille (2016) furthermore reported that the social and economic context in which the child will be born and raised as well as spiritual and religious factors played a minor role in decision-making. The factors listed were the intolerance for disability in the French society, lack of infrastructure for caring for persons with disabilities, religious beliefs, spirituality and religious background. These factors did not seem to play a direct role in decision making, but was considered to play an indirect role as they contributed to the parents' concern for their future child's quality of life.

The influence of religion on the decision-making process was further highlighted by Skotko (2005). Skotko (2005) conducted a survey study amongst 141 mothers who decided to continue their pregnancy after receiving a prenatal diagnosis of DS. This study assessed which factors affected their decision and found that most women continued their pregnancy due to religious reasons. All of these women affiliated themselves with Christian religious groups. This finding was also supported by a Turkish study conducted by Balkan *et al.* (2010) amongst Muslim women. The participants in this study mentioned that they were against TOP as they believed that a child is a gift from God. The participants did however mention that they would reconsider their decision if the mother's health was in danger.

Personal factors like maternal age, gestational age and obstetric history all seemed to influence the decision-making process regarding TOP. Previous studies have reported that younger women (usually under the age of 35) were significantly more likely to continue a pregnancy affected with a trisomy than older women (Schechtman *et al.*, 2002; Hurford *et al.*, 2013). Women of an advanced gestational age were also more likely to continue with the pregnancy in comparison to women who found out about the diagnosis earlier in the pregnancy (Heckerling, Verp and Hadro, 1994; Statham, Solomou and Chitty, 2000). The reason for this has been noted to be that women are less attached to their pregnancy during an earlier gestation and are therefore more likely to TOP than later on (Statham, Solomou and Chitty 2000).

In a review by Britt *et al.* (2000) women pregnant with a fetus with DS, who were under 16 weeks pregnant and already had children were more likely to TOP than those women who were further along in their pregnancy and who did not have other children. Women older than

37 years who became aware of DS diagnosis before 16 weeks, with previous children, were also more likely to TOP. A SA study conducted in Johannesburg by Todd *et al.* (2010) investigating women's decision-making regarding TOP supported that gestational age and maternal age plays a significant role. Todd *et al.* (2010) further identified ethnicity as a factor influencing the decision to TOP, as the Black participants were significantly less likely to opt for this procedure.

Hurford *et al.* (2013) conducted a survey study asking American women to rank many of the above mentioned factors from having the least to greatest impact in their decision to continue with their pregnancy after receiving a prenatal diagnosis of DS. They found that participants selected religious/spiritual beliefs and moral beliefs as having the greatest impact, followed by: consideration of the impact that having a child with DS would have on other family members, financial resources, personal experience with DS or other disabilities, and lastly the genetic counselling they received. The participants were allowed to write additional responses and some of the additional factors listed were already feeling attached to their baby (especially after feeling movement), their faith in God, being against TOP, support from family and friends, believing there is a purpose for being pregnant with a child with DS and history of infertility.

### **3.5. SUMMARY**

It is clear from the information presented in this chapter that the decision-making process within the prenatal setting is complex and many factors play a role. As a summary, Figure 3.5 (p.49) combines the factors identified in the proposed theories and models of decision-making with the factors reported in the empirical studies. The factors presented in Figure 3.5 (p.49) were used as the theoretical base when investigating the decision-making processes regarding PND and TOP in the current study.

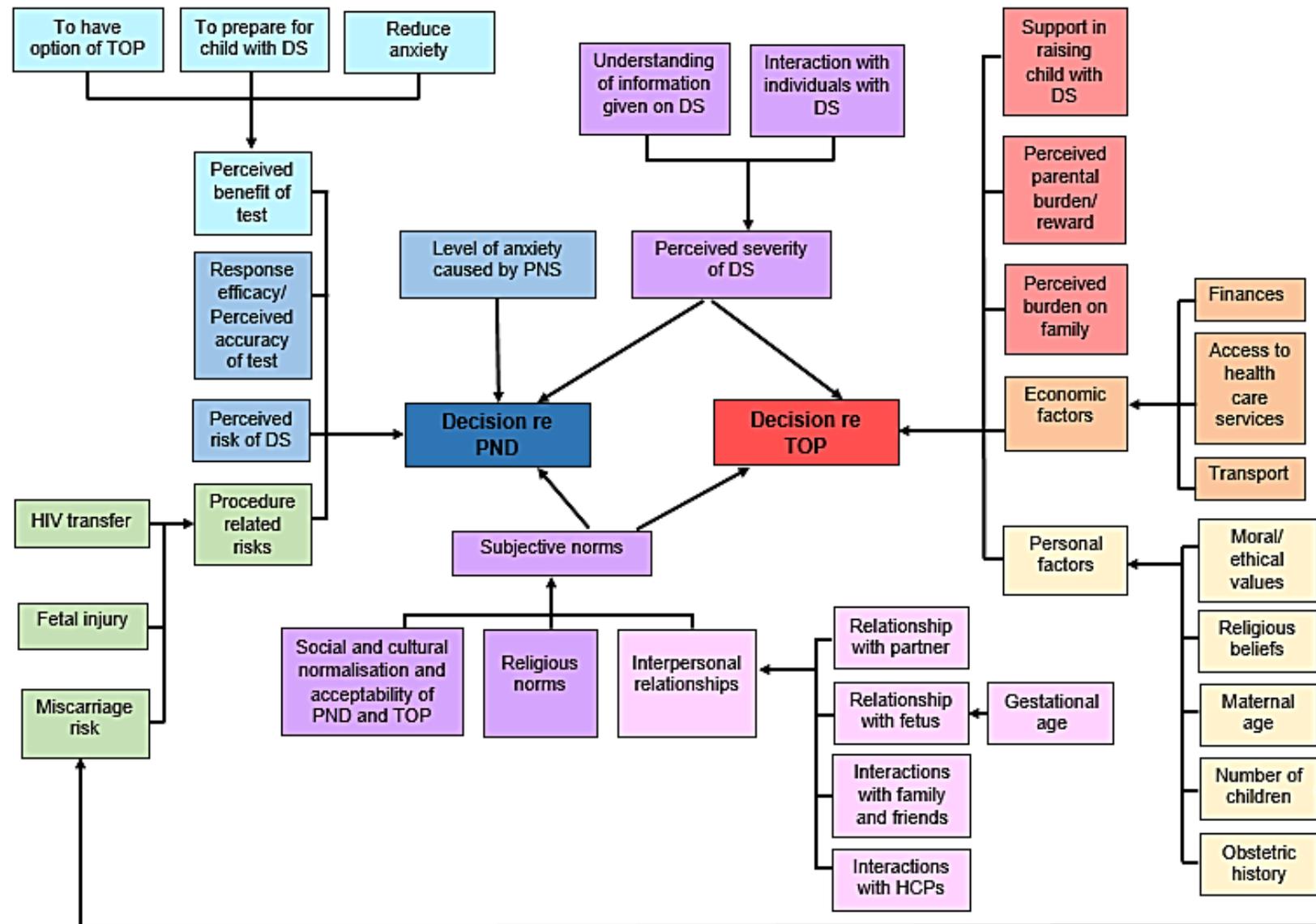


Figure 3.5: Illustration summarising factors influencing decision-making regarding PND and TOP

## CHAPTER 4: RESEARCH METHODOLOGY

### 4.1. INTRODUCTION

The current study used a Qualitative research design with an interpretive phenomenological approach. The theoretical frameworks and philosophical bases of the selected research design will be discussed as well the data collection and analysis procedures.

### 4.2. RESEARCH QUESTION

As mentioned in Chapter 1, prenatal testing services for DS are rapidly advancing. Research is essential when advancing healthcare services in order to appropriately meet the needs of the patients. Therefore, an in-depth understanding of the experiences of the individuals who attended the prenatal clinic at TBH was needed (Biggerstaff and Thompson, 2008). Subsequently the following research question was used to conduct this study:

*How do pregnant women/couples who attend the prenatal clinic at TBH experience their decision-making process around PND for DS and TOP?*

### 4.3. RESEARCH AIM AND OBJECTIVES

The aim of this study was to gain an understanding of how women/couples who attend the prenatal clinic at TBH experience their decision-making process around the option of PND for DS and TOP, in order to improve their satisfaction with the decisions they make.

The objectives of this study were to:

- (1) Gain an understanding of the experiences of women/couples who need to decide whether they would like to have PND for DS.
- (2) Gain an understanding of how women or couples who have received a prenatal diagnosis of DS experience making the decision regarding TOP.
- (3) Determine which factors the women/couples report as influencing their decisions in the prenatal setting and how this fits into the proposed decision-making models.
- (4) Investigate how the decisions women/couples make in the prenatal setting influence their emotional well-being as well as their family and daily life.
- (5) Determine whether the women/couples report feeling that their decisions are congruent with their personal beliefs and values.

- (6) Determine whether the women/couples report being satisfied with the decisions they make in the prenatal setting.
- (7) Synthesize the findings into a model or practice guideline that might shape how services are delivered in the prenatal setting in future.

#### **4.4. QUALITATIVE RESEARCH DESIGN**

In order to fulfil the aim of this study, an in-depth understanding of the participants' experiences were required. Quantitative research methods focus on measurable matters and identifying key factors that influence decisions within the prenatal setting. However, these methods do not provide an understanding of how these factors interact with each other and how the decision-making process in the prenatal setting is experienced (Biggerstaff and Thompson, 2008). Therefore, a Qualitative research design was deemed most appropriate as these approaches offer the researcher the opportunity to develop an understanding of what it means for the participants, within their own social reality, to be in a particular situation (Bryman, 1988).

In addition a qualitative design was seen as more fitting, as this study was exploratory in nature and aimed at yielding new insights in a relatively unexplored SA context (Babbie and Mouton, 2001). Quantitative methods would have been limiting when exploring a relatively new area of research as these designs are too static, as a fixed hypothesis or theory is tested using a pre-determined set of concepts and variables (Cresswell, 1994). A qualitative design is not as strictly formalised as the researcher is able to add variables and statements reported by the participants as the study progresses. A big advantage of qualitative methods are the possibility of utilising slumbering variables. Henning (2004) defined these variables as those properties of the phenomenon not observable to the naked eye for which the researcher is needed to further zoom in on the detail in order to provide a thick description of the full picture of the phenomenon being investigated. Using this method enabled the researcher to explore any statements during the interviews for more clarity, which gave rise to richer, more comprehensive data. This led to more detailed descriptions and a much better understanding of the participants' experiences and decision-making process regarding PND and TOP.

Qualitative research is seen as a legitimate science and employs its own set of philosophical assumptions, strategies of inquiry and methods of data collection and analysis (Cresswell, 2009). The current study met the essential characteristics of a qualitative research study. The data was collected by the researcher within the natural setting of the phenomenon, in other words the

prenatal clinic where the participants experience the problem under study. Multiple sources of data collection was used, such as participant folder notes, field notes, informal observation and interviews. The study aimed at learning the meaning that the participants held about the problem, not the meaning that the researcher brought or what was expressed in the literature. Data analysis was therefore done inductively. The design of this study was emergent and the initial plan was changed after the researcher started collecting the data in order to ensure that the data collected provided the best description of the phenomenon under investigation. The interpretive process entailed making an interpretation of what the researcher saw, heard and understood. This interpretation could not be separated from the researchers own background experience in the clinic, history, contexts and prior understandings. A holistic account was provided of the issue under study. The researcher develop a complex picture of how participants experienced making decisions regarding PND for DS and TOP. This picture reported multiple perspectives and many factors were mentioned in order to provide recommendations on how to improve existing decision-making models (Cresswell, 2009).

#### **4.5. PHENOMENOLOGICAL APPROACH**

Within the qualitative design a phenomenological approach was used. This approach was selected as this approach has been previously used within the health care setting to enrich and guide professional clinical practice (Van Manen, 2014). This approach leads to an increased understanding of a bio-psycho-social phenomena which is essential in order to appropriately meet the needs of the patients and affords exciting possibilities for informing clinical practice (Boyle, 1991; Biggerstaff and Thompson, 2008).

The philosophy of phenomenology was initiated by Edmund Husserl at the beginning of the 20<sup>th</sup> century. This method started off as a study of the consciousness (Giorgi and Giorgi, 2008). Husserl argued that people can be certain about how things appear in or present themselves to their consciousness and therefore reduced the experience of the external world to the contents of personal consciousness (Fouché, 1993). According to Stewart and Mickunas (1990), phenomenological approaches are based on four philosophical perspectives. Firstly the return of philosophy to the original Greek conception as a search for wisdom and not exploring the world by empirical methods. Secondly phenomenology is seen as a philosophy without presuppositions. This means that the researcher needs to suspend all judgement about what is real until they are founded on a more certain basis (Cresswell, 2007). Husserl suggested the concept of epoche or bracketing in order to ensure that the researcher is fresh and maximally open to concrete

experiences being researched. Bracketing means that the researcher brackets his or her own knowledge and experiences with regards to the phenomenon being researched while collecting and analysing data (Giorgi and Giorgi, 2008). The intentionality of consciousness is seen as the third important philosophical perspective. Consciousness is always directed toward some world or the other, whether it is the real world, imaginary world or dream world. Intentionality means that all acts of the consciousness are directed to objects that transcends the acts themselves for example loving is directed towards a loved object and grief is directed to an object that is a reminder of loss. The perceptual act perceives a perceptual object. Husserl believed that if acts of consciousness grasp objects in the world then these objects of consciousness or experience can be communicated by careful description (Giorgi and Giorgi, 2008). The final perspective is the refusal of the subject-object dichotomy thus perceiving the reality of an object within the meaning of the experience of an individual (Creswell, 2007).

In essence the phenomenological approach aims to clarify situations lived through by persons in everyday life and to remain as faithful as possible to the phenomenon and to the context in which it appears in the world. In order to study a particular phenomenon, a situation is sought in which individuals have first-hand experiences of the phenomenon. These experiences are described as they took place in their lives. Furthermore this approach aims to capture as closely as possible the way in which a phenomenon is experienced within the context in which the experience takes place and within the context of the participant's life. (Giorgi and Giorgi, 2008).

As the concept of phenomenology has developed over the last century, many different approaches with their own set of concepts and rules have been developed. For the purposes of this study the interpretive (hermeneutic) phenomenological approach was selected. This was deemed to be the best suited approach as the research question asked for the meaning of the phenomenon with the purpose of understanding the human experience (Crist and Tanner, 2003).

#### **4.5.1. Interpretive Phenomenology**

Van Manen (2014) describes interpretive phenomenology as an approach of abstemious reflection on the basic structures of lived experiences. Abstemious means that the reflection on experience aims to abstain from any theoretical, polemical, suppositional and emotional indulgences. Lived experience means that phenomenology reflects on the pre-reflective or pre-predicative life of human existence as living through it. This approach is also underpinned by the philosophy of hermeneutics, which is the science of interpreting human meaning and experience

(Polkinghorne, 1983). Hence the researcher does not only describe, but also makes an interpretation of the phenomenon being investigated (Cresswell, 2007).

Within this approach, the hermeneutic circle is used as a framework when interpreting the data. This interpretive process is achieved through the movement from the parts of the experience, to the whole of the experience. This movement occurs back and forth again and again, to increase the depth of engagement and understanding of the data gathered. The end of this circle is seen as a place where the researcher reaches a sensible meaning of the phenomenon, free of any inner contradictions and a true reflection of the participant experiences (Laverly, 2003).

The interpretive phenomenological approach has the capacity to uncover, highlight, articulate, and bring recognition to embedded qualitative aspects of the experiences of clinical services and practice that are not apparent from a quantitative perspective (Chan *et al.*, 2010). This approach allowed the participants to share their experiences of receiving genetic counselling and subsequently having to make a decision regarding PND for DS and/or TOP. As the socially situated meanings, habits, practices, and skills from within the person's lifeworld are the foci of interpretive phenomenology, it allowed the researcher to gain insight on how these factors influenced the decision-making process (Chan *et al.*, 2010).

Interpretive phenomenology opens up our understanding of human experiences but also helps to extend caring practices, like Genetic counselling, and the well-being of the patients they exist to protect. This approach led to an understanding of which practices supported the participants to feel satisfied with the decision they made in the prenatal setting. As a research approach, interpretive phenomenology revealed both the practices in their depth and also helped to preserve and shape the ethos of genetic counselling practice within the prenatal setting (Chan *et al.*, 2010).

#### **4.6. RESEARCH SETTING**

The research study was conducted at the Prenatal Counselling Clinic at the Ultrasound Unit at TBH, a tertiary level academic hospital in CPT, SA. The women or couples who attend this clinic, either do so because a congenital anomaly was detected on ultrasound or they are at a high risk for fetal anomalies, including DS. The majority of the individuals who attend this clinic are Coloured, Afrikaans speaking and of a lower socio-economic status. As mentioned in section 2.2.2, the risk of DS increases with age, therefore most of the women are of AMA. Genetic counselling is offered to these women and their partners as outlined in section 2.5 (p.25).

## 4.7. RESEARCH POPULATION AND SAMPLING

During the recruitment period between 1 November 2013 and 31 June 2016, 1832 women/couples were counselled regarding their risk of DS and were offered PND. Of these women/couples 791 had a risk of higher than 1 in 100 for DS, due to AMA, the detection of one or more markers for DS and/or the presence of a congenital abnormality. Out of these individuals, 550 declined and 241 requested testing. Fifteen tested positive for DS and 10 requested a TOP. As discussed in section 4.5 (p.52), in a phenomenological study it is essential that all the participants have experienced the central phenomenon being studied in order to inform an understanding of the research problem (Cresswell, 2007). Consequently purposive sampling was the strategy used to select suitable participants from the research population (Cresswell, 2009). This strategy used the following list of inclusion and exclusion criteria.

The inclusion criteria was either a pregnant woman or couples who:

- were older than 18 years of age.
- were at risk of equal to or higher than 1 in 100 for DS.
- was offered PND at the prenatal clinic at TBH.
- had to make decisions either regarding PND for DS or TOP.

The exclusion criteria was either a pregnant woman or couples who:

- were expecting multiple fetuses as this would have influenced the risks and the procedures offered and therefore their decision-making process.
- were diagnosed with a severe psychiatric illness by as noted in their medical records by either a psychologist or psychiatrist, as participating in this study could have aggravated this condition due to the sensitivity of the topics that were discussed.
- are intellectually disabled as they would not have been able to make independent decisions.

All the individuals who met the selection criteria were invited to participate. An effort was made to draw single women as well as couples into the sample. In order to meet the objectives of this study individuals were also selected based on what their decision was regarding PND and TOP as illustrated in Figure 4.1 (p.56).

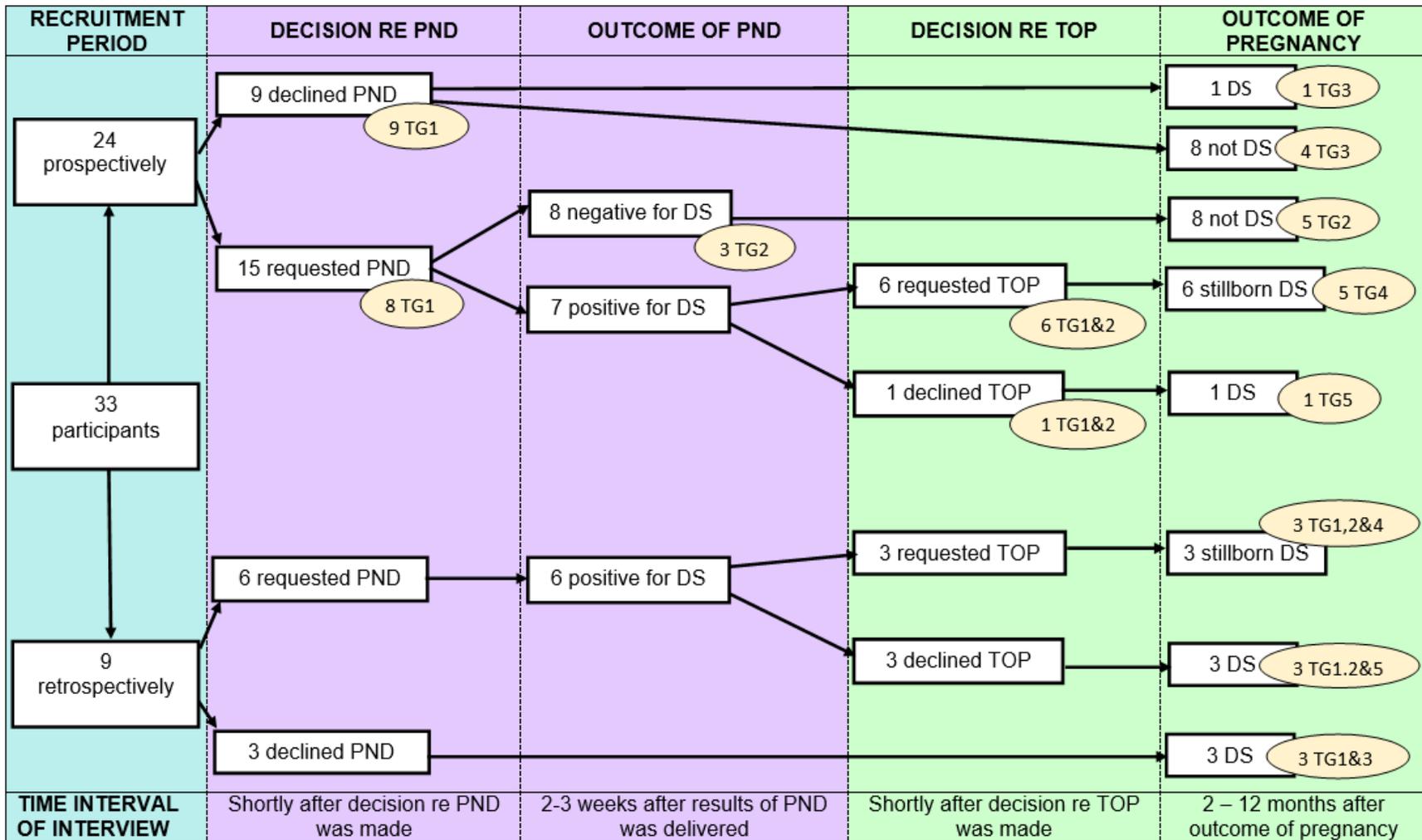


Figure 4.1: Illustration of participant recruitment process as well as timing of interviews and topic guides (TG) used

A total number of 33 participants were recruited. Five of these participants had joint interviews with their partners. Twelve participants who declined and 21 who requested testing were included. More individuals who requested testing were included in order to allow the inclusion of enough participants who tested positive for DS. Eight of these participants tested negative for DS and 13 tested positive. Nine of these participants requested a TOP and 4 decided to continue with the pregnancy.

The majority of the participants were selected prospectively, meaning before the outcome of their pregnancy (DS or not) was known. In order to gain adequate representation of each group as shown in Figure 4.1 (p.56), 9 participants were selected retrospectively, meaning after the outcome of their pregnancy was known. All of the retrospective participants either had a TOP or gave birth to a baby with DS, as these were two groups which were inadequately presented.

Recruitment was stopped in each grouping once the researcher felt data saturation was reached. In broad terms data saturation is when the collection of new data does not add anything to the overall story as it does not shed any further light on the issue under investigation. (Mason 2010). The point at which data saturation is achieved is a rather subjective and largely depends on the researcher, research topic and study design (Fusch and Ness, 2015; Mason, 2010). In the current study data saturation was the point at which:

- (1) the findings from the previous interviews became redundant (Benner, 1994). In other words, further interviews did not produce any new findings as the participants' responses reiterated the responses given during the previous interviews. This was true in even the smallest grouping of four participants who decided to continue the pregnancy after receiving a PND of DS. At this point no new themes or codes emerged.
- (2) the data collected addressed all of the objectives as listed in section 4.3 (p.50).
- (3) the researcher believed the data collected was rich and thick enough to provide a detailed description of the phenomenon under investigation (Guest *et al.*, 2006).

Additionally, Mason (2010) reviewed the methods of 560 qualitative PhD studies using interviews and concluded that the mean adequate sample size was between 28 and 31 participants. At the time recruitment stopped, the researcher had interviewed 33 participants and therefore, the sample size seems to be sufficient.

#### **4.7.1. Participant Sociodemographic and Pregnancy Information**

The hospital folders of the participants were used to collect the basic demographic and pregnancy information. If the information was not present in their folders, it was gathered by contacting the participant telephonically. Table 4.1 (p.59) provides a summary of the sociodemographic information of the 33 participants who participated in the study. Table 4.2 (p.60) provides information on the obstetric history, pregnancy of interest and PND decision of each participant.

**Table 4.1: Sociodemographic information of participants**

| Participant | Age (years) | Ethnicity     | Language  | Relationship status | Employment status | Estimated socioeconomic status* |
|-------------|-------------|---------------|-----------|---------------------|-------------------|---------------------------------|
| P1          | 41          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P2          | 31          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P3 Female   | 42          | White         | Afrikaans | Single              | Unemployed        | Middle                          |
| P3 Male     | 42          | White         | Afrikaans |                     | Self-employed     |                                 |
| P4          | 28          | Black African | Xhosa     | Married             | Unemployed        | Middle                          |
| P5          | 40          | Black African | Xhosa     | Married             | Employed          | Low                             |
| P6          | 39          | Black African | Xhosa     | Stable relationship | Employed          | Low                             |
| P7          | 42          | Black African | Xhosa     | Married             | Employed          | Low                             |
| P8          | 37          | Black African | Xhosa     | Stable relationship | Employed          | Low                             |
| P9 Female   | 46          | Coloured      | English   | Married             | Employed          | Middle                          |
| P9 Male     | 43          | Coloured      | English   |                     | Employed          |                                 |
| P10         | 47          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P11         | 32          | Coloured      | Afrikaans | Single              | Unemployed        | Low                             |
| P12         | 34          | Coloured      | Afrikaans | Single              | Employed          | Middle                          |
| P13         | 20          | Coloured      | Afrikaans | Single              | Unemployed        | Low                             |
| P14         | 39          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P15         | 41          | Black African | Xhosa     | Married             | Employed          | Low                             |
| P16         | 21          | Black African | Xhosa     | Stable relationship | Unemployed        | Low                             |
| P17         | 42          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P18         | 36          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P19         | 41          | Black African | Xhosa     | Married             | Self-employed     | Low                             |
| P20 Female  | 41          | Coloured      | Afrikaans | Married             | Unemployed        | Middle                          |
| P20 Male    | 32          | Coloured      | Afrikaans |                     | Employed          |                                 |
| P21         | 20          | Coloured      | Afrikaans | Stable relationship | Unemployed        | Low                             |
| P22 Female  | 44          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P22 Male    | 46          | Coloured      | Afrikaans |                     | Employed          |                                 |
| P23         | 43          | Black African | Xhosa     | Single              | Employed          | Middle                          |
| P24         | 36          | Coloured      | Afrikaans | Stable relationship | Employed          | Middle                          |
| P25         | 38          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P26         | 41          | Black African | Xhosa     | Married             | Employed          | Low                             |
| P27         | 24          | Coloured      | Afrikaans | Single              | Unemployed        | Low                             |
| P28         | 20          | Coloured      | Afrikaans | Stable relationship | Unemployed        | Low                             |
| P29 Female  | 30          | Coloured      | Afrikaans | Married             | Employed          | Middle                          |
| P29 Male    | 28          | Coloured      | Afrikaans |                     | Employed          |                                 |
| P30 Female  | 38          | Coloured      | Afrikaans | Single              | Employed          | Middle                          |
| P30 Male    | 54          | Coloured      | Afrikaans |                     | Employed          |                                 |
| P31         | 43          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |
| P32         | 38          | Black African | Xhosa     | Married             | Unemployed        | Low                             |
| P33         | 43          | Coloured      | Afrikaans | Married             | Unemployed        | Low                             |

\*Researcher's personal qualitative assessment based on living area, level of education and employment status

**Table 4.2: Obstetric history and pregnancy information of participants P1-P18**

| Participant | Gravida (G) vs Para (P)* | Ultrasound findings   | DS risk (1 in ...) | Gestation when PND offered | PND decision | Outcome of pregnancy |
|-------------|--------------------------|---|--------------------|----------------------------|--------------|----------------------|
| P1          | G5P4                     | Brachycephaly, sandal gap, EIF, clinodactyly and absent NB      | 2                  | 20w2d                      | Requested    | TOP                  |
| P2          | G3P2                     | Hypoplastic NB and EIF  | 22                 | 19w6d                      | Declined     | Normal               |
| P3          | G2P1                     | Thickened NT  | 7                  | 13w5d                      | Requested    | Normal               |
| P4          | G3P2                     | Absent NB and EIF   | 31                 | 20w4d                      | Declined     | Normal               |
| P5          | G3P2                     | Absent NB   | 41                 | 13w2d/17w0d                | Requested    | Normal               |
| P6          | G4P2                     | Hypoplastic NB  | 27                 | 19w1d                      | Declined     | Normal               |
| P7          | G3P2                     | Normal  | 42                 | 20w2d                      | Declined     | Normal               |
| P8          | G2P1                     | Hypoplastic NB  | 47                 | 22w3d                      | Declined     | Normal               |
| P9          | G8P4                     | Hypoplastic NB, brachycephaly and polyhydramnios                | 11                 | 22w4d                      | Requested    | Normal               |
| P10         | G4P3                     | Hypoplastic NB and sandal gap                                   | 2                  | 22w5d                      | Requested    | Normal               |
| P11         | G2P1                     | Hypoplastic NB and EIF  | 19                 | 20w4d                      | Declined     | Normal               |
| P12         | G2P1                     | Hypoplastic NB  | 97                 | 20w3d                      | Requested    | Normal               |
| P13         | G1P0                     | Short humeri  | 45                 | 22w2d                      | Declined     | Normal               |
| P14         | G3P2                     | Absent NB, short femurs and AVSD                                | 4                  | 18w1d                      | Requested    | TOP                  |
| P15         | G3P2                     | Hypoplastic NB and EIF  | 39                 | 19w3d                      | Requested    | Normal               |
| P16         | G1P0                     | Nuchal oedema and EIF   | 44                 | 21w1d                      | Requested    | DS                   |
| P17         | G8P7                     | Hypoplastic NB and EIF  | 2                  | 22w6d                      | Requested    | Normal               |
| P18         | G3P2                     | Nuchal oedema, ventriculomegaly, pyelectasis and hypoplastic NB | 9                  | 21w1d                      | Requested    | TOP                  |

AVSD= atrioventricular septal defect, EIF= echogenic intracardiac focus, NB= nasal bone, NT= nuchal translucency, VSD= ventricular septal defect

\*Gravida and Para before outcome of pregnancy of interest

**Table 4.3: Obstetric history and pregnancy information of participants P19-P33**

| Participant | Gravida (G) vs Para (P)* | Ultrasound findings  | DS risk (1 in ...) | Gestation when PND offered | PND decision | Outcome of pregnancy |
|-------------|--------------------------|--|--------------------|----------------------------|--------------|----------------------|
| P19         | G5P4                     | Short long bones, AVSD and flat face   | 2                  | 20w6d                      | Requested    | TOP                  |
| P20         | G6P2                     | EIF and single umbilical artery  | 61                 | 16w3d                      | Requested    | Normal               |
| P21         | G2P1                     | Hypoplastic NB, short humeri and hyperechogenic bowel  | 45                 | 22w5d                      | Declined     | Normal               |
| P22         | G7P6                     | AVSD, ventriculomegaly, brachycephaly, nuchal oedema, hypoplastic NB, short humeri, EIF and hyperechogenic bowel | 2                  | 21w1d                      | Declined     | DS                   |
| P23         | G4P2                     | Hypoplastic NB and EIF   | 33                 | 21w3d                      | Requested    | TOP                  |
| P24         | G3P2                     | Short long bones, absent NB, AVSD, EIF and pyelectasis   | 3                  | 22w1d                      | Requested    | TOP                  |
| P25         | G5P4                     | AVSD, brachycephaly and clinodactyly   | 2                  | 21w1d                      | Requested    | DS                   |
| P26         | G1P0                     | Talipes, short humeri, nuchal oedema, AVSD and brachycephaly   | 4                  | 19w4d                      | Declined     | DS                   |
| P27         | G2P1                     | EIF and Talipes  | 13                 | 22w2d                      | Requested    | DS                   |
| P28         | G1P0                     | Absent NB, Short humeri, EIF, echogenic and bowel  | 45                 | 22w5d                      | Requested    | TOP                  |
| P29         | G3P2                     | VSD, EIF, nuchal oedema and pyelectasis  | 8                  | 21w5d                      | Requested    | TOP                  |
| P30         | G2P1                     | Absent NB, AVSD and thickened NT   | 4                  | 13w0d                      | Requested    | TOP                  |
| P31         | G7P5                     | EIF  | 43                 | 19w5d                      | Requested    | DS                   |
| P32         | G2P1                     | Absent NB, EIF and short femurs  | 2                  | 20w1d                      | Declined     | DS                   |
| P33         | G5P4                     | Absent NB  | 6                  | 20w6d                      | Declined     | DS                   |

AVSD= atrioventricular septal defect, EIF= echogenic intracardiac focus, NB= nasal bone, NT= nuchal translucency, VSD= ventricular septal defect

\*Gravida and Para before outcome of pregnancy of interest

The women who were interviewed together with their partners were assigned the same participant number, with an F to indicate the female partner and an M to indicate the male partner as listed in Table 4.1 (p.59). The participants were aged between 20 and 47 years, with a mean age of 36 years. Most of the participants were Coloured, of AMA and Afrikaans speaking, which was representative of the majority of the women who attend the prenatal clinic at TBH as described in section 4.6 (p.54).

The majority of the participants were from a low socioeconomic status and were either from an urban township located in the northern suburbs of CPT or from a rural farming area within the WC. The bulk of the participants were either married or in a stable relationship and unemployed.

Most of the participants had at least one other child prior to the pregnancy of interest. All of the participants screened high risk for DS (above 1 in 100) either based on their age or their ultrasound findings. The vast majority of the participants were in their second trimester of pregnancy, mostly further than a gestation of 19 weeks, when PND was offered.

#### **4.8. DATA COLLECTION METHOD: SEMI-STRUCTURED INTERVIEWS**

Intricate nuanced narrative descriptions are the essence of interpretive phenomenological research, which dictates that data should be collected through situation-based in-depth interviews (Cresswell, 2007; Chan *et al.*, 2010). In-depth interviewing is a well-established technique and aims to discover the participant's own framework of meanings, by exploring what is said in as much detail as possible and going below the surface of the topic being discussed (Britten, 2006). For the purposes of this study a semi-structured in-depth interviewing technique was used.

Semi-structured in-depth interviews are conducted on the basis of a loose structure consisting of open-ended questions known as a topic guide (Britten, 2006). These guides are used to indicate the general area of interest and to provide cues when the participant has difficulties. However, the researcher's role in a semi-structured interview is to facilitate and guide, rather than dictate exactly what will happen during the interview. Therefore, this approach allows the researcher to follow the agenda of the participant and to diverge from these guides in order to pursue an idea or response in more detail (Smith, 2008). In order to address the research aim and objectives an in-depth understanding of the topic was needed. This approach was used as the topic guides ensured that the needed information was gathered during the interviews. The looseness of the structure allowed the researcher to be guided by the participant and to

explore areas of interest in as much depth as possible. The topic guides (Appendix A, p.207) used as well as the interviewing procedure will be discussed in more detail in the following sections.

#### **4.8.1. Topic Guides**

Different topic guides were used during different intervals of the decision-making process. The outcome of PND and the pregnancy were also used to dictate which topic guides were the most suitable. These topic guides consisted of open-ended questions. The first question on each schedule was general and emotionally neutral. This helped to establish rapport so that the participants would feel more comfortable answering the more topic focused and emotionally loaded questions.

Topic guide (TG) 1 was used to explore how the participants experienced the pregnancy, being told that they are at a high risk for DS and decision-making regarding PND. They were also asked to elaborate on the factors that influenced their decision-making process. This topic guide was designed to address objectives 1 and 3.

TG 2 was used to interview the participants who had requested PND in order to explore how they experienced the waiting period for the results, the news of the result and the satisfaction of their decision to have PND. Additionally, the participants who tested negative for DS, were asked how they experienced the birth of the baby and how they would improve the decision-making process with regards to PND. In order to address objectives 2 and 3 the participants who received a positive diagnosis of DS, were asked to elaborate on their decision-making process regarding TOP and which factors influenced their decision.

TG 2, 3, 4 and 5 all addressed objectives 4, 5 and 6. The participants were all asked to elaborate on how they experienced the remainder and the outcome of their pregnancy, whether they felt satisfied with the decisions they made and how these decisions impacted on their daily lives and relationships. TG 3 was tailored to explore the experiences of the participants who declined PND after the outcome of the pregnancy. TG 4 explored the experiences of the participants who requested TOP after a PND of DS. TG 5 was used to explore the experiences of the participants who declined a TOP after a PND of DS. The final question on all of these guides asked them if they had any recommendations in order to improve the decision-making process with regards to PND or/and TOP for DS.

## 4.9. DATA COLLECTION PROCEDURE

### 4.9.1. Informed Consent

The individuals who met the recruitment criteria were invited to participate by informing them of the aim and objectives of the study, what was expected of them during the study, their rights as a participant as well as the possible risks and benefits of participating. Not all of the women or couples who were approached consented to participate. Four participants who declined either felt they had nothing useful to add or that it would take too much of their time. There were also three individuals who had severe emotional reactions towards the news of being at risk of having a baby with DS and who were unwilling to participate. Two of these participants agreed to participate after being approached again at a later stage. One of these women was approached again after being admitted to the labour ward at TBH, to have a TOP as she received a positive PND result for DS. She was happy to join the study at this time as she had had enough time to overcome her emotions she experienced due to grief and had come to terms with the diagnosis. The other participant, who declined PND, was approached again after giving birth to a baby with DS. This participant added that she originally did not want to participate due to the words “*termination of pregnancy*” in the title of the research study as listed on the consent form. She thought if she signed she had to agree to have a TOP.

The individuals who agreed to participate were asked to sign an informed consent form in a language that they understood. A copy of the Afrikaans and English consent forms have been included as Appendix B (p.212). The researcher had the contact details of a Xhosa speaking research assistant, who would have verbally translated the consent form into Xhosa, had there been any participants who were not fluent in either Afrikaans or English. Provisions were also made for any illiterate participants, as they would have been allowed to give a thumbprint as consent for participation. All of the participants were literate and were able to provide a signature as consent. By signing this form they agreed to be interviewed and for the audio-recording of this discussion. The participants were given a copy of this consent form with the contact details of the researcher. A suitable time, date and venue for the interviews was set up with the women or couples who were willing to participate.

Prior to conducting the interviews, the participants gave their verbal consent for the gathering and use of their sociodemographic information as presented in Table 4.1 (p.59) and their obstetric history and pregnancy information as presented in Table 4.2 (p.60). This information was gathered from the participant’s hospital folder or telephonically. During the interviews the researcher made sure that the information gathered was accurate.

#### 4.9.2. Conducting Interviews

The interviews were conducted with either the pregnant woman by herself or together with her partner, if he was available. The participants were given a choice of venue between the hospital, their homes or a quiet public space. The majority of the face-to-face interviews were conducted in a private room at the hospital apart from two interviews. Both of these participants had a TOP and did not want to return to the hospital, as it brought back unpleasant memories of their loss. One participant was interviewed in her home and the other in a quiet public space.

Face-to-face interviews were preferred as it allowed the researcher to pick up on some non-verbal cues (Giorgi and Giorgi, 2008). Any vocal intonations, physical expressions, changes in posture and gestures made throughout the interview process were included in the researcher's field notes. Telephonic interviews were used to conduct follow-up interviews only when the participants were unable to attend a face-to-face interview due to time constraints or transport problems. In total 52 interviews were conducted (33 initial and 19 follow-up interviews). Thirty-nine interviews were conducted face-to-face and 11 telephonically. Two follow-up interviews were conducted over text messaging via WhatsApp Messenger as neither one of these participants wanted to speak to the researcher over the telephone or face-to-face. Both of these interviews were short interviews of about 10 text messages. During these interviews the researcher was only able to ask how these participants had been since their initial interview. Five couples were interviewed and 28 women.

The interviews were conducted by the researcher as all the participants were fluent in either English or Afrikaans. The interviews were audio-recorded to help the interview run smoothly and to enhance the process of building rapport with the participant. It also enabled the researcher to gather the responses as a whole and not only the gist of each response (Smith 2008).

As illustrated in Figure 4.1 (p.56), the interviews were conducted at different time intervals throughout the decision-making process in order to explore how decisions regarding PND and TOP develop. This was also done in order to explore how the factors that influence the decision-making process (as described in Chapter 3) influence the participants' decision-making over time. Where possible repeated interviews were done with the same participants in order to gain a deeper understanding of their experiences and the decision-making process. In interpretive phenomenological studies using repeated interviews not only increases the depth of the findings, but also enhances the interpretation thereof (Benner, 1994; Mishler, 1986). Figure 4.1 (p.56) also illustrates the number of participants who were interviewed at

each interval as well as the combination of TGs (Appendix A, p.207) used. These TGs were not strictly followed as the researcher allowed the participants to freely express themselves and lead the conversation. The initial question of each topic guide was used to build rapport and start the conversation. The researcher then based the order of her questioning on the participants' responses as the participants often naturally addressed some of the issues listed on the topic guide. The researcher used the TGs to focus the conversation if the participants starting speaking about topics that were not relevant to the research study. The TG was also used to guide the researcher in asking questions to make sure that all relevant topics were covered during the interviews. The next question was asked when the participant seemed to have said all they had to say about the previous question. In order to illustrate how the interviews were done, an extract of two of the interview transcripts are provided in Appendix C (p.224).

Twenty-four participants were interviewed retrospectively at two intervals during the decision-making process. Nine of these participants declined PND, and 15 requested PND. All of the participants who declined and 8 who requested PND were interviewed shortly after they made their decision regarding testing. The average duration was 27 minutes and 19 seconds. In general the initial interviews of the participants who declined testing were shorter as they seemed less anxious about their situation. All of these interviews were conducted face-to-face in a private consultation room at TBH. The timing of these interviews allowed the researcher to explore the immediate reactions of the participants when hearing the news of being at high risk and having to make a decision.

Of these nine participants who declined PND, the researcher was only able to get hold of 5 for a follow-up interview 2 to 12 months after the birth of their baby. The participants either did not attend their scheduled appointment for their follow-up interview or they were lost to follow-up due to a change in address or contact number. All of these interviews were conducted telephonically with only the women as per convenience of the participants. They were unable to attend a face-to-face interview due to time or transport constraints. The follow-up interviews with the participants who gave birth to a healthy baby were short and on average lasted 15 minutes and 20 seconds. The follow-up interview with the participant who gave birth to a child with DS was 44 minutes and 26 seconds as she had a lot more to share about her experiences. The researcher conducted interviews at this time interval in order to allow sufficient time for the participants to experience their baby and reflect on how this impacted their satisfaction with their decision to decline PND.

Of the 15 participants who requested PND, 8 participants tested negative for DS. Three of these participants had their follow-up face-to-face interviews 2 to 3 weeks after their initial interview as this is the time it took to receive their PND results. These interviews were conducted in a private consultation room at TBH. During these interviews the participants mentioned that there was still a concern that their baby will be born with a disability, despite receiving a negative result for DS. In order to explore this finding further, 5 other participants had their follow-up interview between 2 and 12 months after their baby was born. This allowed the researcher to establish whether the concern that their baby might have a disability subsided after the birth of their baby. All of these interviews were conducted telephonically. The average duration of these interviews were 24 minutes and 7 seconds.

Of the 15 participants who requested PND, 7 tested positive for DS. Six requested a TOP and had their initial interview shortly after making this decision. They were interviewed in the hospital ward after being admitted for the TOP procedure. The researcher was unable to interview these women at an earlier time interval as they were too emotionally distraught. Interviewing the women at this interval allowed the researcher to pick up on the immediate emotions the women experienced while being in hospital and waiting to deliver their stillborn baby. These interviews were much longer than the others as the participants were dealing with a lot of raw emotions. The audio-recorder often had to be stopped as these participants started crying and needed some time to compose themselves. The average duration was 48 minutes and 40 seconds. Three of these participants opted for a telephonic follow-up interview. Two opted for a face-to-face interview, one at a private consultation room at TBH and the other preferred being interviewed at her home. One participant was lost to follow-up due to a change in telephone number. The follow-up interviews lasted 35 minutes and 24 seconds on average. These interviews were conducted between 2 and 12 months after they were discharged from the hospital in order to explore the long-term impact of this decision. The timing of these interviews also allowed the participants sufficient time to reflect on their decision and to go through certain ceremonies of closure.

The remaining prospective participant who received a positive PND for DS was initially interviewed shortly after deciding to continue with the pregnancy. She was interviewed in a private consultation room at TBH and the duration of the interview was 37 minutes and 13 seconds. The timing of this interview was chosen in order to explore the immediate emotional impact of this decision. The participant had a face-to-face follow-up interview 12 months after her baby was born. The interview was conducted in a private consultation room at TBH and lasted 15 minutes and 41 seconds. The timing of this interview allowed enough time for the participant to experience raising a child with DS. This allowed the researcher insight into the

impact of the decision to keep the baby on her daily life and relationships. This interview was short as the participant's baby did not have any major health concerns and the participant had a lot of support raising her baby.

As the selection criteria for the participants were strict and the topic being investigated was emotionally loaded, nine of the participants were interviewed only once between 2 and 12 months after the outcome of their pregnancy. These retrospective interviews allowed the researcher a final look into how the process as a whole impacted the emotional state and daily lives of the participants. All of these interviews were conducted face-to-face. Six of these participants requested PND and 3 declined. The six who requested PND all tested positive for DS. Three requested a TOP and 3 decided to continue with the pregnancy. The three who declined PND all had a baby with DS.

Of the three participants who requested TOP after receiving a positive diagnosis of DS, two were interviewed in a private consultation room at TBH and one opted to be interviewed in a quiet public space away from the hospital. These interviews were lengthy and on average lasted 58 minutes and 55 seconds. These participants were still dealing with the grief of their loss and often became tearful during the interviews.

The three participants who continued the pregnancy after receiving a positive diagnosis of DS, were interviewed in a private consultation room at TBH. On average, the duration of these interviews were 45 minutes and 58 seconds.

The three participants who declined PND and gave birth to a baby with DS was specifically included as it allowed the researcher to explore the satisfaction of the decision to not have PND after having a baby born with DS. The average duration of these interviews were 30 min and 20 seconds.

#### **4.10. DATA ANALYSIS**

The aim of data analysis in an interpretive phenomenological study is to reveal the meaning of the lived experiences. The researcher transforms what is implicit to the explicit, in other words the analysis reveals meanings that are lived but not necessarily clearly articulated or in full awareness of the participants. The end product of analysis is an articulate description of the phenomenon in order to increase the understanding thereof. The interview transcripts were examined simultaneously with the emerging interpretation, in order to never lose sight of each participants' story and context (Crist and Tanner, 2003).

The researcher used a combination of the steps of phenomenological data analysis as described by Hycner (1999) and Cresswell (2009) to derive meaning from the data collected. Atlas.ti 7 software was used to assist the researcher with this process.

***Step 1: Bracketing.***

Bracketing is the first step in the process of phenomenological data analysis in which the researcher sets aside, as far as humanly possible, all preconceived and past knowledge of the experience in order to understand the experiences of participants in the study at a deeper level (Merleau-Ponty, 1956; Moustakes, 1994). This process also entails setting aside one's beliefs, feelings and perceptions in order to be more open and faithful to the phenomenon being investigated (Streubert and Carpenter, 1999). The researcher kept a research journal and stated her own presuppositions beforehand in order to ensure that her own biases and presuppositions did not interfere with the analysis process.

***Step 2: Organising and preparing the data for analysis.***

The researcher transcribed the audio-recordings of the interviews verbatim. Those interviews conducted in Afrikaans, were translated into English. The initial translation was done by the researcher. The original transcripts and the translations were then given to an Afrikaans speaking genetic counsellor for review. This genetic counsellor ensured that the transcripts were appropriately translated and maintained their authenticity. The field notes the researcher used to note any changes in body language, physical expressions or vocal intonations during the interviews were incorporated into the narrative texts. This allowed for the simultaneous analysis thereof. An extract of two of these transcripts are provided in Appendix C (p.224).

***Step 3: Reading through all the data.***

As the phenomenological perspective is a holistic one, the researcher needed to firstly obtain a general sense of the information describing the phenomenon being investigated before further analysing the data (Giorgi and Giorgi, 2008). Thus the researcher started off by reading through all the transcripts as a whole in order to reflect on its overall meaning. This process of familiarization ensured that the researcher stayed true to the phenomenon without imposing her own ideas on the data (Hycner, 1999). During this stage the researcher added memos on the general thoughts about the data in the margins of each of the interviews

***Step 4: Detailed analysis with coding process.***

Coding is defined as the process of organizing narrative data into segments of text before bringing meaning to the information (Rossmann and Rallis, 1998). This process entails

segmenting sentences in the transcripts into categories and labelling each of these categories with descriptive terms. These labels are known as the codes. The codes are identified by carefully reading over every word, phrase and paragraph to elicit the meaning expressed by the participants.

The researcher used a combination of predetermined and emerging codes to analyse the data. The objectives of the study and literature was used to create an initial list of codes. The researcher then started with one transcript from each group of participants (requested PND, declined PND, requested TOP and declined TOP) to further build on this list and to create a codebook. Subsequently the other transcripts were coded using this codebook and adding new codes as they arose in the data. The final list of codes were refined by clustering together the ones that are similar or relate to each other. This process is called creating code families. An example of the families of codes used during the analysis of the data is presented in Table 4.3 (p.61) and the full list in Appendix D (p.250). For consistency in coding a code list as well as a description of each code was added in the Atlas.ti program.

**Table 4.4: Example of code families used in data analysis**

| Family  | Codes   |
|---|---|
| <i>Emotional reactions towards being at high risk for DS (HRDS)</i>           | Upsetting<br>Why my baby?<br>Worry<br>Guilt<br>Sadness<br>Stress<br>Punishment from God   |
| <i>Impact of being at high risk for DS (IHRDS)</i>                            | Praying for miracle /good outcome<br>Anxiety at birth<br>Doubt in ultrasound findings<br>Negative feeling towards pregnancy<br>Preparing for the worst<br>Thinking positive<br>Tentative pregnancy  |
| <i>Factors influencing decision-making prenatal diagnostic testing (DPND)</i> | Initial indecision<br>Influence of partner<br>Perception of soft-markers<br>Risk perception of DS<br>Risk perception of miscarriage<br>Would not TOP<br>Gender of baby<br>Perception of DS<br>Miscarriage risk<br>Religion<br>Baby's health<br>Compulsory test<br>Acceptance of family<br>Previous experience<br>Number of children<br>Obstetric history<br>Impact on other children<br>Finances<br>Impact of disabled child on couple's relationship<br>To be prepared<br>Influence of information given<br>Satisfaction |
| <i>Experience of PND procedure (PND Pro)</i>                                  | Fear of pain (of needle)<br>Fear of miscarriage   |
| <i>Waiting period for test result (WTR)</i>                                   | Anxiety<br>Isolation<br>Hopeful<br>Tentative pregnancy  |

Table 4.5: List of major themes and subthemes

| Major theme  | Subthemes   |
|--|---|
| <i>Being at high risk for Down syndrome</i>          | Impact of being at high risk for DS <ul style="list-style-type: none"> <li>• <i>Grief response</i></li> <li>• <i>Anxiety about disability</i></li> <li>• <i>Feelings of self-blame</i></li> <li>• <i>Delayed disclosure of pregnancy</i></li> </ul>   |
|  | Coping with high risk for DS <ul style="list-style-type: none"> <li>• <i>Social isolation</i></li> <li>• <i>Remaining positive vs preparing for the worst</i></li> <li>• <i>Remaining occupied</i></li> <li>• <i>Support</i></li> </ul>   |
| <i>Decision-making processes in prenatal setting</i> | Experience of making decisions regarding PND and TOP  |
|  | Self-reported factors influencing decision regarding PND <ul style="list-style-type: none"> <li>• <i>Partner's opinion</i></li> <li>• <i>PND procedure related risks</i></li> <li>• <i>Family structure</i></li> <li>• <i>Risk perception</i></li> <li>• <i>Perceived benefit of testing</i></li> <li>• <i>Attitude towards TOP</i></li> </ul>  |
|  | Self-reported factors influencing decision regarding TOP <ul style="list-style-type: none"> <li>• <i>Perceived severity of DS</i></li> <li>• <i>Health of baby</i></li> <li>• <i>Prevent suffering</i></li> <li>• <i>Partner's opinion</i></li> <li>• <i>Family's opinion</i></li> <li>• <i>Impact on other children</i></li> <li>• <i>Available support in raising child with DS</i></li> <li>• <i>Finances</i></li> <li>• <i>Personal values and religious beliefs</i></li> </ul> |
| <i>Impact of decision regarding PND</i>              | Impact of decision to decline PND <ul style="list-style-type: none"> <li>• <i>Receiving a postnatal diagnosis of DS</i></li> <li>• <i>Impact of raising a child with DS</i></li> </ul>  |
|  | Impact of decision to request PND <ul style="list-style-type: none"> <li>• <i>Experience of PND procedure</i></li> <li>• <i>Impact of waiting period for and receiving PND results</i></li> </ul>   |
| <i>Satisfaction with decision regarding PND</i>      | Satisfaction with decision to decline PND   |
|  | Satisfaction with decision to request PND   |
| <i>Impact of decision regarding TOP</i>              | Impact of decision to decline TOP <ul style="list-style-type: none"> <li>• <i>Impact of raising a child with DS</i></li> </ul>  |
|  | Impact of decision to request TOP <ul style="list-style-type: none"> <li>• <i>Experience of TOP procedure</i></li> <li>• <i>Impact of having a TOP</i></li> <li>• <i>Finding closure</i></li> </ul>   |
| <i>Satisfaction with decision regarding TOP</i>      | Satisfaction with decision to decline TOP   |
|  | Satisfaction with decision to have TOP  |

***Step 5: Generating a general description and interpretation of the data.***

The codes that were identified were reduced and transformed into units of meaning. These units of meaning reflected the major recurrent verbal and non-verbal cues for example the expression of emotions, acts or similar event descriptions. The units of meaning which were related to the objectives of the study and contributed to the understanding of how women or couples experience the decision-making process regarding PND for DS and TOP were selected and clustered together to form themes. Some of these themes consisted out of a single code family, while others entailed a combination of code families. These themes involved a detailed rendering of information about the research setting, the participants, the events they experienced and the decision-making process regarding PND for DS and TOP. The importance of each theme was reflected by the number of times it was stated by the participants in relation to the contexts in which it was raised, the emphasis of the theme and its interaction with other themes in the text. Six major themes were identified which are presented as headings in the results section. A list of the major themes and subthemes are provided in Table 4.4 (p.71).

***Step 6: Presenting the themes.***

The description of the major themes and subthemes were presented as a narrative passage. Firstly, a textural description (“What happened?”) was developed, followed by a structural description (“How the phenomenon was experienced”) in order to develop the essence of the theme. These descriptions were illustrated by using quotations from the interviews conducted with the participants. These descriptions are presented in Chapter 5.

***Step 7: Making an interpretation of the data.***

The interpretation process followed the hermeneutic circle framework. This process was started by first reading the available literature on the phenomenon being investigated. The researcher then read each individual part of the interviews and then as a whole. Each individual interview was interpreted and then all the interviews were interpreted as a whole. The researcher then went back to the available literature to help with interpreting the data. The described process followed a circular movement and the researcher kept moving back and forth between the available literature, the individual interview transcripts and the data as a whole, until the researcher obtained a sensible understanding of the phenomenon. The final interpretation was done by the question “What were the lessons learned?” By answering this question the researcher captured the essence of the idea (Lincoln and Guba, 1985). These lessons were established by deriving meaning from a comparison of the findings with the information presented from previous literature. This step was used to address objective 7 of this study. The data was compared with the previous models of decision-making presented

in the literature. These models were then appropriately modified and developed into a decision-making guide specific to the SA context. Subsequent recommendations were made to improve future supportive practices in the prenatal setting. The researcher also made personal interpretations based on her history and experiences of working within this setting.

#### **4.11. VALIDITY**

The validity of a research study corresponds to the degree to which the findings are regarded as trustworthy, useful, legitimate and authoritative by people with an interest in the research findings. Furthermore validity in an interpretive phenomenological study refers to the degree to which the explanations of the phenomena match the realities of the world (Yardley, 2008).

According to Lincoln and Guba (1985) validity is evaluated based on the following five elements: credibility, transferability, dependability, confirmability and authenticity. Credibility refers to the extent to which the interpretations reflect the lived experience of the participants (Lincoln and Guba, 1985). Transferability is the degree to which the findings in this context can be applied to the experiences of other individuals in a similar context or setting (Holloway, 2008). For the purposes of this study, transferability refers to the degree to which the findings of the current study can be applied to the prenatal clinics within the SA context. Dependability is reached when the results are consistent and subject to change and instability. Confirmability means that the researcher has represented the reality of the participants and that the findings emerged from the collected data and not the opinions and subjectivity of the researcher. Authenticity relates to the degree to which the researcher reported the participants' perspectives fairly and whether the results will help them to understand and improve their situation (Holloway, 2008). In interpretive phenomenology authenticity is strengthened when a multiplicity of individual realities are presented within a collective interpretation of the lived experiences (Tobin and Bagely, 2004). The following strategies were used to address these five elements of validity:

##### ***a) Prolonged engagement in the field***

Prolonged engagement refers to the investment of sufficient time within the field to achieve specific goals like learning the participants' perspectives, building trust and testing for contradicting information and distortions introduced by either the researcher or the participants (Lincoln and Guba, 1985). The researcher has been a genetic counsellor in the prenatal setting for eight years. The persistent observation in the field strengthened the interpretation of the collected data as it enabled the researcher to identify the core issues related to the decision-making processes within the prenatal setting. Furthermore the data was collected

over a period of three years and the collection of data over different time intervals of the decision-making process meant meeting with the participants at more than one occasion. The researcher was able to develop rapport with the participants through conducting lengthy face-to-face initial interviews. Following the initial contact the researcher often followed-up with telephone calls before their next interview in order to build a relationship of trust.

***b) Debriefing with research supervisors and peers***

The researcher met with her research supervisors once a month in order to debrief and review the research process (Cresswell, 2009). The researcher also had informal conversations with colleagues knowledgeable about the research topic, but who were not directly involved. These conversations allowed the researcher to share her experiences while conducting the interviews as well as her interpretations of what the participants said during these interviews. This reduces researcher bias as it allowed her colleagues the opportunity to offer alternative explanations for her findings (Lincoln and Guba, 1985). The researcher held meetings with her two supervisors to discuss the emerging codes from the data. The purpose of comparing coding with her supervisors were to triangulate their perspectives. This ensured that the analysis was not confined to one perspective, and makes sense to other people. These discussions also helped to identify potential themes in the data that may not yet have been captured by the codes, and highlight the clarifications or modifications of codes that might be needed in order to increase the consistency and coherence of the analysis (Yardley, 2008).

***c) Member checking***

This strategy elicits the participants' views on the credibility of the findings and interpretations. The preliminary themes were telephonically presented to one participant from each decision-making category (declined PND, requested PND, declined TOP and requested TOP). This was done to see if they felt the researcher interpreted their experiences accurately (Appleton, 1995). Furthermore due to the sensitive nature of the research topic a full rough draft of the preliminary themes were not presented to the participants themselves, but to two other Genetic counsellors working within the prenatal setting. They were given a written draft of the results chapter describing the emerging themes in order to assess. This was done to ensure that the emerging themes did not arise from the researcher, but from the experiences of the participants (Manning, 1997).

***d) Providing a rich, thick description of methods used***

The researcher provides a rich, thick description of the methodology used to conduct the research study and analyse the data in order to allow the readers to make decisions regarding transferability. This will enable the readers to transfer the information to other settings and to

determine whether the findings can be transferred because of shared characteristics (Cresswell, 2009).

#### **e) *Disconfirming case analysis***

Disconfirming cases are those cases that do not fit in to the themes that were derived from the data or the viewpoints of the researcher. The researcher paid special attention to reporting on all cases that were relevant to the research topic, even if they did not fit into her viewpoint or those stated in previous literature. This was done in order to assure the readers that the researcher had taken into account and presented all the data, rather than just selecting the parts that fit into her viewpoint (Yardley, 2008).

#### **f) *Commitment and rigour***

The aim of a qualitative research study is to achieve a thorough description of the phenomenon which will have relevance to many different contexts. Therefore, the researcher needed to sample from many different perspectives that are likely to be encountered (Yardley, 2008). This was achieved by sampling individuals in each of the decision-making categories: those who requested PND, declined PND, requested TOP and declined TOP. A thorough description was possible as the researcher engaged extensively with the topic by working in the prenatal clinic for 6 years and assisting pregnant women or couples with decision-making regarding PND for DS and TOP.

#### **g) *Reflexivity***

Reflexivity is done to verify the research process through the description of how the researcher's experience and knowledge could have affected the interpretation and the understanding of the study findings (Todres and Wheeler, 2001). The researcher made her views explicit by providing a description in section 4.12 (p.76) of her past experiences, current position and personal assumptions and orientations about the topic which could have impacted the inquiry. The researcher kept a research diary and constantly did self-reflection throughout the data collection and analysis procedure to ensure that it did not lead to a biased approach towards the study and influenced the interpretation of the results.

### **4.12. DECLARATION AND REFLECTION OF SELF**

*This section of the dissertation is written in the first person as the researcher was practicing self-reflection.*

I am a Caucasian woman who speaks Afrikaans and have strong Christian values and beliefs. I am a Genetic counsellor by profession with a keen interest in qualitative research to improve

caring health services. I grew up in a middle-class household in the Northern Suburbs of CPT. I was exposed to disability at a young age as my mother was a special needs education teacher. I often spent time with my mother at the school and got to meet the parents and their children. I have also been a volunteer at a support group for parents of children with DS, the Down Syndrome Association of the Western Cape, since 2009, and recently been appointed as their chairperson. These experiences opened my eyes to the experiences of parents who raise a child with a disability – good and bad. It also made me realise that I would like to be in a profession that helps these children and their parents.

I completed my undergraduate B.Sc. degree in Human Life Sciences as well as my Honours degree in Genetics at Stellenbosch University. I started my M.Sc. in Genetic Counselling at the University of Cape Town in 2009. I completed my degree in 2011 and my internship in 2013.

Currently, I am a HPCSA registered genetic counsellor doing sessions in the state and private sector. I have had exposure to working in the prenatal counselling setting for more than 8 years. I was also in charge of running the prenatal genetic counselling clinic at TBH for women/couples who are at an increased risk for DS from 2012 until 2016.

I have assisted numerous couples and women with the decision-making process regarding PND for DS and TOP if their baby is affected. Working in the field has made me realise how overwhelming it can be for the couples to hear that their baby could possibly have DS. It is even more traumatic having to decide whether you would want to terminate the pregnancy when the baby is diagnosed with DS. I have witnessed the devastating effects that inadequate decision-making can have on these couples as I have had women that want to stop the process of termination half-way through the process. I have also seen the psychosocial impact of these decisions on the lives of these women and couples and their families. Many live with long-term regret. I have always felt that we as genetic counsellors (or HCPs) can offer better support in order to limit the negative psychological impact of these decisions.

My values cause me to be against having children if you are not in a committed relationship or if you do not have the resources to properly take care of them. My beliefs also causes me to be against the act of abortion for social reasons. However, I can fully understand why women or couples would opt to terminate the pregnancy if the baby is diagnosed with a congenital abnormality or syndrome. I have never been faced with a similar situation as my participants, therefore I do not know how I would react and what decisions I would make. I believe that making a decision regarding PND for DS and TOP is an extremely personal one

and I do not believe there is a right or wrong decision. I, therefore, respected the decisions of my participants.

My skills as a Genetic counsellor enabled me to be aware of my own feelings and beliefs throughout the interviewing process as that is what I do during my counselling sessions. I did at times find it hard to switch between the role of a researcher and counsellor during the interviews. To help with this, I preferred recruiting participants who were counselled by a different genetic counsellor or medical geneticist. Therefore the majority of the participants received genetic counselling from a different HCP.

#### **4.13. ETHICAL CONSIDERATIONS**

A study proposal was submitted for ethical review and was approved by the Health Research Ethics Committee of the Faculty of Health Sciences of Stellenbosch University (Appendix E, p.255).

The researcher was aware that the participants of the current study were classified as a vulnerable population group. Vulnerable populations are defined as social groups with a higher risk of health problems (Flaskerud and Winslow, 1998). What made the participants of the current study vulnerable were their low socioeconomic status and being of an ethnic group known to be previously disadvantaged within the SA context. These factors limited their access to higher education, financial resources and healthcare services (Kalabunga *et al.*, 2016). Furthermore, being pregnant added to their vulnerability as women are known to be at a higher risk of health problems during a pregnancy. The pregnancy also added to their emotional trauma when hearing about the high risk of DS, as it is known that pregnant women become more emotional during a pregnancy. As many of the participants in the current study were of an AMA when they fell pregnant, they might have experienced some form of stigma, as it is frowned upon in some societies (Flaskerud and Winslow, 1998; Kalabunga *et al.*, 2016; Dugas *et al.*, 2017) and SA article). The researcher considered these vulnerable factors when conducting this research study, especially when obtaining the informed consent for participation.

The participants were asked to sign the informed consent form (Appendix A, p.207) before participating in the research study. The aims and objective of the study by the researcher in a language that they understood. They were also informed that participation is entirely voluntary and of their right to withdraw from the study at any stage without their withdrawal having an impact on the further management of their pregnancy or the care they received at TBH. After

the understanding of the provided information was checked and the participants were given the opportunity to ask questions, they had to either sign or provide a thumbprint on the informed consent form. By signing these consent forms the participants indicated they were voluntarily participating in the research study and granted the researcher permission to audio-record the interviews. The participants were allowed to request that the audio-recorder be stopped when they were disclosing information they did not want to be included in the research study.

The participants were informed of the potential psychological risks of participation. As the participants had to discuss sensitive topics it was a stressful experience for some of the participants and did evoke unwanted or suppressed emotions. As the researcher is a genetic counsellor who has been trained to be sensitive to the participants' emotional state, she was able to pick up on negative emotions caused by a traumatic event or grief. She followed-up with regular telephone calls if she felt concerned about the emotional state of the participant to ensure that their feelings were appropriately addressed. The option of further referral to social or psychiatric services were offered, but none of the participants opted for this. All of the participants were given the opportunity to discuss their emotional issues at a follow-up appointment with a genetic counsellor (including the researcher) which some opted for. They were also given the contact details of a social worker if the need arises at a later stage.

The participants were informed that participation will not lead to any direct benefit for them. However, the long-term benefit was using the information provided to improve the prenatal services offered to pregnant women and couples. It is important to note that some of the participants described a therapeutic benefit in participating in the interviews. The therapeutic value of qualitative research interviews have been previously described (Rossetto, 2014; Birch and Miller; 2000; Hutchinson, Wilson and Wilson, 1994). These interviews provide a space for sharing stories and subsequent release of emotions which can make people feel better. Speaking to another person also has the potential to raise self-awareness and help individuals to better understand their situations (Birch and Miller, 2000). The organisation of their thoughts may incite new perspectives on their experiences and promote resolutions of their negative emotions related to the trauma of the event (Rossetto, 2014). Participating in a research study may also lead to a sense of purpose (Hutchinson, Wilson and Wilson, 1994).

As the participants were from a vulnerable population group, they were given control over deciding upon a suitable date, time and venue to conduct the interviews. They were also compensated for any travel expenses that incurred during participation. The majority of the participants were given R50 in cash. However, those participants who had a further journey

and attended both an initial and follow-up interview, were given a R100 grocery shopping gift voucher.

The information the participants disclosed during the interviews were kept confidential and the anonymity of the participants was ensured. The names of the participants were replaced by an assigned participant number (P) and this was used during the write-up of the findings. Each couple was assigned the same participants number, and the letter “F” was used to indicate the responses from the female partner and “M” to indicate the response from the male partner. All personal identifiers were removed from the transcriptions to ensure anonymity. The recordings, transcriptions, researcher’s journal and the handwritten notes of the interviews are locked away in the office of the researcher. The electronic copies are stored on a password-protected computer. The researcher and her two supervisors are the only individuals that have access to these files. All of the research documents will be destroyed five years after the completion of the study.

#### **4.14. CHALLENGES**

The researcher experienced the following challenges which delayed the completion of the research study:

- The researcher initially struggled to fully grasp the philosophical assumptions of the research approach. She attended numerous qualitative research methodology courses and read up extensively on the philosophical underpinnings of phenomenology. This process took time, but was necessary in order to conduct good research.
- The news of the possibility for DS is distressing for the women which made it difficult to seek consent and for the women to make informed choices to participate in the research study. This limited the number of participants who could have been included in the study (Marteau and Dormandy, 2001).
- The sensitivity of the research topic led to the expression of a lot of emotion during the interviews. The interviews had to be stopped at times or be postponed until the participants felt composed enough to speak to the researcher.
- The selection criteria of the participants were strict which made it challenging to find enough participants who were willing to participate. The grouping of participants who had a positive PND for DS were particularly difficult to recruit. The researcher had to prolong the period of data collection to overcome this challenge.
- There is a paucity of research studies on the decision-making process of TOP for DS, especially within the SA context. This made it challenging to compare the findings of the current study with the findings reported in the literature.

#### **4.15. SUMMARY**

This chapter provided a detailed description of the interpretive phenomenological approach that was used to conduct the study. In-depth semi-structured interviews were conducted with 33 participants in order to gain an understanding of the decision-making process with regards to PND for DS and TOP of an affected pregnancy. The researcher made use of field notes during the interviewing process. The interviews were transcribed and the field notes were added onto these transcriptions. The researcher did self-reflection throughout the research process in order to limit the influence of her presuppositions on this process. A detailed outline of the data analysis was provided. The establishment of methodological rigour to ensure validity was describes as well as the ethical considerations. The next chapter presents the findings that were established using the methodological approach discussed in this chapter.

## CHAPTER 5: RESULTS

### 5.1. THEME 1: BEING AT HIGH RISK FOR DOWN SYNDROME

Most of the participants described the pregnancy as being unplanned and initially feeling surprised, shocked or disappointed when they were told that they were expecting. As the pregnancy progressed, these initial negative feelings quickly subsided and were replaced by feelings of joy and excitement. Even though the pregnancy was unplanned for most, all the participants accepted their pregnancy and were looking forward to welcoming the new addition to the family. However, after being told that there is a high risk that the baby could have DS their initial negative feelings about the pregnancy resurfaced. All of the participants described the news of being at high risk for DS as traumatic and difficult to hear, which had a major impact on their emotional state and how they experienced the remainder of their pregnancy.

#### 5.1.1. Impact of Being at High Risk for DS

When the participants shared their experience of being told they are at high risk of having a baby with DS, the following subthemes arose: grief response, anxiety about disability, feelings of self-blame and delayed disclosure of pregnancy.

##### 5.1.1.1. Grief response

For many participants, the mere possibility of DS caused a state of grief over the loss of their expected normal healthy child. They described intense feelings of sadness, shock and disbelief after being told about their risk of DS. The participants frequently mentioned incessantly crying upon hearing the news. As the majority of the participants attended the prenatal clinic by themselves, they had to convey the news to their partners upon their return home. Most of the participants described their partners having a similar reaction to the news. P25, a 38 year old woman who requested PND, recalls:

*“Hulle het vir my vertel dat die baba kan ‘n Down sindroom baba wees. Ek het gesit en huil. Ek het huis toe gegaan, ek was so ontsteld, en toe het ek met my man gesels. Ons albei het gehuil.”*

*“They told me that my baby could be a Down syndrome baby. I sat and I cried. When I went home I was so upset and when I spoke to my husband, we both cried” (translation).*

These feelings of grief rose during the interview and many of the participants became tearful or cried while describing their experiences of being told about their risk for DS. In some instances the interview had to be stopped to allow time for the participants to compose themselves. For a few participants, the emotional trauma caused by hearing they were at a

risk of DS was so severe that they refused to speak about it during a follow-up interview. This was especially true for some participants who had declined PND as they felt they did not want to be reminded of that time of uncertainty even though all of them gave birth to a healthy baby who did not have DS. A text message from P4, a 31 year old woman who declined PND, reads: *“My apologies. I don’t want to talk about it as I don’t need to take my memories back there.”*

#### **5.1.1.2. Anxiety about disability**

The participants frequently described feeling worried that their child will be disabled throughout the remainder of the pregnancy. This was especially true amongst the participants who did not have PND. Their minds kept wondering back to what was seen on the ultrasound scan and about the possibility of DS. During the final interviews of these participants they described that they were able to manage their anxiety during the remainder of their pregnancy. However, even though these feelings had slowly subsided, it re-emerged once they went into labour. They described feeling anxious until shortly after delivery after seeing and examining their baby. They expressed feeling completely relieved once they saw their baby and were told the baby did not have a disability. P2, a 31 year old woman who declined PND, explains:

*“Wat hulle vir my by die sonar gesê het was altyd daar in my agterkop, totdat ek by die kerk uitgekom het. Toe worry ek nie, maar toe hy nou gebore is, toe vra ek dadelik vir my man hoe lyk die kind. Lyk die kind gesond? Toe sê hy nee, alles is fine.”*

*“I went to church and eventually put those thoughts of what they told me at the sonar out of my mind. I stopped worrying about it, but when he was born I immediately asked my husband what he looked like. Does he look healthy? Then he said no everything is fine” (translation).*

The participants who opted for PND described feeling some relief from their anxiety after the test confirmed the baby did not have DS. However, many still expressed concerns that there might be something else wrong due to the ultrasound findings. As with the participants who declined PND, all of the participants who had a negative test result described a desire to see and examine their baby after birth in order to be sure nothing is wrong. P9F, a 46 year old woman who requested PND, explains: *“Even though the test results came back and said everything is fine. I still don’t feel the same, because in the back of my mind there will always be something telling me listen they said everything is fine ... the child won’t be Down syndrome but I still got a long way to go to give birth. So the time when I give birth my mind will always tell me hey but the child’s maybe (disabled) you know... they don’t pick up everything... So I will actually only be relieved when the baby is born and everything is fine for me.”*

### 5.1.1.3. *Feelings of self-blame and guilt*

Upon hearing of their high risk of DS, the participants seemed to try and find a logical explanation for their high risk status. Often they expressed feelings of self-blame and guilt as they felt as though their former negative thoughts about the pregnancy, AMA, actions or unhealthy habits (such as smoking tobacco cigarettes or alcohol use) caused the ultrasound findings and high risk of DS.

As previously mentioned in Section 5.1 (p.82), the majority of the participants initially expressed negative feelings towards the pregnancy as it was unplanned. A few of these participants felt that they were being punished because of this initial reaction towards the pregnancy, and that that was why their pregnancy screened high risk for DS. P18, a 36 year old woman who requested PND, explains: *“Sometimes I think it is a punishment of some sort, because I did not want this pregnancy in the first instance. And now look what happened (the baby had confirmed DS). It was an accident (unplanned pregnancy) and now it is one big accident.”*

Furthermore, the participants of AMA stated feeling that their age was to blame. When the participants were asked to elaborate on why they felt their age was the cause, it became clear that in their communities there is a strong general belief that all women who are “old” have babies with problems. This belief was enforced by the information they were given by the nurses working at their local community clinics. Some of the participants also mentioned being reproached by the nurses because they fell pregnant at an AMA.

Those participants who formerly or currently practiced unhealthy habits such as smoking tobacco cigarettes or drinking alcohol, expressed concerns that this may have led to their high risk status for DS. P3M, the male partner of a 42 year old woman who requested PND, recalls: *“Ja, die eerste ding wat mens dink is, ja, ek het nou miskien te veel gedrink toe ek jonger was of ek het ander goedjies gedoen wat ek weet ek nie moes doen nie.”*  
*“The first thing you think is maybe I drank too much (alcohol) when I was younger or I did too many things that I knew I shouldn't have been doing” (Translation).*

P21, a 20 year old woman who declined PND, who had been practicing similar bad habits, described feeling it was God's way of punishing her for her actions. She explains: *“Dit voel amper asof God jou straf, dis hoe ek gevoel het (toe hulle vir my vertel het van die risiko vir DS), omdat, ek vir die Here gevra het om vir my 'n babatjie te gee en ek het below ek sal alles in my vermoë doen om dit te laat gebeur. Ek sal die alkohol los, die sigarette los, ek sal kerk gaan en alles dit. En toe ek uitvind het ek is swanger, toe het ek die alkohol*

*gelos, maar toe het ek nogsteeds aangegaan met die rook en ek gaan nie meer so gereeld kerk toe nie. En soos ek nou voel, wil die Here vir my nou straf.”*

*“It almost feels like God is punishing you, that is how I felt (when they told me about the risk of DS), because I asked God to give me a baby and I promised to do everything in my power to make it happen. I will stop drinking alcohol, I will stop smoking, I will go to church and things like that. And when I found out I was pregnant, I stopped the alcohol, but I continued smoking and I stopped going to church regularly. And I feel now it is like God wants to punish me” (translation).*

The above-mentioned feelings were addressed by the genetic counsellors and medical geneticists during their initial and follow-up consultations. The participants expressed gratitude towards their counsellor or doctor for giving them the information needed to resolve their feelings of self-blame and guilt. P14, a 39 year old woman who requested PND, recalls: *“I thought it was my fault, I kept wondering to myself and asking God what I did wrong for this to happen to me? Where did I step out of line? What did I do? But I realise now that it was nothing we did, as the doctor said things like this happen and there is no one to blame. It doesn't work like that. I found a lot of reassurance in what the doctor told me.”*

#### **5.1.1.4. Delayed disclosure of pregnancy**

There was a clear delay in fully sharing the news of the pregnancy with others. The majority of the participants who opted for PND did not share the news of their pregnancy with anyone, not even their other children or extended family. They felt it was best to hide their pregnancy until they were certain that they were going to continue with the pregnancy. These participants explained not wanting to feel anything and get excited about a baby that they might not have. They also felt hiding their pregnancy would make it easier for them to cope after a TOP as they would not have to explain to everyone what happened. P5, a 40 year old woman who requested PND, explains: *“It is only me and my husband that knows that we are in this situation. I hide my pregnancy, because I don't want someone to see me that way and then there is a problem and the pregnancy is not there anymore. I always make sure I don't wear tight things and that my stomach must always be like I am flat. Because what if the results come and they tell us there is something wrong and it is gone. Why, what happened? What am I going to tell them?”*

Some hid their pregnancy from their other children as they wanted to protect them from the anxiety caused by the possibility of DS. They also felt it would not be fair to burden their children with the news that their sibling had DS and that they decided to have a TOP in the

case of a confirmed diagnosis. Some participants described feeling that they were protecting their other children against the harsh reality of losing a sibling. P20M, male partner of a 41 year old woman who requested PND, explains: *“Our son is not someone who easily forgets things. So if we tell him there is a baby and there is something wrong and we have a termination, then he is going to want to know why and I don’t want to burden him with that answer. I do not want to burden him with having to deal with questions about death at such a young age.”*

The participants whose PND result confirmed that their baby did not have DS, happily shared the news with their families and other people in their close social circles. A few of these participants who requested PND, treated this as a tentative pregnancy and only fully embraced and bonded with their pregnancy after receiving the news of the PND result. The participants who declined PND shared their news of the pregnancy with their families, but decided to withhold the information about the risk of DS as they did not want them to worry. Some participants described withholding the information from their friends and family as they did not want people to pity them. They felt they needed to strengthen themselves first and be sure about the diagnosis before dealing with other’s questions and sympathetic remarks. P22F, a 44 year old woman who declined PND, explains:

*“Ek probeer myself sterk kry. Ek wil nie daai hoor van: ‘haai shame, is jy oraait? Gaan die baby dit maak?’”*

*“I am trying to keep myself strong. I don’t want to hear: ‘shame, are you alright? Is the baby going to survive?’”(translation).*

### **5.1.2. Coping with High Risk for DS**

The participants reported using various coping mechanisms in order to deal with the trauma and anxiety caused by having a high risk pregnancy for DS. The mechanisms most frequently mentioned by the participants were remaining positive vs preparing for the worst, social isolation, remaining occupied with non-pregnancy related activities and support.

#### **5.1.2.1. Social isolation**

Shortly after hearing about the possibility of DS, many participants described socially isolating themselves in order to come to terms with the news. The participants described locking themselves in their rooms or refusing to leave their house during this period of isolation. They felt they needed this period of isolation in order to gain control over their emotions and to build up the courage needed to face the world. Additionally, P5, a 40 year old woman who requested PND, described doing so in order to not take out her anxiety on her family: *“And I come home (from work) just to go to bed and sleep. I don’t want to sit with them (family) and talk. And I*

*wish to go and be alone where no one can ask me nothing. I just want to be alone, because I pick fights with my husband and I am not nice to him.”*

The duration of this period of social isolation varied between participants and usually lasted between one week and two months. The participants who had PND seemed to isolate themselves until they received their test result. Those who received a negative result for DS were able to face the world again shortly after hearing this news. The participants who received a positive diagnosis of DS, described prolonging this period of isolation until coming to terms with the diagnosis. P16, a 21 year old woman who decided to continue the pregnancy after receiving a PND result of DS, recalls: *“I kept wondering if my baby is going to be normal or if she is going to have the Down syndrome. While I was waiting for the test results I locked myself in my room and I did not want to see anyone. When you told me about the Down syndrome it was difficult. After speaking to my boyfriend and my sister, who said they will help with the baby, I accepted it.”*

The period of isolation was the longest for those participants who requested a TOP after receiving confirmation of DS. This period lasted for up to two months after the TOP procedure. The participants described social isolation as their way of dealing with the grief over their loss of their pregnancy. P18, a 36 year old woman who opted for a TOP, describes:

*“Ek het myself heeltemal omsluit van mense af, want mense is mos geneig om iets te sê en baie vrae te vra en dit maak my so bietjie ongemaklik. So ek was maar heelyd in die huis gewees en het dit self probeer verwerk in my mind en my siel en so aan. Ek was baie een kant gewees en het myself heeltemal afgesonder vand mense en dinge vir maande na die tyd.”*

*“I isolated myself completely from other people, because people like making comments and asking a lot of questions and that made me feel uncomfortable. So I was at home the whole time and I was trying to process and accept it in my mind and soul and so on. I kept to myself and completely isolated myself from people and things for months afterwards (the TOP procedure)” (translation).*

### **5.1.2.2. Remaining positive vs preparing for the worst**

When looking at the mind-set the participants used to cope, two opposing categories arose: they either remained positive by convincing themselves that the baby will not have DS or they started preparing themselves for the worst and rather focused on the thought that the baby will have DS.

When asking the participants why they decided to remain positive while awaiting the outcome of PND or the pregnancy, they gave several responses. The majority of these participants believed that if you think positive, you will attract positive things in your life including a favourable outcome of the pregnancy and the baby will not have DS. Others remained positive as a form of stress relief as they did not want to subject their unborn baby to their negative feelings. They believed it was important for their baby's health to remain calm. Having a positive mind-set worked out well for those participants who did not receive a diagnosis of DS as their pregnancies were not subjected to unnecessary stress. However, for those who received a diagnosis of DS, this confirmation of DS seemed to hit them much harder than expected. P14, a 39 year old woman, who requested PND and received a diagnosis of DS, explains:

*“Mevrou het vir my man gesê van die toetsresultate oor die telefoon. Toe hy huis toe kom die Vrydagaand, toe het ons gesels en dit het my baie geruk, want ek het mos nou net die positiewe gedink, ek het mos nou nie negatiewe goed gedink nie.”*

*“You told my husband about the test result over the telephone. When he came home the Friday night he told me and the news shook me hard, because I was only thinking positive, I wasn't thinking about any of the negative things” (translation).*

The remainder of the participants felt that it was better to focus on the possible negative outcome of receiving a diagnosis of DS in order to prepare themselves for the worst. They felt if they believed the baby had DS, it would be less of a shock and they would be able to cope better upon hearing the diagnosis of DS. P9F, a 46 year old woman who requested PND, explains: *“I don't want to keep my hope high you know? I am going to think more that the baby is Down syndrome. I am actually preparing myself slowly so when I get the results I am fine. I am looking at the worst scenario, you see? ... I can get sick of this (news of Down syndrome) because I'm the one that is pregnant, I am having the baby... So that is why I am just looking for the, preparing myself for the worst.”*

### **5.1.2.3. Remaining occupied**

Another way of coping with the anxiety caused by the possibility of DS, was to remain occupied with activities not related to the pregnancy. The participants described using activities such as work-related tasks, daily-tasks the participants enjoyed doing or hobbies. Those participants who were employed, described how going to work and occupying them with their work tasks helped to keep them sane during the period of uncertainty. They felt that when they were at work they were so focused on reaching their deadlines that they did not have time to worry about whether their baby had DS or not. The participants who were unemployed had to be

more creative in finding things to keep them occupied. The activities they used to make them feel better included singing, dancing, taking long walks or focusing on their hobbies.

#### **5.1.2.4. Support**

A common theme that arose when the participants described dealing with being at high risk for DS, was support. They described making use of various sources of support including their religion, partners, family, friends, employers and HCPs.

The participants who were religious described speaking to their religious leaders and using prayer as a coping strategy for managing their anxiety. They expressed feeling at peace after speaking to God in prayer about their anxieties related to having a child with DS. When asked to elaborate about their prayers, the participants who declined PND, recalled asking their God to put their minds at ease and to accept whatever He decides to give them. For the participants who requested PND, the prayers were different as it mainly focused on asking God to change the ultrasound findings and for a favourable outcome of the test. This is illustrated by a response from P5, a 40 year old woman who requested PND: *“I want God to turn stone into bread. So this thing (nasal bone) they say they can’t see maybe they just can’t see it. They can be there like miracle or they can just make something, I don’t know, you see. So they say if you pray and believe, God can make things possible. And then we prayed, we sang, and prayed and I was crying. And then we go home and when I go home I felt like something is just lifted off my shoulders (big sigh) you see.”*

Even though the majority of the participants found relief in prayer, one participant, P17, described being so overwhelmed by the thought of DS that praying about it did not have the desired effect of calming her down. P17, a 42 year old woman who requested PND, describes: *“When I walked away from the hospital, I spoke to God in my thoughts, asking him to please not let it be like that. And if it is like that that He must give me the peace or so to accept it. I have been talking to God the whole time, even last night before I went to sleep I did another prayer. But after that I felt so sad. I prayed about it, but the thought of DS remains in my thoughts.”*

Many of the participants mentioned that receiving support from their partners, family, friends, employers and HCPs were essential in coping with their risk of DS. They felt it was extremely helpful to be able to speak to others and to gain their support in coping with the possibility of DS. The participants frequently described how speaking to others set their minds at ease about their decisions and finding confidence and strength in hearing what their support system had to say. The participants also highlighted the genetic counselling sessions as helping them

to cope with their anxiety over their high risk status for DS. The information they received during these sessions helped them to gain clarity over what a high risk of DS means and what their options were in order to deal with this status. This increased understanding led to a reduction in their anxiety levels.

## **5.2. THEME 2: DECISION-MAKING PROCESSES IN PRENATAL SETTING**

### **5.2.1. Experience of Making Decisions Regarding PND and TOP**

After the participants were told about their high risk of DS, they were faced with having to make a decision of whether they wanted to have PND in order to establish whether their baby definitely had DS or not. The majority of the participants described being presented with this option while still being in shock after hearing the unexpected news of the possibility of DS. A few of these participants were so distraught that they asked for time to go home and speak to their partners or families before returning to hospital to make the final decision. Once the participants dealt with their emotions and consulted with the important referents in their lives, they described the decision regarding PND as an easy decision to make. The participants did not seem to experience a high level of ambivalent feelings regarding making this decision and seemed clear on what the right decision was for their situation.

Those participants who requested PND and received a positive result for DS, were challenged with having to make an additional decision regarding TOP. This decision seemed to raise a high level of uncertainty amongst the participants regarding their decision of whether to continue their pregnancy or have a TOP. All of these participants described this decision as extremely difficult to make as they were still dealing with the grief and sadness over the confirmed diagnosis of DS while having to make this decision. As the majority of these participants were already of an advanced gestational age (past 22 weeks of pregnancy), they had the added pressure of making this decision within a short time period before the allowed TOP gestation of 24 weeks.

The majority of the participants described the genetic counselling session as useful in guiding them in their decision-making processes regarding PND and TOP. They described the information and support from the counsellor as helpful. They also appreciated having the opportunity to ask questions about their options in order to be properly informed before making their final decisions. It is however important to note that in some instances the participants did not find the initial genetic counselling session helpful as they were unable to comprehend the information they were presented with due to the shock and grief caused by the news of their high risk of DS. They only described these sessions as useful after gaining control over their

emotions. Overall both the decisions regarding PND and TOP, were complex and the participants reported many factors as playing a role in their decision-making processes.

### **5.2.2. Self-Reported Factors Influencing Decision Regarding PND**

Six subthemes emerged when the participants described the factors they took into consideration when making their decision regarding PND i.e. partner's opinion, PND procedure related risks, family structure, risk perception, perceived benefit of test and attitude towards TOP.

#### **5.2.2.1. Partner's opinion**

The participants frequently described consulting their partners prior to making their final decision regarding PND. As only a few of the participants' partners accompanied them to their hospital visits, they either chose to discuss their options with their partners over the telephone or to go home to discuss it in person. Those participants who declined PND often mentioned that they did so as their partners either agreed with their decision or stated that they would accept whatever they decided. They expressed that making the decision to decline PND was easier for them once they knew they had their partners support and that their partners would accept the baby regardless of the outcome.

When asked what their reasoning were to include their partners, some married participants expressed doing so as on their wedding day, they made a commitment to each other that they would support each other in every big life decision. They also added that the baby belonged to both themselves and their partners and therefore both needed to be involved in making the decision. P17, a 42 year old woman who requested PND, explains:

*“Op daai oomblik het dit nogal belangrik gevoel om eers huis toe te gaan en by hom (my man) te hoor, omdat ons mos nou as man en vrou saam een geword het. So by huislike besluite en goed sal ek sommer self besluit, want hy is mos nie by die huis nie, dan doen ek dit self. Maar ek het gevoel oordat dit ek en sy babatjie is en omdat dit rondom die babatjie se gesondheid gaan... Maar toe voel ek, ek moet eers luister wat sy antwoord sal wees en om vir hom te vra kan ek dit doen. Hoe sal hy daarvoor voel? Toe sê hy dis oraait, hy voel dit gaan nou om sekerheid te kry, dan voel hy dis reg.”*

*“In that moment it felt rather important to first go home and hear what my husband thought, because we became one as husband and wife. So with household decisions and things I will make the decision by myself, because he is not at home, so then I do it myself. But I felt because it is mine and his baby and because it is a decision regarding the baby's health...so I felt I must first listen to what he says, what his answer will be and to ask him if I may have*

*the test. How will he feel about that? So he said it is alright, he feels if I want to get certainty, then he feels it is right* (translation).

Additional reasons for including their partners in their decisions were the perception of their husbands being the head of the household and as a sign of respect. P22M, the male partner of a 44 year old woman who declined PND, commented on how he felt respected by his wife as she included him in the decision. He also went on to say that it would have had a serious negative impact on their relationship if she had made the decision without consulting him. P22M commented:

*“Sy het huis toe gekom toe sê sy vir my... toe sê ek not a damn, ons gee die kind ‘n kans, ons weet nie wat is die uitslag op die ou einde van die dag nie. Ek sal agter haar staan... because as sy daai besluit moes geneem het sonder my toestemming dan het ek haar uitgesit. That means, jy vat dan nie vir my kop toe nie en dit nie... Ons twee het besluit ek is die hoof van die huis, sy is nie my vloerlap nie. Ons is equal en ons neem saam besluite...”*

*“She came home and then she told me... Then I said not a damn (are we going to do the test), we give the child a chance, we don't know what the outcome will be at the end of the day. I will stand with her... Because if she had made that decision without me then I would have put her out. That means that you do not take me to heart and that... We both decided I will be the head of the house, she is not my doormat. We are equal and we make decisions together...”* (translation).

Due to the perception of the man being the head of the household some of the participants solely relied on their male partner to make the decision. If after discussion with their partner, their partners felt they would not be able to support a child with DS, they would opt for PND with the idea of having a TOP if the baby had DS. In some instances the participants mentioned feeling that having the test was more their partner's decision than their own. P27, a 24 year old woman, who requested PND, explains:

*“Ek wil nie eers die toets gedoen het nie. Die pa was die een wat eintlik gesê het ons doen maar die toets sodat ons kan weet is dit nou so en waarnatoe van daar af.”*

*“I did not even want to do the test. It was the father who actually said we must do the test so that we can know if it is like that and if it is like that where to go from there”* (translation).

Lastly, the participants were also motivated to include their partners in their decision due to their concern that their partners would blame them if they miscarried due to the PND testing procedure. They feared that their partners would hold them responsible for the loss as they made the decision to have PND without consulting them and therefore it would cause a divide in their relationship. P9F, a 46 year old woman who requested PND, explains: *“I would've*

*done the test on Friday ... but then I also thought uhm... as we were talking right I remember but I've got a husband also. So I have to speak to him about it also. Because now I do the test without him and if anything happens, men always blame the wife, doing my own thing you know whatever."*

#### **5.2.2.2. PND procedure related risks**

The procedure related risks of having a miscarriage or transferring HIV in the case of a mother who is HIV positive, were two factors frequently mentioned by the participants as playing a role in the uptake of PND.

##### **a) HIV transfer**

Both participants who were HIV positive, described that their status influenced their decision with regards to PND. Both declined PND as they did not want to risk transferring HIV to their child. They were both on highly active anti-retroviral therapy in order to prevent mother to child transfer during labour and therefore had a small risk of transferring the virus to their baby during PND procedure. They felt that any risk was too high as they would much rather have a child with DS than knowing they transferred HIV to their child. It seemed that it would be more acceptable for the participants if the baby had a condition that they did not cause, than for them to pass on HIV to their child. P4, a 28 year old woman who declined PND due to her HIV status, explains: *"Uhm, I think, as for me I had a choice going into that marriage and her having it (HIV) without her making that decision or getting it sexually, but just because of your mother. I don't think, even to her, she would think of me differently knowing she got it from me. I don't think I want it."*

##### **b) Miscarriage risk**

The PND procedure related miscarriage risk of 1% was a major factor in the decision-making process and was identified as the determining factor for declining PND amongst the participants. The participants explained that not only will it be traumatic for them to lose the baby, but they will also harbour feelings of guilt. They would blame themselves as they made the decision to have testing done so they would be the indirect cause of the miscarriage. In contrast, the participants who requested PND frequently expressed their need to know whether the baby has DS was stronger than their fear of having a miscarriage. In some instances the participants were not concerned about the risk of losing the pregnancy as it was unplanned to start off. One participant, P10, a 47 year old woman, felt extremely negative about having a baby with DS, so much so that she initially had suicidal tendencies. She therefore requested PND as she was hoping that either God would let her have a miscarriage

after the test or he would make a miracle happen and the baby would not have DS. P10 commented:

*“Dit is ‘n bietjie swaar, Ek het mos laas vir u gesê ek voel om myself onder ‘n kar in te gooi en so... God het daardie lewe daar geplant en wat in Sy plan is, as jy glo, dan sal Hy dit verwyder. Dis daarom dat ek vir u gesê het as dit nie in Sy plan gewees het nie, dan sal die Here, dan sal daar ‘n miracle of iets gebeur.”*

*“It is a bit heavy, so even at the start I spoke to you about throwing myself in front of a car and all that... God planted that life there and what is in His plan, if you believe, He will remove it. That is why I told you if it was not in His plan, then God would have made a miracle or something happen” (translation).*

Some of the participants commented that they were not aware of this miscarriage risk, even though they had signed a consent form stating that they knew the risks and were fine with taking that risk. These participants were possibly so distressed by the possibility of DS that they did not recall being told about the miscarriage risk during the genetic counselling session. P25, a 38 year old woman who requested PND, recalls:

*“Nee, ek was nie bekommerd nie. Hulle het nie eintlik vir my gesê ek gaan ‘n miskraam kry nie. Ek kan nie eintlik onthou dat hulle vir my gesê het ek kan ‘n miskraam kry as gevolg van die toetsie nie.”*

*“No, I wasn’t worried. They didn’t actually tell me I was going to get a miscarriage. I can actually not remember that they told me I could get a miscarriage because of the test” (translation).*

### **5.2.2.3. Family structure**

Many of the participants based their decision regarding PND on their current family structure, which largely tied in with the miscarriage risk as discussed in section 5.2.2.3 (b) (p.94). The factors related to their family structure that seemed to influence their decisions were the number of children they had with their current partner as well as the gender of their previous children. Those participants for whom this was their first pregnancy, those who lost their previous children due to an accident or who had multiple miscarriages were less likely to have PND as they did not want to risk losing another baby. Those participants who had had a previous miscarriage, described this loss as traumatic as they felt the excitement of being pregnant and started preparing for their new addition only to lose the pregnancy. P6, a 39 year old woman, who had one prior miscarriage, explains: *“It was traumatic in a way because you plan to have a baby and you know okay the baby is there, but you lose it in a way you don’t know how it like stresses you...”*

Some participants added that their previous loss of pregnancy caused them to be much more connected to their current pregnancy. They felt it gave them hope of a new child and something to cling to. Due to this stronger connection they felt they would continue with the pregnancy regardless of the outcome and therefore did not want to risk having a miscarriage due to the PND procedure. P11, a 32 year old woman who previously gave birth to a stillborn baby, describes:

*“...ek voel gelukkig, want my eerste kind het ek verloor, dit was ‘n stillborn. Maar met die tweede een is ek nogal gelukkig daaroor of dit nou Down sindroom is of whatever. Ek voel ek gaan maar die kind behou as om weer ‘n kind te verloor.”*

*“...I feel happy, because my first child I lost, it was a stillborn. But the second one I am quite happy about whether it is a Down syndrome or whatever. I feel I am going to keep the child, rather than lose another child” (translation).*

In contrast, those participants who had several other children were more likely to have PND as they were happy with the current size of their family. These participants felt that if anything happened to the current pregnancy or if they had a miscarriage after the test, they would at least have their other children.

The gender of the previous children played a role in one particular participant’s decision-making regarding PND. P2’s two previous children were both females. Therefore, she felt so happy about expecting a boy that she declined PND. She seemed to be able to completely forget about the risk of DS and only focus on the joy of having a baby boy added to her family. P2 describes:

*“Ek ervaar ek is baie opgewonde, omdat hulle vir my gesê het dis ‘n seuntjie en dis my eerste seuntjie... Ek wil maar voortgaan al is die baba hoe. Ek wil dit net, want ek is baie excited”.*

*“I feel excited, because they told me it is a boy and this is my first boy. ... I want to continue (the pregnancy), no matter what the baby is like. I just want to, because I am very excited” (translation).*

#### **5.2.2.4. Risk perception**

##### **a) Perception of soft-markers**

There seemed to be a lack of understanding of the concept of ultrasound soft-markers for DS amongst the participants. Only a few of the participants gave an accurate description of the soft-marker detected during the ultrasound scan of their baby and the implications thereof. The other’s perceived the soft-markers as either less or more serious than it actually was. The more soft-markers detected on the ultrasound scan the more difficult it seemed to be for the participants to understand. Their understanding of the soft-markers seemed to have a major

impact on their decision regarding PND as all those participants who classified soft-markers as severe congenital abnormalities, opted for the test. To illustrate the participants' lack of understanding, their interpretation of the most common soft-markers detected on the ultrasound scans will be discussed.

Amongst the participants a hypoplastic or absent nasal bone was the most prevalent soft-marker detected on the ultrasound scan. This is not surprising as a flat nasal bridge is one of the characteristic facial features of the SA black and coloured population groups. Those who had an accurate understanding of what this meant used this understanding to find reassurance that the baby will be fine. The fear of having a baby with DS was enhanced in those participants who struggled to understand the concept of an absent or hypoplastic nasal bone. The word "absent" caused the most confusion as it led quite a few participants to believe their baby will be born with a hole in their face. P5, a 40 year old women, in whom an absent nasal bone was detected on the ultrasound scan, describes her experience: *"They put me on the scan. Long time. They write, they look, they write... And my heart start beating faster, because I wonder what is it ... And then she said to me. Your baby is fine, but we are not 100% sure. I say why, what is the problem? And then she said, we don't see the nasal bone. What is a nasal bone? ... They put me (on the other scan and) say no sisi we don't see the nasal bone, it's absent... Yoh it was the worst day of my life."*

Another common soft-marker detected amongst the participants was an echogenic intracardiac focus. It seemed as though the participants found this concept even more difficult to grasp than an absent nasal bone. With an absent or hypoplastic nasal bone they could at least see this feature in themselves, their partners or other children, but with an echogenic intracardiac focus they had no frame of reference to make it easier to comprehend. Therefore this soft-marker was often misinterpreted as a serious cardiac condition, which raised a lot of anxiety amongst the participants. This misconception is illustrated by the following response from P27, a 24 year old participant who requested PND:

*"Ek gaan miskien geboorte gee aan hom en dan gaan hy nie eers lewe nie, dan is sy hartjie nie sterk genoeg nie... Ek gaan baie hospitaal toe moet gaan, hospitaal in en hospitaal uit oor daai verkalkte wit stukkie op die hart wat hulle gesien het."*

*"Maybe when I give birth to him, then he is not even going to be alive, because his heart isn't strong enough... I am going to have to go to the hospital a lot, hospital in and hospital out because of that calcified white bit they saw"* (translation).

**b) DS risk**

The participants' perception of their risk for DS seemed to have an influence on their decision regarding PND. Generally the participants seemed to be able to accurately interpret their risk of DS. Most of the participants who believed the risk for DS to be low or who felt the chances were still high enough to have a child without this condition were less likely to have PND. In contrast, some participants who understood that they were at a high risk of DS, declined PND as they would accept the child with DS and did not want to have a miscarriage post-PND testing.

Despite screening high risk for DS, some of the participants remained positive and believed that their baby would not have DS and therefore declined PND. This perception was attributed to their doubt in the accuracy of the PNS tests used to calculate their risk. In addition, some couples mentioned finding reassurance in hearing about other women in their communities who were similarly told they had a risk of DS and then gave birth to a healthy baby. P22M, the male partner of a 44 year old woman, who declined testing after PNS indicated a risk of 1 in 2 for DS, explains:

*“Want ek ken ‘n dametjie... ook dieselfde. Die kind het ook ‘n vel gehad en die neus ook. Die neus is nog altyd heeltemal plat. Maar daai was normaal gewees, hy werk en alles. Toe sê hulle vir haar dit is ook Down sindroom...”*

*“Because I know a lady... also the same. The child also had skin (thick nuchal fold) and the nose also. The nose is still completely flat. But that was normal, he works and everything. They also told her it is Down syndrome...”* (translation).

It was found that even though the participants generally understood their level of risk for DS, this was rarely the motivating factor for requesting or declining PND. The participants mostly based their decisions by reflecting on the other factors mentioned in this section (section 5.2.1). Lastly, it also has to be noted that the participants who were extremely distraught by the news of possible DS, were unable to comprehend their risk figure for DS. These participants did not rely on the risk figure itself when making their decision regarding PND as they felt any risk was a high risk and therefore opted for PND.

**5.2.2.5. Perceived benefit of testing**

All the participants who felt they would gain some sort of benefit from having PND, requested the test. The benefits frequently mentioned by the participants were wanting to know in order to reduce their level of anxiety or to aid their decision-making regarding TOP. Additionally, if they continued with the pregnancy, this information would allow them time to prepare themselves for the arrival of a baby with DS.

**a) To know**

The participants described feeling anxious by their uncertainty of whether their baby had DS or not. The participants expressed a desire to have PND in an effort to either reduce their anxiety by receiving a negative PND result for DS or in order for them to have the option of having a TOP if the baby is affected. Additionally, those who were not yet entirely sure whether they would have a TOP if the baby is affected, wanted this certainty to aid them in making the final decision regarding TOP. The participants described a feeling of desperation and determination to have a definite answer as they could not base their decision on uncertainty. P3F, a 42 year old woman who requested PND, explains:

*“Ons moet weet want dit gaan dit gaan ons die hele tyd worry en dit gaan strain op ons verhouding sit... Ons moet weet of ons moet aangaan met die swangerskap of of ons dit moet beëindig. So uhm, maar whatever die resultaat is, soos hy (my man) gesê het, dis ‘n besluit wat ons saam moet neem.”*

*“We have to know because it is going to worry us the whole time and put strain on our relationship... We have to know if we must continue with the pregnancy or whether we want to end it. So uhm, but whatever the result, like he (partner) said; it is a decision we have to take together” (translation).*

An interesting alternative theme, was the feeling of having the test done in order to have proof that the ultrasound findings were wrong. Some participants expressed feeling convinced that the baby did not have DS and therefore wanting to prove to others that their feeling was correct.

**b) To prepare for arrival of baby with DS**

The participants who had PND frequently mentioned having the test in order to prepare themselves for the arrival of a baby with special needs, if applicable. These participants expressed feeling that the uncertainty was worse than knowing your child will have DS. They felt that at least when you know, you are able to prepare yourself and therefore saw this as a major benefit of PND. The preparation time the test allowed, was appreciated by those participants who decided to continue with the pregnancy after receiving a PND of DS. They were able to gather enough information on how to raise a child with DS and put all the necessary plans in place before the baby’s arrival. These participants added that the test gave them the time needed to make peace with the diagnosis so that by the time they gave birth they were able to fully enjoy their baby. One such a participant, P27, a 24 year old woman, describes:

*“Ek is bly ek het die toetsie gedoen, want toe weet ek vroegtydig en toe kan ek vrede maak daarmee. En okay hy is nou Down sindroom en ons moet vir hom prepare vir die ergste...”*

*“I am glad I had the test done, because then I knew beforehand and I could make peace with it. And okay he is now Down syndrome and we have to prepare for the worst...”* (translation).

#### **5.2.2.6. Attitude towards TOP**

One of the most important factors the participants needed to consider when deciding about PND, was their attitude towards TOP. The participants described needing to first establish how they felt about having a TOP if a diagnosis of DS is confirmed, before being able to make a decision regarding PND. Those participants who were opposed to having a TOP, declined PND. These participants did so as they did not perceive any benefit in having the test as the results would not lead to any action as there are no treatment options available for DS during the pregnancy. P4, a 28 year old woman who declined PND, explains: *“If you say you have the test, there is nothing you can do afterwards. If you wait until the baby is born there is nothing you can do afterwards... So rather not (do the test), if it is not going to be useful in any way doing the test...”* They added it would be senseless to take the risk of miscarriage if it would not lead to any advantage for them or their unborn baby. In contrast, those participants who were certain they would opt for a TOP as they would not be able to raise a child with DS, all requested PND. The participants reported taking many factors into consideration when establishing whether they would opt for a TOP. These factors will be discussed in the following section (section 5.2.3).

#### **5.2.3. Self-Reported Factors Influencing Decision Regarding TOP**

Nine subthemes arose when the participants described the factors they considered when making their decision regarding TOP i.e. perceived severity of DS, health of baby, prevent suffering, partner’s opinion, family’s opinion, impact on other children, available support in raising child with DS, finances and lastly personal values and religious beliefs.

##### **5.2.3.1. Perceived severity of DS**

The perception of the severity of DS seemed to have a major impact on the decision-making process regarding TOP. As DS is such a common condition many participants had some prior knowledge thereof. The participants often described having had some interactions with parents of a child with DS, or an individual with DS or hearing stories in their communities about children with DS and their parents’ struggles. They were also extensively counselled by a genetic counsellor or medical geneticist and some were shown a video describing how DS will affect the baby. So it is likely that the participants had some understanding of the challenges the baby would have. These experiences contributed to the participants’ perspective on the severity of DS and what it would be like to raise a child with DS.

Those participants who had a positive perception of DS and did not feel they were different from other children, were more likely to be opposed to having a TOP if the baby had DS. A few of the participants who had personal encounters with parents raising a child with DS, felt that seeing how these parents were able to cope, made them confident that they would be able to do the same. P6, a 39 year old woman who declined PND as she was opposed to TOP, recalls: *“Well, since I do have a friend of a friend, like my friend’s mother, she has a sister who has uhm a child with Down syndrome. That child I know, I’ve known that child since 1992. So I’ve grown close to that child, like I’ve known, I know everything about her. Like it’s something acceptable. I can live with that.”*

The opposite seemed to be true for those participants who felt negatively about the life standard and abilities of children with DS. These participants felt that it would be too much of a struggle raising a child with DS. The participants understood that a child with DS would require a lot more attention from them and often felt that their current lifestyle and responsibilities would not allow sufficient time to cater for the needs of their child with DS. Therefore, they decided to have a TOP once the diagnosis of DS was confirmed. P1, a 41 year old woman, explains how this decision was made:

*“Ons kan sien hoe die ouers sukkel met die kinders... Die ouers moet baie energie het om daai kinders te guide en daar moet altyd iemand by die kind is om na die kind te kyk. Veral as die ma miskien wil gaan shopping doen, die pa werk, want dan moet die ma nou spesiaal iemand betaal om te kyk, of vir iemand vra om na die kind te kyk... Dan het ons gekyk na my man se suster wat ook Down sindroom gehad het... My man het saam met hulle in die huis gebly. En hy het altyd vir my gesê dit was nie lekker om sy suster so te gesien ly het nie. Sy suster het ook net gelewe vir 12 jaar.”*

*“We can see how the parents struggle with their children. ... The parents must have a lot of energy to guide those children and there must always be someone to look after them. Especially when the mother maybe wants to go do shopping and the dad is working, then the mother must pay someone to look after the child or ask someone to look after the child... Then we also looked at my husband’s sister who also had Down syndrome... My husband lived in the house with them. And he always said it was not nice to see his sister suffer. His sister also only lived until she was 12” (translation).*

Some participants, like P3M, the male partner of a 42 year old woman who requested PND, added that their personalities were not strong enough to deal with the struggles of a child with DS:

*“Op die einde van die dag, ek sal nie eers myself as ‘n candidate sien om so ‘n kind te kan grootmaak nie... Veral waar my ma gewerk het, hulle het met gestremde mense gewerk, en*

*die dinge wat ek gesien het. Ek het baie daar gekuier of het my ma my daar gekry of so en jy weet dit vat aan jou.”*

*“At the end of the day, I will not even nominate myself as a candidate to raise a child like that. Especially where my mother worked, they worked with a lot of disabled people, and the things I saw there. I often went to go visit my mother there or I went to go pick her up or so and you know these things affect you” (translation).*

An interesting comment from a participant, P19, who was expecting a child with DS and a serious cardiac defect, was that she would have accepted the child if it was not for the diagnosis of DS. She felt she would be able to deal with a baby with a serious cardiac defect as this could possibly be surgically corrected. She felt she would be able to cope with the hospital visits and the stress of the baby having to go for surgery as the baby would be able to function normally after recovery. She perceived DS as much more severe as this causes a lifelong disability which she would not have been able to cope with on top of the cardiac defect. Therefore, she opted for a TOP.

### **5.2.3.2. Health of baby**

Most of the participants commented that their decision regarding TOP was influenced by the possible condition of their baby's health after birth. Those participants, who had babies with multiple complications due to DS, were more likely to have a TOP. When the participants were asked to elaborate on their reasoning, they frequently mentioned not being able to attend the regular hospital visits their baby would require. They were either constrained by finances or living too far away from the hospital. These participants also added that they would be unable to deal with seeing their child in hospital and that the time spent in hospital would be unfair towards their other children and partner as they would feel neglected. P18, a 36 year old woman who decided to have a TOP as she perceived her baby to have serious complications related to DS (see table 4.2, p.60), explains:

*“Want soos hulle ook mos nou verduidelik het, hy gaan baie infeksies het. Die blaas is mos nou vergroot en die niere wat vernou is en die uriene nie deurvloei nie dan spoel dit terug in die liggaam in... Ek meen toe het ons besluit ons gaan dit beëindig, want ons wil nie dit aan hom doen nie, want dit is te veel... En om hospitaal in en hospitaal uit te wees. Dit meen ons moet nou hospitaal toe ry uit [plattelandse dorpie] uit, wat 'n probleem is. Dit is ook basically onregverdig vir my man en my twee ander kinders.”*

*"Because like they also explained he is going to get a lot of infections. The bladder is enlarged and the kidneys are narrowed and (urine) doesn't flow through them it washes back into the body... I mean so we decided we are rather going to end the pregnancy because we don't want to do that to him, because it is too much... And to be hospital in and hospital out. That*

*means we have to drive to the hospital from (rural hometown) which is a problem. It is also not fair towards my husband and other two children” (translation).*

In addition to struggling to attend regular hospital visits the participants feared that the baby would pass away shortly after birth due to the complications. The participants described feeling it would be easier for them to have a TOP than losing the baby after birth. They felt that it would be too difficult to deal with the loss after having built a stronger bond with their child by the time spent getting to know their child. P14, a 39 year old woman, who opted for a TOP as she was expecting a baby with DS and a serious cardiac defect (see table 4.2, p.60), explains: *“Ons was ook bang. Al is dit nou ‘n sindroom baba met die kwale van die hart en ons sê vir die dokter ons gaan aan met die swangerskap, ons gaan niks doen of so nie. Nou word die kind gebore daar. Die kind kan dood wees met geboorte of hy kan lewe... Dit is beter as ons dit nou verwyder as wat ek nou die kind moet baar en voortbring en dan is hy net ‘n tydjie by ons en dan, dit sal... dit sal erg wees.”*

*“We were also afraid. Even if it is a syndrome baby with complications of the heart and we told the doctor we are going to continue with the pregnancy, we are not going to do anything or such. Now the child is born. The child can be dead at birth or he can be alive... It is better that we remove now, rather than carrying the child and giving birth to the child and then he is only with us for a short period of time, that will... that will be difficult” (translation).*

Some of the participants even commented that they would have continued the pregnancy if the baby had DS with less serious complications related to the condition. P24, a 36 year old woman who opted for a TOP as she was expecting a baby with DS and a serious cardiac condition and pyelectasis (see table 4.2, p.60), commented:

*“As sy nie nog siektes by gehad het nie, dan sou ek vir haar gehou het. Dan sou ek definitief vir haar gehou het. ‘n Down sindroom kind, maak nie saak nie. Hulle is uniek en mooi op hulle manier. En jy gaan so lief wees vir hulle.”*

*“If she did not have additional illnesses then I would have kept her. I definitely would have kept her, a Down syndrome child, it does not matter. They are unique and beautiful in their own way. And you will love them so much” (translation).*

### **5.2.3.3. Prevent suffering**

The participants who opted for TOP, expressed wanting to protect their child from suffering as a strong determining factor in their decision to opt for TOP. They described their love for their child as too strong to be able to witness their child suffering. They expressed feeling they were saving their child from a lifetime of suffering due to the health complications that go hand in hand with DS. In addition to this they were also saving their children from the heartache and

pain caused by being continually teased by other children or members in the community. P1, a 41 year old woman who requested a TOP, explains:

*“Ons wil nie hê die kind moet verwyte hê in die buite wêreld nie, want baie keer dan noem die kinders name vir kinders, nou nie net kinders nie, maar grootmense ook. Hulle sê sommer die kind is mal of die kind is gestrem en al daai goed gaan gepaard met die besluit wat ons geneem het om die baba te laat aborteer.”*

*“We didn’t want the child to be treated badly by the outside world, because many times the children will call other children names, not just the children, but the adults also. They will say the child is crazy or the child is disabled and all those things went together with our decision to have the baby aborted” (translation).*

These participants who opted for a TOP, often explained how they felt it was the parent’s duty to protect their children against pain and suffering. They felt that it was not fair to bring a suffering child into the world just because of your own need to have a baby. Additionally, they described not only wanting to prevent pain and suffering for their baby, but also for themselves as the parents. As they felt so much love towards their children, they expressed that it would break their hearts every time they had to see their baby suffer while going through a difficult time. P24, a 36 year old participant who requested a TOP, commented:

*“Ek kan nie, ek sou nie met haar siekte kon deal nie, om te sien hoe sy ly en ly en ly.”*

*“I cannot, I will not be able to deal with her illnesses, to see how she suffers and suffers and suffers” (translation).*

#### **5.2.3.4. Partner’s opinion**

There was a subtheme of consulting with their partners before making the decision regarding TOP. The participants expressed feeling more comfortable with their decision to either have a TOP or continue the pregnancy, if they knew they had their partner’s support. The male partners usually seemed to respond by stating that it was more the female partner’s decision and that they would wholeheartedly support her decision. They felt the female partner would be more heavily impacted by the decision as she is the one carrying the baby. If they chose to have a TOP, she would be the one who would have to go through the procedure. Also if they chose to continue the pregnancy, she would be the main caregiver of the child with DS. Therefore, it seemed as though the female partner’s opinion weighed heavier on the final decision than the male partner’s opinion.

Some of the participants mentioned that there was a degree of convincing to be done, when their decision was not in agreement with their partners. However, they were mostly able to

reach an agreement and the women were usually able to convince their partners that what they wanted is the better option. P18, a 36 year old women, who opted for a TOP, describes: *“Uhm aan die begin wil hy (man) gehad het ek moet die kind hou. Ek moes my werk gelos het en aandag aan die kind gegee het, maar toe het ek vir hom mooi verduidelik, sommige tye is hy baie vas. Dit is nie hy wat met die kind gaan sit nie. Dit is ek wat met die kind gaan sit en dit is nie dat ek nie wil nie, maar dit is net die hartseer van pyn wat daai kind moet deurmaak.”* *“Uhm at first he (partner) wanted me to keep the child. I had to leave my job to give all my attention to the child, but then I kindly explained to him that there are times where he cannot leave work and help. It is not him that has to sit with the child. I am going to sit with the child and it is not that I don't want to, but it is just seeing the heartache and pain that child has to go through”* (translation).

Unfortunately not all the couples were able to reach an agreement about which option is the best choice. In these instances, the women had the final say and they did what they felt was the right thing to do. Those participants who went against their partner's wishes to have a TOP and rather kept the baby with DS, felt that they made the right decision as they would not have been able to live with the guilt of ending a pregnancy. In contrast, there was also one participant, P23, a 43 year old woman, who described going through with the TOP despite her partner's initial wishes of continuing with the pregnancy. She felt it was better to have the TOP as he had not been very supportive throughout the pregnancy and never wanted to accompany her to the hospital. She feared that he would continue to be unsupportive once the baby was born.

#### **5.2.3.5. Family's opinion**

Some of the participants described how it was important for them to first discuss their options with their families, specifically their parents, before making their final decision. They felt more at peace with their decisions when they knew their families supported and accepted their decision. The participants who decided to have a TOP, seemed more at ease with their decision once they established that their families would not judge them because of their decision. P23, a 43 year old participant, who requested a TOP, described finding immense comfort in knowing that her cousin, who is a midwife, agreed with her decision: *“I went to see her (cousin), last night ... and she also told me no it is the right thing to do, because look I also wanted to speak to her because she is a midwife. She is a nurse there, and she said go for this, because you know what we see here (hospital) when we deliver these babies, you don't want to see what we deliver. It is the right thing for the baby and for you.”*

Some participants relied more heavily on the opinion of their families than the opinion of their partners when making the decision of whether to have a TOP or keep the baby. P27's decision-making process was particularly interesting as she described partially basing her decision to continue with the pregnancy after receiving a PND of DS, on something that her deceased father had told her. This was her response after asking why she felt her deceased father played a role in her decision: *"He was the one who always said, to me and my older sister, if you come home one day and you come tell me that you are pregnant then I will never expect you to go for an abortion. Because he was actually the one who made us believe that abortion is not the right thing to do. So he also, when they told me, when they gave me the option of abortion, he immediately came to mind, and I said no, no, no."*

#### **5.2.3.6. Impact on other children**

The participants who had children, took into consideration the impact it would have on their other children when making the decision of whether to keep their baby with DS or to have a TOP. They felt that they needed to consider the impact it would have on the future of their other children. Many who had a TOP, did so because they felt that having a child with DS, would mean that they would not be able to fund their other children's education. Others were concerned about the psychological impact it might have on their children. They expressed worrying that their other children might become rebellious as they would feel neglected by their parents. P18, a 36 year old woman, who has two other children, explains: *"It is basically unfair towards my two children. It is not that they are really small, they are independent, but it will also be an adjustment for them to understand what is going on, because the poor baby is going to get more attention than they are... they have been alone for a long time and they won't be able to understand why this little one is getting more attention."*

Those participants who decided to keep their child with DS, did so either because it was their first child or it was their first child that they would be raising. There were a few of the participants who had other children who were being cared for by their parents. P25, a 38 year old woman with four other children who are all being cared for by their grandmother, explains: *"In die begin sal dit baie moeilik wees, my aandag sal hy baie nodig hê, dit het hulle vir my gesê. En omdat my ander kinders, my ander kinders bly nie by my nie, hulle is ouma se kinders. En (baba se naam) is myne en ek gaan hom grootmaak en vir hom al die aandag gee wat hy nodig het."*

*"It will be difficult in the beginning, he will need all of my attention that is what they told me. And because my other children, they are not with me, they are grandmother's children. And (baby with DS) is mine, and I am going to raise him myself and he will get all the attention he needs"* (translation).

### 5.2.3.7. Available support in raising child with DS

The available sources of support in raising a child with DS was an important determining factor in whether the participants would consider a TOP or not. For this reason many participants either spoke to their families or considered their family situation when establishing whether they would have the needed support to raise a child with special needs. Those participants who felt they had a large support system frequently mentioned that they would not consider having a TOP under any circumstances. Those participants who received a PND of DS and continued their pregnancy, often made this decision as they felt they had an all-encompassing support network including their parents, siblings, extended family members, support groups and HCPs. P27, a 24 year old woman, who lives with her mother and siblings decided to keep her baby with DS as she felt supported. This was her response when asked about her support system:

*“Op die oomblik is my familie ondersteunend. My ma en my susters en broers. Die hele gesin ja. En my anties, hulle is te lief vir hom. Hulle ondersteun my baie, ek het geen probleme. As ek hospitaal toe kom dan sal hulle miskien ‘n plan maak dat ons hier kom. En hulle vat hom baie van my hande af, dan sê hulle rus jy nou eers ‘n bietjie, dan vat ons nou weer vir hom.”*

*“At the moment my family is supportive. My mother and my sisters and my brothers. The whole family yes. And my aunts, they love him so much. They support me a lot, I have no problems. When I have to come to the hospital, they will make a plan to get us to the hospital. And they take him off my hands and tell me to rest for a while and then I will take him again” (translation).*

In contrast, those participants who felt they would not have enough support in raising a child with special needs were much more likely to opt for a TOP. There seemed to be a diminished support system amongst the participants as the majority of them were of AMA, which meant their parents were either deceased or of an old age and required additional care. The female partners often had to care for their elderly parents or in-laws. This meant that they were unable to hold a job and the male partner was the only breadwinner in the household. As the male partners were working long hours, they were unable to support their partners with the daily tasks associated with raising a child with DS. Some participants who opted for a TOP even commented that they would have reconsidered their decision had they had enough support in raising a child with DS. P23, a 43 year old woman, whose partner seemed unsupportive and whose family lived in a different province, commented: *“Of course (I would have kept the baby), if I had like, you know, if I had money to take my child to the best place where I know she is going to get 24hr care and where I know that she is gonna be, you know, have someone looking after her you know. I know she is going to need that attention and I am not that person, I can't get someone, because that person needs to get paid and there is no one, I don't have that thing (support from family).”*

As children with DS require lifelong care, the participants of AMA had added concerns about what will happen to their child once they have passed on. P20M, the male partner of a 41 year old woman who requested PND, describes his concerns: *“When he goes into the adulthood phase, what will happen then? Because we are getting older until we cannot anymore. Who will look after him then? Look our families are actually not, my family is not, yes my mother and father is still here, but they are already in their years so they will not be able to look after him. Her (wife) mother is already in her years. Her father doesn’t live anymore.”* These participants added that TOP would be the only option as they would not be able to bear the thought of their child being institutionalized or being a burden on their other children once they are unable to care for their child with DS.

#### **5.2.3.8. Finances**

As the majority of the participants were from a low-income or single-income household, finances seemed to play a role for some of the participants who decided to have a TOP. The participants expressed that their current income was barely enough to sustain themselves and their existing children. This meant that they would definitely not be able to afford the additional expenses related to raising a child with special needs. P24, a 36 year old participant, who opted for a TOP after receiving a PND for DS explains: “

*“En dan moet die kind permanent help het, en ek moet die heelyd daar wees. En my salaris, my kêrel se salaris is nie so goed nie... Ek weet vir ‘n feit ons het nie ‘n mediese fonds nie... so dit gaan geld op geld wees wat ons daarop moet spandeer.”*

*And then the child will need permanent help and I have to be there the whole time. And my salary, and my partner’s salary is not that decent.... I know for a fact that we do not have medical aid... so it is going to be money on top of money that we have to spend on that”* (translation).

All of the participants who were concerned about their current financial status opted for a TOP. It is important to note that financial status by itself was not a major determining factor in the decision to have a TOP, but a contributing factor. Often finances were associated with the number of other children the couples had or the additional support in raising a child with DS. If the participants did not have the finances and had many other children, or had no additional support in raising their child with DS, they would opt for a TOP.

#### **5.2.3.9. Personal values and religious beliefs**

When making the decision of whether to have a TOP or not, it was important for the participants to reconcile their personal values or religious beliefs with their final decision. The

majority of the participants had strong personal values and religious beliefs against the act of abortion. Those participants, who were able to morally distinguish between having a TOP for social reasons and having one for medical reasons, were able to go ahead with having a TOP despite their beliefs.

They frequently mentioned a social TOP being unacceptable as it was a selfish decision as the mother did not want the baby. They described a medical TOP as being acceptable as the mother acted in the best interests of her baby as this decision spared the baby from a life of suffering. This belief is clearly illustrated by the following response from P24, who initially decided against a social TOP, but later on requested a medical TOP after receiving a PND of DS:

*“P24: When the doctor phoned to tell me that I am pregnant, I asked him what my options were because I really did not plan a child. Then he mentioned adoption... And abortion, he explained abortion is legal at the current gestation of my pregnancy... And at first it (abortion) sounded like a possible way out and then I went to sit and think in silence. Then I told myself there are people who cannot have children. There are people who have sick children. I got pregnant without trying, through the injection (contraception), it is a blessing. So what, it feels like this now, but when you start feeling that baby move inside your stomach, then you can forget about it, it is your child... And so I decided no, abortion is out.*

*I: And how is this different now?*

*P24: For me it is completely different now. The baby has problems... abortion is out, but the baby is sick. For me it does not feel like a selfish decision because I am saving the child a lot of suffering”.*

In contrast, those participants who did not make a clear distinction between having a TOP for social reasons and having one for medical reasons, decided to continue with their pregnancy. These participants used the term “*abortion*” when speaking about TOP. They emphasised that according to their personal values and religious beliefs the act of abortion was wrong and unacceptable regardless of the circumstances. They believed that “*God knows best*” and that God will help strengthen them in order to raise their child if the child has DS. A few of the participants described initial feelings of hurt as God was possibly going to give them a child with DS. However, after further deliberation and speaking to other family members with the same beliefs they found peace and comfort in knowing that God is in control. They described their child being “*a gift from God*” and that they would accept whatever He decided to give them. P7, a 42 year old woman who declined PND, recalls: “*It was yoh! At first it was, I was so hurt. But I told myself no, no it’s from God. If God want to be, If God want my baby to be like that so I have to accept it. So I have to say no I don’t want to do the test so. If he’s, if my*

*baby's got Down syndrome so he's got Down syndrome. The Gods wanted him to be like that. So I have to accept my baby.*" A few of the participants also felt that this was a test from God and that God would not test them beyond their capability. These participants also felt that if God did not want them to have a baby with DS, they would have had a miscarriage or God would have given them a child who did not have DS.

Additionally, the participants with strong religious beliefs, described praying about their decision and consulting with a religious leader before acting on it. The participants, who continued with their pregnancies, described finding peace after praying about their decision as they felt that God would give them the strength to raise the child. They felt prayer helped them to accept their baby with DS. Those who had a TOP, described asking God for forgiveness and finding peace in their decision after prayer. They felt God enabled them to make this choice in order to protect their unborn baby from a life of pain and suffering. P1, a 41 year old woman with strong Christian beliefs, recalls:

*"Ons het gebid daaroor en ons het vir die Here gevra en ons het vir die Here vergifnis ook gevra vir dit wat ons nou gaan doen. Ons is vir die Here dankbaar ook vir die baby, maar ons het net gevoel ons moet die keuse maak om vir baby lyding en pyn te bespaar."*

*"We prayed about it and asked God what to do and we also asked God for forgiveness for what we were about to do. We are grateful to God for the baby, but we just felt we had to make the decision to spare the child from suffering and pain"* (translation).

### **5.3. THEME 3: IMPACT OF DECISIONS REGARDING PND**

#### **5.3.1. Impact of Decision to Decline PND**

A total of twelve participants declined PND. The majority of these participants had an uneventful remainder of the pregnancy and gave birth to a healthy baby without any complications. There were only a few participants who experienced complications either related to the pregnancy or their own health, which made their concerns about DS resurface. In total four of the participants gave birth to a baby with DS. Two of these babies were healthy at birth and given a good prognosis as they did not present with any serious comorbidities related to the condition. The remaining two babies had serious cardiac conditions requiring surgical correction. The one recovered well after surgery, but the other was sadly only given a few months to live as the cardiac condition was too severe to be surgically corrected.

##### **5.3.1.1. Receiving a postnatal diagnosis of DS**

The majority of the participants who received a postnatal diagnosis of DS, described finding it easy to accept the news as they had already made peace with having a baby with DS when

they were told about the risk during their pregnancy. The participants were told about the diagnosis of DS a few days after the baby was born. Some mentioned having to ask for this result as they felt their doctors did not prioritise giving them the information of the genetic test result for DS. One particular participant, P32, a 38 year old woman, was only told that the baby had DS long after birth. As she had numerous hospital visits and the doctors did not inform her of any complications beforehand, she struggled to believe the test result was true. P32, recalls: *“At the day hospital they saw signs of DS on the baby and asked me if I noticed anything in the baby. I said no. And they asked me if the doctors said anything. I said no they just took blood and they did not say what for and they said I must go to Karl Bremer. So they phoned Karl Bremer and Karl Bremer told them that it was for DS. So I didn’t believe the nurses when they said the baby is DS. I said no it is not DS, because the doctor didn’t say anything to me.”*

Even though the participants accepted the diagnosis they described an initial feeling of fear in raising a child with DS. They were unsure whether they would be able to cope with a child with a disability. The participants informed their family members of the possibility while they were still pregnant which they reported helped them to deal better with receiving the postnatal diagnosis of DS. They found peace in knowing their partners and families would accept and help raise their baby with DS. P22F, a 44 year old woman who declined PND and gave birth to a child with DS explains:

*“As jy dit hoor, dan voel dit, joh gaan ek dit maak om die kind groot te maak? Nou sê die dokters die kind gaan siek wees, die kind gaan die wees en die kind gaan daai wees. Wat ek sê, dit is nie ‘n maklike besluit nie, maar as jou man saam met jou staan, dan voel dit eintlik vir jou makliker. Dan weet jy jou hoop is daar.”*

*“When you hear it, you feel joh, am I going to cope raising this child? The doctors say the child is going to be sickly, the child is going to be like this and the child is going to be like that. I can say that it is not an easy decision, but if your husband stands with you, everything feels easier for you. Then you know your hope is there” (translation).*

### **5.3.1.2. Impact of raising child with DS**

This section will focus on the impact raising a child with DS had on those participants who declined PND and subsequently received a postnatal diagnosis of DS. When the participants were asked to elaborate on how having a child with DS had impacted their lives, three areas seemed to be impacted, namely their emotions, interpersonal relationships and day-to-day life.

**a) Emotional impact**

The emotional impact of having a baby with DS was directly related to the health of the baby. As there are a few comorbidities that are associated with DS, the participants had to attend regular hospital visits to make sure that their baby did not have any of these comorbidities. The participants described this initial period as rather stressful as they were worried that they would pick up a serious condition in their baby. Those participants whose babies did not have serious comorbidities felt relieved and content with their baby. In contrast, those participants with babies with a lot of comorbidities, described a rollercoaster of emotions.

In two instances a serious cardiac abnormality was picked up which required correction with open heart surgery. These babies required additional care and therefore had to stay in the hospital after birth. The participants had to either stay in the hospital with their babies or take daily trips to the hospital. The participants described this period as mentally and physically exhausting. The participants described the actual event of their babies undergoing surgery as extremely stressful as there was a possibility that their baby would not survive. The participants described praying when things got too difficult and they struggled to cope. They seemed to find peace and comfort in doing this. Another way these participants dealt with their emotions was going home and spending some time with their other children. They felt that being out of the hospital environment and cuddling their children helped renew their strength.

**b) Impact on interpersonal relationships**

Amongst the participants who declined PND and gave birth to a child with DS, having a child with DS did not seem to have a major impact on their interpersonal relationships. Rather, their relationships with their partners and families seemed to be strengthened. These participants frequently mentioned making the decision to decline PND together with their partners, as they both agreed that they would accept the baby regardless of the outcome. They were afraid that their partners would change their minds about their initial decision to accept the baby, now that the diagnosis was confirmed. They also feared that their partners would end their relationship as they could not accept the baby. Luckily, this fear did not become a reality as all of the partners remained satisfied with their decision and continued to be supportive despite the baby having DS.

Overall, the participants' nuclear and extended families also accepted their child with DS and were often described as being supportive and loving towards the new addition to the family. P32, a 38 year old woman who has a large extended family, explains: *“And the other children (in the family), they are also happy. Even if he is sleeping they even make him wake up and I*

*am always stopping them. They want to kiss him... I say no he is sleeping. They (are) always waking him up."*

### **c) Impact on day-to-day life**

The participants described having a child with DS had impacted on their daily work life, but none noted any change in their social lives. Those participants who were employed, either gave up their job or reduced their working hours in order to take care of their child with DS. The participants described feeling content with their decision, as they seemed to gain greater satisfaction from raising their child with DS, than working.

Those participants who were working part-time described only trusting other family members with their child. They did not want to put their child in a crèche or day care centre as they feared their child would pick up an illness from the other children. The participants whose babies had to go for surgery, seemed to be more protective over their children as they did not want to go through seeing their child in the hospital and fearing for his or her life again.

None of the participants who declined PND and gave birth to a child with DS, noted any change in their social lives as they mostly only socialised with their families who accepted their child with DS. None of them expressed experiencing negative comments from members in the community and still felt included in all the usual social events. However, it is important to note that some of the participants mentioned that the community members did not notice that their baby had DS and therefore this could have contributed to their experience.

## **5.3.2. Impact of Decision to Request PND**

Twenty-one participants requested and underwent the PND procedure. Of these participants eight received a negative PND result for DS and were able to continue with the remainder of their pregnancies without any complications. The remaining thirteen participants received a prenatal diagnosis of DS.

### **5.3.2.1. Experience of PND procedure**

Overall the participants who had PND were content with how the procedure was performed by the fetal medicine specialists, which enhanced their satisfaction with their decision to have the test. They appreciated how the specialists were respectful of their feelings and made an effort to make them feel at ease during the procedure. Most of the participants also expressed being surprised by how quick and painless this procedure was. P29F, a 30 year old woman who requested PND, explains:

*“Om die toets te doen was nog ‘n ding bo-op die Down sindroom. Jy is klaar heeldag opgetense en nou moet jy nog deur daai toets gaan. Die dokter wat met ons gewerk het, sy was regtig, ek waardeer vir haar regtig. Ek waardeer dit wat sy gedoen het. Die manier wat sy met my gewerk het, sy het alles so comfortable laat voel, die toetse so maklik laat verby gaan.”*  
*“To have the test done was another thing on top of the Down syndrome. You are already tense and now you have to do the test. The doctor that did the test was really nice and I really appreciated the way she worked with us. I really appreciate what she did. Just the way she worked with me, she made me feel comfortable and made the test go by so easy and quickly”* (translation).

There were some concerns regarding the needle used to perform PND. The participants commented on fearing the pain of the needle. This fear increased when they saw the length of the needle either while watching the video explaining the procedure or while undergoing the procedure. P27, a 24 year old woman who requested PND, recalls:

*“Ek is nie eers bang vir naalde nie, maar die feit dat hierdie lang naald gaan nou in my maag moet afgaan het my bang gemaak. Ek was so bang dat ek alles wat die dokter vir my gesê het uigeblok het.”*

*“I am not even afraid of needles, but just seeing that long needle that needed to go down my stomach made me scared. I was so scared that I completely blocked out what the doctor was telling me”* (translation).

A few of the participants described being highly anxious before the procedure and seemed to have experienced the testing procedure as a lot more painful than the other participants. In addition to the pain of the procedure itself, some participants described experiencing a numbing pain for a few weeks after the procedure. They described feeling sensitive around the area where the needle was inserted. P18, a 36 year old woman who requested PND, explains:

*“Die toets self was nie seer nie, maar na die tyd aan die binnekant was dit seer. Nie die naald nie, dit was nie so seer nie. Maar die are self, dit het so 3 dae gevat om gesond te word en vir die pyn om weg te gaan.”*

*“The test itself was not painful, but afterwards it was painful on the inside. Not the needle, that was not so painful. But the area itself, it took about three days to heal and for the pain to go away”* (translation).

### **5.3.2.2. Impact of waiting period for and receiving PND results**

Usually it takes about 2 weeks for the patients to receive their PND results after having the procedure. The participants who requested testing often described the waiting period for the

results as a stressful period in their lives. Some of the participants also expressed having major concerns about having a miscarriage post procedure. These participants described making sure they followed the advice to take things easy for at least 24 hours after the procedure. The one participant described taking things easy for a longer period than recommended just to be sure that a miscarriage does not occur. P17, a 42 year old woman who requested PND, recalls:

*“Ek was baie bekommerd oor die kans vir ‘n miskraam. Toe ek by die huis kom van die hospitaal, toe beweeg ek nou baie mooi, toe het ek my nou mooi gehou toe ek van die trein af gekom het huis toe. Vir my baie stil gedra, en alles wat julle genoem het, dat net na die toets moet ek uh dat daar ‘n moontlikheid is van ‘n miskraam. Maar ek het my mooi gedra, maar dit was vir my ‘n baie groot bekommernis gewees. Om die waarheid te sê, het ek nog ‘n dag of twee daarna het ek nog altyd vir my baie rustiger gedra.”*

*“I was so worried that I would have a miscarriage that I made sure to limit my movement when I got home from the hospital. I even walked very carefully from the train station to my house. I kept still and did everything they told me to not have a miscarriage after the test. Even though I kept myself still and behaved well, the possibility of having a miscarriage was still a major worry. To tell you the truth, I even took things easy and kept still for a day or two afterwards just to be sure” (translation).*

The majority of the participants in this study described receiving the PND results over the telephone. When the participants described the process of finally receiving this telephone call, it was clear that the waiting period was a stressful time as they could recall the exact day and time they were informed of the result. P5, a 40 year old woman who requested PND, recalls:

*“They phoned me. It was on Tuesday in the morning. It was 9:00. I still remember the time, because I was waiting for the call on the Monday, and then I was praying nonstop as I worried why they weren’t phoning because it had been a month... So on Tuesday morning when I see the private number, joh, I answered: Hello. Then the person talks: Hello, it is me doctor ... Then I said yes, what is it, what does the results say? Everything is normal. I was screaming here at home. I was so happy... Even the baby was moving in my belly that time, because of the joy.”*

#### **a) Impact of receiving a negative PND result for DS**

All of the participants who tested negative for DS were told about the outcome of their test over the telephone. These participants felt it was acceptable for them to receive the news over the telephone as they were already anxious and having to come in to hospital and wait to be seen would have prolonged this stressful period. The participants were happy as they received the good news as soon as possible and were able to inform their husbands and families

immediately after the telephone call. These participants mostly expressed positive emotions of happiness and relief. P15, a 41 year old woman who received a negative PND result, recalls: *“I was so happy. I couldn’t wait to tell my husband. I was worried, because I cannot take care of a baby with Down syndrome. I was so relieved. My husband was also very worried, but he was also happy when I told him it was negative.”*

Additionally, the participants experienced relief as a negative PND result for DS meant that they did not have to face another difficult decision of whether they wanted to have a TOP. It is important to add that not all the participants who received a negative PND result for DS, experienced complete relief from their anxiety. Some participants described remaining slightly anxious as they had concerns about the accuracy of the test results.

#### **b) Impact of receiving a positive PND result for DS**

Delivering a positive PND result for DS were approached a bit differently in comparison to delivering a negative result. The participants who received a positive PND result for DS described being asked if they were able to come in to the hospital to discuss their PND results. These participants said that once they were asked to come in to hospital, they started preparing themselves for the worst as they saw this as a sign that they were going to receive bad news. P23, a 43 year old woman who received a positive PND result for DS, explains: *“She phoned me to say the results are back... as soon as she dropped the phone, I just broke down and I couldn’t do anything. I couldn’t carry on working as I couldn’t concentrate. I had to phone my boss and tell her what was happening and I told her I have to be here (the hospital) the following morning, but I couldn’t cope, I couldn’t, I was so anxious, I knew there was something wrong. So my boss took me here the same day.”*

Even though this telephone call raised their anxiety, they would not have changed how the results were delivered. They appreciated not being told over the telephone and preferred receiving the result in person. They felt this showed that the counsellor respected their feelings and confidentiality. P29M, a 28 year old male partner or a 30 year old woman who received a positive PND result for DS, commented:

*“Ek sou dit nie anders wou gehad het nie, want ek sou nie daarvan gehou het as sy (vrou) oor die telefoon vertel was terwyl niemand by haar was nie.”*

*“I would not have wanted it differently, because I would not have liked it if she (wife) was told over the telephone when I was not with her” (translation).*

The majority of these participants who tested positive for DS, were able to attend a follow-up hospital appointment as it was easy for them to access transport. There were a few exceptions

of participants who opted to receive these results over the telephone as they lived quite a distance away from the hospital and did not have easy access to public transport. In these instances they were told about the result over the telephone and asked to come in to the hospital as soon as possible if they wanted to discuss this further or have a TOP. The participants appreciated the support they received from the counsellor when discussing the results. They felt this helped them to cope with the news and enabled them to make a decision about the pregnancy which they felt comfortable with. P27, a 24 year old woman who received a positive PND result for DS, recalls:

*“Dit was baie lekker om met haar te gesels, want toe ek uitgevind het hy het Down sindroom het ek eers ‘n hele boks tissues van haar gebruik, en sy het daar gesit en getroos en alles gaan oraait wees en ek is die ma, ek kan besluit wil ek hom hou of wil ek hom laat afmaak. Sy is net regtig baie nice en dit was baie lekker om saam met haar te gesels, want op daai stadium het ek iemand soos haar nodig gehad.”*

*“It was nice speaking to her (genetic counsellor), because when I found out he had DS I firstly cried out a whole box of tissues and she sat there and consoled me. She told me everything was going to be okay, I am the mother and I can decide if I want to keep him or if I want to let him come down. She was really nice and it was good speaking to her as I needed someone like her at that time” (translation).*

It needs to be noted that one couple, P31, was not telephoned with the results. According to the couple they waited for a month and when they did not receive a telephone call about the results, they became very anxious and decided to drive to the hospital in order to find out what the result was.

The participants described experiencing a series of emotions upon receiving the positive PND result for DS. These participants often described feeling shock, intense grief or sadness. When recalling this experience during the interviews, most of the participants became tearful or cried. P18, 36 year old woman who received a positive PND for DS, recalls:

*“Dit was ‘n skok vir my, want ek het nie verwag dat dit gaan gebeur nie. Ek het uitgesien na hierdie baba en nou is dit ‘n skok om hom te moet laat gaan. Ai, ek weet nie...(begin huil).”*

*“It was a shock for me, because I did not expect this to happen. I looked forward to having the baby and now it is a shock that I have to let him go. Oh I don’t know... (starts crying)” (translation).*

Despite this being difficult news to hear all the participants were able to process and accept the diagnosis of DS. This acceptance grew by speaking to their families, the HCPs or from their religious beliefs. This feeling of acceptance was evident amongst both the participants

who had a TOP and those who decided to continue with the pregnancy. P14, a 39 year old woman who requested a TOP after receiving a positive PND for DS, explains:

*“Die nuus was regtig moeilik vir my om te hoor, want ons was so opgewonde oor die swangerskap, veral my man. Nadat ek met my man daaroor gepraat het, het hy gehelp om my te kalmeer en vrede te maak met die nuus. Jy kan nie bo God se werke gaan nie. As dit so is en wanner iets gebeur, kan jy probeer om die kant toe en daai kant toe te redeneer, maar dit is so en jy kan dit nie verander nie.”*

*“The news was really difficult for me to hear, because we were so excited about the pregnancy, especially my husband. After speaking to my husband about it, he helped me calm down and I have made peace with the news. You cannot go above God’s works. If it is like that and when something happens, you can try and argue this way and that way, but it is like that and you cannot change it” (translation).*

#### **5.4. THEME 4: SATISFACTION WITH DECISION REGARDING PND**

The participants were asked to comment on their level of satisfaction with their decision regarding TOP and how this level of satisfaction changed after the outcome of their pregnancy.

##### **5.4.1. Satisfaction with Decision to Decline PND**

Despite the outcome of the pregnancy, all of the participants who declined PND expressed being satisfied with their decision. The only instance where the participants experienced some ambivalence, was during the pregnancy when further complications regarding their baby’s or their own health was detected. These additional complications were only detected in a small minority of the participants. This caused their initial concerns about DS to resurface leading them to doubt their decision. However, after further deliberation they gained confidence in their decision to decline PND.

Those participants who gave birth to a healthy baby, expressed a high level of satisfaction with their decision as their pregnancy had a favourable outcome. They explained that they were content with their decision, as having the test would have put their pregnancy at risk and they possibly could have lost their healthy child. P21, a 20 year old woman, who declined PND and gave birth to a baby without DS, reflects:

*“Ek is baie gelukkig daaroor, want ek het nog vir my ouma gesê hulle wou gehad het ek moes die toets doen en meanwhile het my kind nie die toets oorleef nie. Ek is baie bly ek het nie die toets gedoen nie, want dit sou onnodig gewees het.”*

*“I am very happy about it, because I still said to my grandmother they wanted to do this test and meanwhile my child did not survive the test. I am very happy I did not do the test, because it would have been unnecessary” (translation).*

Those participants who gave birth to a baby with DS also expressed being content with their decision to decline PND, as they had already made peace with the fact that the baby could have DS at the time they were offered PND. P33, a 43 year old woman, who declined PND and gave birth to a baby with DS, commented:

*“Ek is glad nie spyt ek het die toets laat doen nie. Nee, ek is tevrede met my kind soos sy is.”*  
*“I do not regret not having the test at all. No, I am content with my child as she is”* (translation). Even though these participants experienced a lot of challenges in raising their child with DS as described in section 5.3.1.2 (p.110), this did not make them regret their decision to not have PND.

When the participants were asked to elaborate on what played a role in the level of satisfaction with their decision to decline PND, they commented that making their decision in support of their partners and families were vital. As they were included in their decision, having a baby with DS did not have any negative impact on their relationship with their partners or families, which lead to greater satisfaction with their decision. They also added that despite the negative emotions they experienced at times, overall their child with DS had brought more love, joy and purpose into their lives. They therefore expressed being content with their decision as having PND could possibly have led them to miss out on these experiences.

#### **5.4.2. Satisfaction with Decision to Request PND**

All of the participants were satisfied with their decision to have PND, regardless of whether they received a positive or negative PND result for DS. Those who had tested negative for DS, felt it was still the right decision to have PND as they felt it was the parents' responsibility to make sure that they had all the facts with regards to their baby's health.

Additionally, the majority of the participants described feeling content with their decision to have PND as a negative result relieved them completely from the anxiety they had felt after hearing about the possibility of DS. Once they gained certainty that the baby did not have DS, they were able to enjoy the remainder of their pregnancy. P20, a couple who requested PND, explained:

*“P20F: I feel it was the right decision to have the test done, because I wanted to know for certain if the baby had a syndrome or not. If I did not know I always would have been worried about the possibility of having this syndrome baby. I am happy I did the test.*

*P20M: I agree with my wife and feel it was the right decision. If we happened to land on this same path again I think we would do the same”.*

As previously mentioned in sections 5.1.2 (p.86) and 5.3.2.2(a) (p.113) not all of the participants experienced complete relief after the test confirmed that their baby did not have DS. However, these participants reported that this did not influence their level of satisfaction with their decision, as the result did offer a bit of reassurance that the baby will not have a disability.

Some participants who received a PND of DS, expressed being satisfied with their decision to have the test as it allowed them the opportunity to make the decision to have a TOP before they became too emotionally attached to the baby. P23, a 43 year old women who requested TOP after receiving a PND of DS, explains: *“The reasoning for doing the test was to catch whatever was there in time. You know, before the further stage of pregnancy where I have maybe connected already with the baby...”* In turn, those participants who decided to continue with their pregnancy after receiving a positive diagnosis of DS, also found the test beneficial as it allowed them sufficient time to prepare for the arrival of their baby and to ensure they have the necessary support to help them cope with their baby.

## **5.5. THEME 5: IMPACT OF DECISION REGARDING TOP**

### **5.5.1. Impact of Decision to Decline TOP**

The four participants who declined TOP after receiving a prenatal diagnosis of DS, successfully gave birth to a baby with DS. Two of these participants had to deliver their babies prematurely at 36 weeks of gestation as their baby’s heartbeat was too slow. In total, three of the babies with DS received a good prognosis. After delivery these participants needed to adjust to and face the challenges associated with raising their child with DS. One of these babies sadly passed away shortly after birth. This baby had a serious cardiac defect as well as Hirschsprung disease.

#### **5.5.1.1. Impact of raising a child with DS**

This section will focus on the impact raising a child with DS had on those participants who received a PND of DS and decided to continue with their pregnancy. When the participants were asked to elaborate on how having a child with DS had impacted their lives, the same subthemes arose as discussed in section 5.3.1.2 (p.110) i.e. emotional impact, impact on interpersonal relationships and impact on day-to-day life.

##### **a) Emotional impact**

The health of the participants’ baby with DS had a major impact on their emotional well-being. The participants all screened high risk for DS as the ultrasound scan indicated the possibility

of some of the comorbidities associated with DS. Those participants whose babies did not have serious comorbidities felt relieved as they were preparing themselves for a baby with many health problems. All of the babies, even those with less serious complications, required regular hospital visits in order to make sure that they did not develop any of the health problems related to DS as outlined in section 2.4 (p.22).

The babies with serious health problems, had to remain in the hospital after birth. This was especially true for the babies who were delivered prematurely at 36 weeks gestation due to their decelerating heartbeat. The participants described this event in itself as traumatic. The participants also had to stay in hospital or take daily trips to the hospital, which was described as mentally and physically draining. P25, 38 year old woman, who stayed in hospital with her baby as she lives in a small rural town far from the hospital, describes:

*“Jy voel, jou lyf voel, jy voel jy moet by jou kind sit, maar jou lyf is te moeg.”*

*“You feel, your body feels, you feel you should be sitting by your child, but your body is exhausted”* (translation).

This same participant also described finding it particularly difficult to deal with her baby's complications as the baby was unexpectedly diagnosed with Hirschprung's disease (which is related to DS) after birth. She was prepared for the other complications picked up on the ultrasound scan (see table 4.2, p.60), but felt this additional diagnosis was too much for her. P25 tearfully recalls:

*“Gisteroggend toe ek hier aan kom, toe hulle dit weer gedoen het, het ek nie lekker gevoel nie. Alles het te veel geword en ek het begin huil, want alles gaan verkeerd, want ek het van die hartjie uitgevind. Maar na sy geboorte, hy het net 'n stoelgang daai een dag gehad en die res van die week was sy magie geswel, en dit is wanneer hulle hom begin dreineer het.”*

*“Yesterday morning when I came in here, when they did it (drained his bowels) again I did not feel well. Everything got too much and I started crying, because everything is going wrong, because I found out about the heart. But after his birth, he just had bowel movements that one day and the rest of the week his tummy was swollen, and that is when they started draining him”* (translation).

What made P25's situation even more difficult was that her support system all lived far away from the hospital and they did not have the finances to pay for transport to the hospital. She went on to explain:

*“Dit is 'n bietjie moeilik vir my, want sê nou iets gebeur met hom, dan is ek alleen en moet ek die trauma op my eie voel.”*

*“It is a bit difficult for me, because say now something happens to him then I am alone and then I feel that trauma by myself”* (translation). Additionally, the participants whose babies had serious complications, described living in fear that their baby was going to die at any moment. Sadly this was the case for P25’s baby.

### ***b) Impact on interpersonal relationships***

Amongst the participants who declined TOP and gave birth to a child with DS, having a child with DS seemed to either have a positive or negative impact on their interpersonal relationships. The two relationships most often affected was the relationship within the couple, and the relationship with their families.

Those participants who made the decision together with their partner’s to continue with the pregnancy despite receiving a prenatal diagnosis of DS, seemed to cope well with raising their child with DS. They supported each other with daily tasks related to the care of their baby with DS and described how this experience had strengthened their relationship. In contrast, the diagnosis of DS seemed to have a major negative impact on the couple’s relationship in those participants who either did not consult or did not agree with their partners when making the decision to keep the baby with DS. P25, a 38 year old woman, who went against her husband’s wishes to have a TOP, recalls:

*“Aan die begin het ek baie gehuil, want vir hom was dit moeilik omdat ek die besluit sonder hom gemaak het. Toe lewe, ons het toe verby mekaar gelewe in die huis. Maar op die einde van die dag het ons vrede gemaak, wane ek het gevoel ek kan nie my kind so onstel nie, want did is nie goed vir die baba nie, want ek huil, en ek huil, en ek huil. So ek het besluit om vrede te maak.”*

*“I cried a lot in the beginning, because for him it was difficult because I made the decision without him. So then we live, we live past each other in the house. But at the end of the day we made peace, because I felt I cannot keep upsetting my child like this, because it is not good for the baby, because I cry, and I cry, and I cry. So I decided to make peace”* (translation). They were able to resolve their issues for a few months, however after their baby with DS sadly died, things escalated and they eventually split up.

P27, a 24 year old participant who also went against her partner’s wishes to have a TOP, recalls a worse experience in comparison to P25. She and her partner already had issues when they had to decide about PND, as he wanted her to have the test so that they could opt for TOP if the baby had DS. She agreed to have the test, but refused to have a TOP when the result showed the baby had DS. Due to their disagreements, the couple broke up shortly after receiving the PND result. P27 recalls: *“He was still like normal together with me (after the PND*

*procedure). We spoke to each other every day and we spoke about the child, but not in the sense of what if it is like that (he has DS). We spoke about usual things like that will be nice if he is a boy and things like that. And just after two weeks when we found out (test result), the chatting got less and less and later on we did not speak to each other at all. That was when I was still pregnant. Let's say I was about 7 months pregnant when he completely took off"* (translation).

After the baby was born, he was also not interested in meeting the baby, but does however pay maintenance for their child. P27 was saddened by this as she would rather not have his financial support and rather have him involved in the child's life. The participant felt rejected because her child had DS. P27 explains: *"At first it was difficult to accept, because I always asked myself, what is wrong with my child? He already has three other children and he is in all three of their lives. The children know him and they spend time with him... So what is wrong with my child? Is it because my child has DS, now my child is not good enough for him? I started to think things like that, but then afterwards I realised that there is nothing wrong with him. There is definitely something wrong with the dad... Really. And afterwards I made peace with the fact that he did not want to be part of his child's life. I am not going to force him to be"* (translation).

The participants all informed their families of the diagnosis of DS shortly after receiving the news. They described using the remainder of the pregnancy to prepare their families for the arrival of the baby. All of the participants' families seemed to accept the diagnosis and the participants described the family being closer after the birth of their baby with DS. They describe seeing their family members more regularly as they all came to visit to help with the baby. In addition to this, those participants who had other children, described them as being supportive and loving towards their new baby brother or sister.

### **c) Impact on day-to-day life**

The participants expressed that having a baby with DS did not have any impact on their daily work life as none of them were employed prior to having a baby with DS. It did however impact on their future career opportunities. One particular young 21 year old participant, P16, gave up her dream to go study further. For P16, this was an unplanned pregnancy to start off with, but she felt it was more important to keep her child even though she did not feel happy about the idea of not being able to study further.

The two youngest participants who decided to continue with the pregnancy after receiving a PND of DS, both felt they wanted to look for a job once their child is older in order to be able

to better provide for their child. They initially thought they would not be able to return to work, but their families offered to look after their child. P27, a 24 year old woman, explains:

*“Ek het eers gedink ek sou nie kon werk end it nie, maar my ouma het aangebied. Sy het gesê bring hom na my, ek sal met liefde agter hom kyk. Hy is nie ‘n moeilike kind nie, so jy kan gaan werk en wanneer jy moet werk toe gaan sal ek babysit.”*

*“Initially I thought I would not be able to work and all that, but my grandmother offered. She said bring him to me, I will look after him with love. He is not a difficult child so you go work and when you have to go to work I will babysit”* (translation)

This was in contrast to the older participants who had no desire to ever return to some form of employment. They felt that because their child had special needs, they were the only suitable person to look after him or her. When the participants were asked to elaborate on why they felt this way, they commented that other people are not as emotionally invested in their child's well-being and therefore they will not look after their child as well as they would. They feared that something would happen to their child if they placed their child in the care of someone else. P31, a 43 year old woman, explains:

*“Ek kan nie vir ander mense vra nie, vir ander mense vra om a so ‘n kind te kyk nie... Sommige mense kyk na jou kind, maar hulle kyk nie regtig na jou kind nie. Hulle laat jou kind in die straat hardloop.”*

*“I cannot ask other people, ask other people to look after a child like this... Some people look after your child but they do not really look after your child. They let your child run in the street”* (translation).

Socially, the participants expressed feeling that the community and their friends accepted their child with DS. They did not feel like they were being isolated or judged because they had a child with DS. However, it is important to note that not all of the participants shared the information of the diagnosis of DS with others and this is likely the reason for them not receiving any negative comments. Therefore, it is unclear to say whether they would have been stigmatised had they disclosed their baby's diagnosis of DS.

One of the youngest participants, P27, added that she felt having a baby with DS helped her to get her priorities in life right. She said that she did not have such an active social life anymore, but that she did not miss it at all. She now enjoyed quiet evenings at home with her family. P27, explains:

*“Die impak wat hy op my lewe gehad het... hy het my laat kalmeeer, ek kan dit definitief sê. Toe ek uitgevind het hy is oppad, het alles in ‘n oogwink verander. Dis net, goed wat ek nie in my lewe waardeer het nie, waardeer ek baie meer nou... Ek is gelukkig om by die huis te*

*wees met die twee van hulle, hom en sy ussie... Ek sê ander tye sou ek hier, daar en oral gewees het. Maar nou lewe ek rustig by die huis en ek het nooit gedink dat dit is waar ek gelukkig sou wees nie, net om by die huis te wees en 'n movie te kyk. Maar toe kom wys hy vir my daar is better dinge as om net the party en die hele tyd te drink.”*

*“The impact he had on my life... He made me calm down, that I can definitely say. When I found out he was on his way, everything changed in an eyewink. It's just, things that I did not appreciate in life, I appreciate a lot more now... I am now happy to be at home with the two of them, him and his sister... I say other times I would have been here, there and everywhere. But now I am living quietly at home and I never thought that that is where I would be happy, just to be at home and to watch a movie. But then he came to show me there is something better than partying all the time and drinking” (translation).*

### **5.5.2. Impact of Decision to Have TOP**

The nine participants who requested a TOP after receiving a PND of DS, had to go through the added trauma of this procedure. These participants described this procedure as having a major impact on all areas of their daily lives, including their interpersonal relationships.

#### **5.5.2.1. Experience of TOP procedure**

Almost all of the participants had a medical TOP late in their second trimester of pregnancy (after 21 weeks of pregnancy), which entailed induction of labour. The participants recruited were given mifepristone once the decision to TOP was made. The majority of the participants were then sent home and asked to return to the hospital two days later in order to be admitted. The only exceptions were in the instances where the participants lived in rural towns which made it difficult for them to return to hospital. Once admitted they were given a daily dose of misoprostol until labour was successfully induced and the stillborn was delivered. The time it took for the entire TOP process to be completed ranged between three days and one week. All of the participants who underwent this procedure described it as traumatic. It is important to note that the participant, P30F, who had an early second trimester medical TOP at 15 weeks of pregnancy, found the process itself a lot less traumatic than the others. She explained that at the time of the TOP, she was still too early pregnant to feel the baby move and therefore she had not yet bonded with the baby.

When the participants were asked to comment on their overall experience of the TOP process, they frequently mentioned three aspects which increased their trauma. These aspects were a prolonged waiting period in the hospital, labour pains and the nursing staff being insensitive.

**a) Waiting period in the hospital**

The waiting period in the hospital was described as the worst part of the experience of having a TOP as they were separated from the support of their families. This was especially true for those participants who lived far from the hospital as they had to stay in the hospital from making the decision until the stillborn was delivered. For them, the stay in hospital lasted for up to one week, in comparison to between one to three days for those participants who lived close to the hospital. P18, a 36 year old woman, who lived in a small rural town far from the hospital and waited five days for the stillborn to be delivered, recalls:

*“Dit was ‘n bietjie baie lank. Ek was lank baie onder pyn gewees. Die middels wat hulle my ingegee het, was bietjie baie swak gewees, toe moes hulle dit versterk het sodat baba kan kom. Maar dit was pynvol en hartseer proses.”*

*“It was a little bit of a lengthy process. I was in pain for a very long time. The substances they had given me was a bit too weak, so they had to strengthen it in order for baby to come out. But it was a painful and sad process” (translation).*

Many participants mentioned having a strong desire to leave the hospital immediately after delivery. It is standard protocol for the participants to see a social worker after their delivery, but many opted not to wait for the social worker. P24, a 36 year old woman, who lived close to the hospital and waited for five days in hospital, explains:

*“Ja, want die sustertjies sê jy is ontslaan, maar ek wag nog vir iemand om met my te kom gesels, maar die persoon kom nie by my uit nie. Sy het gebel, die persoon is oppad blykbaar. Toe sê ek nee. Ek is al hoe lank, vir vyf dae, in die hospitaal. Ek wil huis toe gaan, ek wil my mense gaan sien. Elke keer is dit ‘n vreemdeling, jy is omring deur vreemdelinge vir so lank.”*

*“The sisters say you are discharged, but you have to wait for someone to come speak to you, but that person never shows up. She phoned, the person is on their way, they are on their way. Then I just said no, I have been in the hospital for five days, I want to go home. I want to go see my people. Every time is it a stranger, you are amongst strangers for so long” (translation).*

**b) Labour pains**

Those participants who had had other children, described the labour pains during the TOP process as much more severe in comparison to the labour pains they had experienced during their previous natural deliveries. What added to the trauma, was that after going through the labour pains they gave birth to a stillborn. The pain of their previous deliveries were overshadowed by the joy of giving birth to a live born baby. Even though the labour pains associated with the TOP procedure were more painful, the delivery process as a whole was quicker in comparison to natural delivery. The participants appreciated how quickly the baby

was delivered as this in turn relieved some of the devastation of TOP. P1, a 41 year old woman who gave birth to a stillborn shortly after taking the medication, recalls:

*“Dit was net die pyne wat baie erg gewees het, maar dit het nie eers ‘n hele dag gevat vir my om die baby te kry nie. Die pyne was so 5 minute uit mekaar uit. Toe het ek net nadat u weg is toe kom baba sommer ook uit.”*

*“It was just the pains that were really bad, but luckily it did not even take a whole day for the baby to be delivered and it was a quick process. The pains were about 5 minutes apart. And shortly after you (the interviewer) left (the hospital room) the baby also came out” (translation).*

The one participant, P30, who had an early second trimester TOP, was the only participant who felt that the labour wasn't painful. She commented that as the fetus was still small, the procedure was over before she even experienced pain. The participant added that she thinks she would have been traumatised if she was subjected to proper labour pains and gave birth to a fully developed fetus. P30F, recalls:

*“Alles het vinnig gebeur. En wat vir my ook baie gehelp het is die fetus was nog baie klein en ek kon niks gevoel het nie. Niks pyn nie en ek kon ook niks sien nie. Ek wou ook nie sien wat daar in was nie, want ek het geweet ek sal nagmerries kry as ek moet kyk wat uitkom. Want die pilletjies wat hulle vir my gegee het, binne 3 uur toe werk dit en toe is alles oor.”*

*“It all happened quickly. And what also helped a lot, was that the fetus was still very small and I could not feel anything. No pain and I also could not see anything. I did not want to see what came out as I knew it would give me nightmares if I had to see what came out. Because the tablets they gave me, within 3 hours it worked and it was all over” (translation).*

### **c) Nursing staff**

The participants expressed a degree of disappointment in how they were treated by the labour ward nursing staff. They described them as being insensitive and uncaring of their needs. The participants felt the staff could have been more involved and could have at least taken more time to explain to them what was going to happen once they arrived at the labour ward. They felt the unknown increased their level of anxiety. P24, a 36 year old woman, describes her experience:

*“Nee ek moet sê, jammer ek weet dit is ‘n hospitaal, maar die kraamafdeling hulle het gesuck om die waarheid te sê. Ek sê as ek alleen was sou ek definitief gesink het, want hulle het niks met jou te doen nie... Die dokter wat vir my, wat gesê het as die ballonnetjie uit is moet ek kraamsaal toe en net vir hom vra, die dokter het vir my gesê julle wag julle beurt af. Vir my ‘n bed gaan soek nêrens nie. Ek het gesit daar en onder pyn het ek gesit tot en net voor 1 het ek eers ‘n bed gekry. En toe gaan roep [employer] die doktertjie... Ek sou nooit alleen daar*

*survive het nie. En hoe die ma's skree, die een het geskree: 'My kind gaan dood, waar is jy?' Dan sal die een dokter sê: 'Jy moet jou beurt af wag, jou baba is nog ver.' Sulke goed.*"

*"Sorry to say, I know it is a hospital, but the labour ward sucked to tell you the truth. They wanted nothing to do with you. If I was alone I would not have coped, because the staff wants nothing to do with you...I asked for the doctor who asked me to come down to the (labour) ward, but another doctor just said I must wait my turn. They were trying to find a bed for me in the ward. I sat there in pain for half a day until (employer) called a doctor to help me... I never would have survived there alone. And how the mothers shout, the one shouted: 'My child is dying, where are you?' Then the one doctor will say: 'You must wait your turn, your baby is still far.' Things like that"* (translation).

Some participants expressed disgust in how their stillborn was treated by the nurses. The nurses seemed desensitised and did not treat the stillborn babies like real babies, but more like objects. The participants were not having a TOP because they did not love their child. As they still loved and cared for their stillborn baby, it was important for the baby to be treated respectfully. P29F, a 30 year old woman, recalls:

*"En die susters kom, en die suster tel my kind so op en sit haar neer, toe voel dit vir my ek kan daai suster wurg, so erg was dit, want dis my babatjie wat jy so optel. Sommer net so onder die arm opgetel en daar neergesit."*

*"And when the sisters came and they just picked my child up like that and put her down again, it felt like I could strangle the sister, that is how bad it was, because it is my baby that you just picked up by the arm and put aside like that"* (translation).

#### **5.5.2.2. Impact of having a TOP**

When the participants were asked to describe how having a TOP for DS had impacted their lives, the following six subthemes emerged from their responses: emotional impact, fear in disclosure, reconciling religious beliefs, impact on relationship with partner, impact on family and impact on future reproductive decisions.

##### **a) Emotional impact**

The participants who had a TOP frequently described this process as emotionally devastating. The emotions most commonly expressed were grief and sadness. These emotions were expressed in the form of crying, and the participants recalled shedding numerous tears before, during and after the TOP procedure. These emotions were also expressed during the interviews and in some instances the researcher had to stop the recorder to allow the participants to compose themselves. Returning to the place where the trauma happened seemed to stir up these negative emotions and therefore many of the interviews were

conducted at a different location away from TBH, telephonically or via text messages. The participants described needing between one and three months to gain control of their emotions and to fully accept that they had lost their child. P1, a 41 year old woman who had a TOP, recalls:

*“(Na die procedure het) ek ‘n bietjie gehuil by die huis en so en toe wil ek nou net alleen wees. My kinders het ook gehuil omdat ek die baby verloor het en so. En alles is nou beter. Ons het seker na ‘n maand, toe besef ons nou, daar is nie meer ‘n baby en so ni... maar alles is nou back to normal.”*

*“(After the procedure) I cried a little bit at home and I just wanted to be by myself. My children also cried because I lost the baby and so. But everything is now better. It took about a month for us to realise the baby isn’t there anymore...but everything is back to normal now”* (translation). Most of the participants were able to carry on with their daily lives after allowing themselves this time to grieve.

Universally, despite being able to continue with their daily tasks, they described this event as something they will never be able to forget and still having moments where they felt the pain of their loss. These feelings were usually brought on by dates the participants had attached certain significance to, like when the baby would have been born or would have reached a particular developmental milestone. P30F, a 38 year old woman who requested a TOP, explains: *“I will always bring it up when the two of us (participant and partner) are having a conversation. Do you still think about the baby? Do you know baby would have been born now in December month? How old do you think baby would have been now? I don’t think it is something I will ever be able to forget”* (translation). These emotions were also brought on by seeing other children bonding with their parents. The participants described how difficult this was for them to witness as it reminded them of their loss and desire to have been able to do life with their child. This was especially true if the child also had DS. P30F, continues to explain: *“A few months ago I met a boy with DS. And that child climbed into my heart. Shoo, really. When I see him, he lives close by, then I will just go and give him a hug, even though he doesn’t know me. And then I think about my child that is not there anymore (starts crying)”* (translation).

### **b) Fear in disclosure**

A theme that arose from the participants’ responses was fear in disclosing the full truth about having a TOP due to DS. The participants frequently described being selective when sharing this information and only told their parents, closest family members or friends the full truth.

As almost all of the participants had a TOP in their second trimester of their pregnancy, their colleagues, families and communities were already aware of their pregnancy. Therefore after the TOP, they were faced with many questions from people in their social circles. The participants often described the easiest response to the questions were to say they had had a miscarriage. By offering this as an explanation they could openly grieve their loss without having to answer more questions and possibly facing the judgment of those apposed to TOP. P1, a 41 year old woman who had a second trimester TOP, explains:

*“Baie het vir my gevra wat het geword van die baby, dan sê ek maar ek het ‘n miskraam gehad. Ek wil nie my persoonlike dingese met hulle deel nie, so dan sê ek maar net ek het ‘n miskraam gehad. Oral waar ek gegaan het, het mense my gevra: ‘Waar is baby?’ Dan sê ek: ‘Nee, ek het ‘n miskraam gehad.’ Dit is maar al wat ek nou kan sê. Ek het net vir die meeste naaste aan my, wie ek kan vertrou, vertel.”*

*“Many (people in the community) asked me what happened to the baby, then I just say I had a miscarriage. I do not want to share my personal stuff with them so I just say that I had a miscarriage. Everywhere I went people asked me: ‘Where is the baby?’ Then I just say: ‘No, I had a miscarriage’. That is all I could say. I just told the people closest to me, who I can trust” (translation).*

Others decided to offer the explanation that their baby was sick or that their baby had died *in utero*. P28, a 20 year old woman who had a second trimester TOP, explains:

*“Ek het maar net gesê ons het sonar kom doen op vyf maande en toe hoor ons maar net die kind is oorlede. En ons weet nie hoekom dit so is nie, dis maar al. Ons het nie nog vir hulle verder vertel nie.”*

*“I just told them we had an ultrasound done at five months and then we heard the child died. And we don’t know why it happened, that is all. We did not explain further” (translation).*

Their major reason for not disclosing that they had a TOP was fear of being judged and stigmatised for their actions. They felt certain family members and people in their communities were quick to pass judgment and give their opinion on why they felt this had happened to them. Some felt they would be told it happened due to them falling pregnant at an AMA or because they fell pregnant out of wedlock, which is seen as sin by some. Some participants chose to not even tell their other adult children about the diagnosis of DS and their decision as they feared their children would judge them. P30F, a 38 year old woman who had an early second trimester TOP, explains:

*“Dit is vir my moeilik, want ek weet nie hoe my seun sal reageer nie, want hy praat van Down sindroom kindertjies, want hy het so ‘n vriend. Hy het nog in die week of verlede week toe sê*

*hy, want daar was 'n Down sindroom kind op die TV, toe sê hy hy sê dis spesiale kinders. So ek is baie skrikkerig dat hy my gaan judge.”*

*“It is difficult for me (to disclose information about TOP), because I am not sure how my son will react, because he talks about Down syndrome children, because he has a friend like that. During this week or last week he even said, because there was a DS child on TV, he said they are special children. So I fear that he is going to judge me” (translation).*

In addition to being judged because they had a TOP, some feared that their children would be stigmatised because they had a sibling with a disability. P1, explains:

*“As mense nou gaan vra en hulle vra nou vir die kinders en die kinders sê nou vir die mense, mammie se baby was gestremd, Down sindroom, dan mense is geneig om vir jou woorde te sê. Jy het met 'n mal kind geloop of met 'n gestremde kind, sulke tipe goed. Dit wil ek nie hê nie, of kinders wat miskien vir my kinders sal sê jou ma het klaar 'n gestremde kind gehad of jou ma het 'n Down sindroom kind verwag. En dit is nie wat ek wil hê nie, want op die einde van die dag gaan my kinders seerkry deur daai woorde. En ek moet vir hulle beskerm ook.”*

*“If people go and ask your children and they say my mother’s baby was disabled, Down syndrome, then people are prone to saying bad things to you. You walked with a crazy child or with a disabled child, things like that. I don’t want that. Or children might say to my children, your mother had a disabled child or your mother expected a child with Down syndrome. And that is not what I want, because at the end of the day my children are going to be hurt by those words and I must protect them as well” (translation).*

Lastly, the participants also chose not to disclose that the baby had DS and that they had a TOP, because they did not feel ready to speak about their experience. They wanted to move on with their lives as quickly as possible and did not want to give a detailed explanation to everyone every time they went somewhere. P14, a 39 year old woman who had a second trimester TOP, explains:

*“Hulle het nie nodig om te weet nie, want oral waar, as ons nou by hulle kom dan wil hulle nou net die geselsie van wat het dan nou gebeur en al die goete. En ons voel so jammer vir julle en dan is ons nou al oor dit en dan haal hulle dit weer op. En dan mag hulle dalk nie verstaan as ons sê dit is so en ons is oor die en ons wil nie daaroor praat nie. Hulle mag dalk aanstoot neem.”*

*“They do not have to know, because then everywhere we go then they want to talk to you about what happened and all that. And then they say they feel so sorry for you and then we have already gotten over it and then they bring it up again. And then they might not understand if we say it is like that and it is over and we don’t want to talk about it. They might get offended” (translation).*

**c) Reconciling religious beliefs**

A large proportion of the participants had strong religious beliefs against having a TOP. Despite this belief, many still opted to have a TOP. Following the procedure these participants had to reconcile their actions with their beliefs. As previously mentioned in section 5.2.3.9 (p.107), the participants felt that a TOP for medical reasons was acceptable as it was done in order to spare their child unnecessary suffering.

The participants described praying about their decision to have a TOP in order to help them reconcile their beliefs with their actions. They described asking for permission during these prayers and asking for guidance to make the right decision. Speaking to other believers also helped them to achieve confidence in their decision to have a TOP. P30F, a 38 year old woman with strong Christian beliefs explains:

*“Wat vir my ook beter laat voel het is wat ‘n vroujie vir my by gesinsbeplanning gesê het. Die suster daar, ek kan nou nie die naam onthou nie... Want sy wou toe weet wat het ek hier kom doen en hoekom is ek by Tygerberg (hospitaal). En ek het vir haar vertel en wat sy toe vir my gesê het is, sy het ook ‘n Down sindroom kind in haar familie en dat ek moet net die Here om vergifnis vra vir dit wat ek gedoen het en dit is wat ek gedoen het en dit het ook vir my baie gehelp.”*

*“What also made me feel better is what the lady at family planning told me. The sister there, I cannot remember her name now... Because she wanted to know what I was doing there and why I am at Tygerberg (hospital). And I told her and what she then said to me, she also has a Down syndrome child in her family and that I must just ask God for forgiveness for what I did and that is what I did and that also helped me a lot” (translation).*

Once the participants were able to reconcile their decision to have a TOP with their religious beliefs, they described their religion as a source of support which helped them find peace in their decision. P24, a 36 year old woman with Christian beliefs, recalls: *“I experienced peace within me and I knew what I had to do, so yes, I believe in my religion and I believe there is a higher hand. Everything happens for a reason. I tell everyone, everything happens for a reason and things cannot always go well with you. And then I still say, God places stumbling blocks in your path for you to overcome in order to learn from it” (translation).* This was even true for a participant, P14, who only turned to religion for support post TOP. She claimed this experienced helped her and her husband to find God and that He has helped them find peace. P14, explains: *“The woman that was here (at the hospital) with me, she is my aunt and she is very spiritual. She helped me a lot. My husband and I are both with the Lord now. We were not there at all before this happened. It really helped to find peace” (translation).*

Two participants struggled with feelings of guilt and regret after having a TOP as this decision was not in line with their religious values. Due to these feelings they described feeling that God was upset with them. P30F, elaborates:

*“En vir my op my geestelike vlak is dit vir my baie belangrik dat ek ook tyd moet spandeer saam met die Here om vir myself te moet vergewe het, maar ek wonder somtyds het die Here my vergewe al het ek vir Hom vergifnis gevra.”*

*“For me on a spiritual level it is very important to also spend time with God in order to forgive myself, but I sometimes wonder if God has already forgiven me even though I have asked him for forgiveness” (translation).*

The one participant, P23, was already struggling with guilt before she went through the TOP process but went ahead as she did not see a suitable alternative option. P23, a 36 year old woman with strong religious Christian beliefs, reflects: *“I still have this thing that this is wrong. There is something to me that is telling me why are you doing this? It is wrong to do this thing you know. But I know that it is right for my situation and my reasoning is not a selfish reason you know. Because I am doing it for the child that I don't want her to suffer and I am doing it for me to be able to support my son I have to be working. There is no way that I can just leave work, there is no other support my son is getting from anywhere else. I need to work you see. So God forgive me.”* These feelings were enhanced after the procedure as this participant had two miscarriages following the procedure. This is what she had to say when asked how she was coping with her decision: *“All I can say is I think about my daughter everyday... And sometimes think that God is punishing me for aborting her... as I have had 2 miscarriages after her, the last one on the 24 of April 2016... with no explanation. Regretting not to having gone for a second opinion.”*

#### **d) Impact on relationship with partner**

Experiencing the loss of a child has a major impact on a couple's relationship. This loss due to TOP was no different and seemed to either strengthen or break-up the relationship. Those couples who stood together and communicated well with each other throughout this trauma seemed to deal better with their loss. These couples described their relationship being stronger than before. A couple, P29, who supported each other throughout the process explains:

*“P29F: I think it drew us a lot closer to each other and we love each other a lot more.*

*P29M: The most important thing was that we allowed each other to show our emotions. Yes and sometimes she was a little stronger than I was. And other evenings we could cry together, especially when we prayed together” (translation).*

For others this trauma caused a lot of arguments in their relationship with their partner. These arguments mostly arose as the one participant wanted to speak about what happened, while the other either pushed the other one away or avoided them as a way of coping with their grief. The women mostly wanted to speak about what happened and had the need to be comforted, while the men wanted to avoid speaking about their loss or keep busy by working long hours. P28, a 20 year old woman who had a TOP and felt unsupported by her partner afterwards, recalls:

*“Hy wou net tyd saam met almal spandeer het, dit het gevoel hy wou nie meer by my gewees het nie. Nou dat die kind dood is voel dit vir my hy wil nie meer by my wees nie. Toe het ek die goed vir hom gevra, dan antwoord hy nie, hy praat nie. En agterna toe sê hy vir my, toe sê hy vir my dit is moeilik, ek moet verstaan. Toe sê ek ek het ook daardeur gegaan, ek het die swaarste gedra, dis amper soos hy moet vir my ondersteun en nou druk hy vir my af.”*

*“He just wanted to spend time with everyone else, it felt like he did not want to be with me anymore. After the child died it felt like he did not want to be with me anymore. Then I asked him these things, then he doesn’t answer me, he doesn’t talk. And afterwards he told me it is difficult for him, I must understand. Then I said I also went through it, I carried the heaviest, I, it was like he was supposed to support me and now he was pushing me lower” (translation).*

Most of the participants were able to overcome these difficulties in their relationships. They described that their relationships fully recovered after they spoke openly to each other about their feelings and grief. The only exception was a couple, P30, who broke up after the loss as they had a difficult relationship to start off with. The female partner also had a lot of feelings of resentment towards her male partner as she regretted the decision to have a TOP. Even though she was able to eventually let go of some of her feelings of resentment by making peace with her decision, the couple felt that circumstances would not allow them to be in a relationship. However, they remain good friends and therefore he was present during the interview.

#### **e) Impact on family**

Going through a TOP did not only impact the women or couples, but also their families. Overall the participants described the experience of having a TOP as drawing their families closer together. The family members also seemed to go through a grieving process over the loss of their family member. P24, a 36 year old participant with a close and supportive family, explains the impact on her family:

*“Sy (ma) is platgeslaan. Kyk ‘n man krop mos nou alles op. My pa praat niks maar sy (ma), en my broer dis nou obvious, my jongste broer, hy’s devastated.”*

*“She (mother) is heartbroken. Look a man crops up everything. My dad doesn’t speak, but she (mother), and my brother, obviously my youngest brother, he is devastated” (translation).*

The participants described their other children as being affected the most by the loss as they actively grieved over the loss of their sibling. The participants described that it was challenging trying to explain the loss to their younger children who did not yet understand the concept of death. The participants often used phrases like the baby “*went to heaven*”. They also referred to the baby being with the other deceased family members, like their grandparents, in order to make this easier for their younger children to understand. These couples are still faced with answering their little ones’ questions which are a continuous reminder of their loss. A couple, P29, who has one young child, shares their experience:

*“P29M: Until today the little boy, the 3 year old one, he still says [baby] is still in mommy’s tummy.*

*P29F: When is [baby] coming? Is [baby] by the doctor?*

*P29M: Yes, he often asks is [baby] by the doctor?*

*P29F: I tell him, [baby] went to Jesus. I tell him [baby] is now by Jesus, she is in heaven or whatever. At first it was difficult for us to speak to him about it” (translation).*

#### **f) Impact on future reproductive decisions**

The majority of the participants were of AMA and already had at least one child. For most their last pregnancy was unplanned and therefore they decided to have a tubal ligation (or some form of permanent sterilisation) after the TOP. P1, a 41 year old woman with 4 other children explains:

*“Ek het myself laat steriliseer, want ons wil nie nog baba’s kry nie, want hierdie was te troumaties. So ons het besluit, my man sou hom eintlik laat steriliseer het, maar toe besluit ons om vir my te laat steriliseer om nie nog baba’s te kan kry nie.”*

*“I had myself sterilised, because we do not want more babies, because this was a too traumatic experience. So we decided, my husband was actually going to have himself sterilised, but then I decided to have myself sterilised in order to not have any more babies” (translation).*

Even the majority of those participants who initially thought that they would try for another baby, changed their minds after the trauma of delivering a stillborn. The participants felt that it would be too stressful to go through another pregnancy as they would constantly be worried about the baby also having DS.

Despite this anxiety, one of the younger participants, P28, who had no other children, unexpectedly fell pregnant again shortly after delivering the stillborn. She described that during the pregnancy she was preparing herself for another child with DS. However, this time she would have been prepared to keep the child, as going through another TOP would have been too traumatic. P28, explains:

*“Ja, ons het altyd gedink dit sal weer so wees. Wat hulle nou gesê het, die eerste keer toe ons ook kom vir die sonar toe sê hulle nou hulle is nie seker nie. Hulle wil maar kyk of sy ook die probleem sal hê. Maar ons het dit nie geglo nie, ons het altyd so vir mekaar gesê, maar ons luister na wat hulle sê, maar hierdie keer gaan ek nie my kind laat gaan nie. As dit so is gaan ek maar my kind behou.”*

*“Yes, we always thought it will be like that again. What they told us when we came for our first sonar, they said they aren't sure. They want to see if she will also have this problem. But we didn't believe it, we always told each other we will listen to what they have to say, but this time I am not going to let my child go. If it is like that I am going to keep my child” (translation).*

For the younger participants, they all described that they would feel anxious in the next pregnancy, nevertheless they still felt they wanted more children. Especially those who had no children or no children with their current partner. P24, a 36 year old woman who had no children with her current partner explains: *“I really want another baby, but on the other hand, you don't want another sickly baby or something similar”* (translation). This participant commented that even though she wants another child, she would not want to deliver the baby at the same hospital. For her, her experience in the hospital's labour ward was the most traumatic part of the whole TOP process. She continues: *“Look, it is such a big hospital, they have too few doctors and there are loads of people that have to give birth. Everyone needs to be helped. Then I would much rather have my baby in my home (rural) town, where it is not so big. Their labour ward is not big, but at least I will be around familiar people. My family will be able to stay with me permanently and my child's father will be there to support me”* (translation).

### **5.5.2.3. Coping after TOP**

The participants described using certain strategies and sources of support in order to make peace and find a sense of closure after the loss of their baby. The following five subthemes emerged from their descriptions: viewing the stillborn, ceremonies of closure, remembrance, changing environment, hearing the struggles of other parents and support.

**a) Viewing the stillborn**

After the participants gave birth, they were given the choice of whether they wanted to see their stillborn or not. The participants were encouraged to think about this option before going into labour and initially half of the participants opted not to see their baby as they felt the image of their stillborn would haunt them. P14, a 39 year old woman who had a TOP, explains why she did not want to see her stillborn:

*“Nee, andersins gaan ek die hele tyd hierdie figuur sien. Ek sal loop met daai prentjie en ek sal slaap daarmee. Dit gaan saam met my oral waar ek gaan, so dit is beter om nie te sien nie.”*

*“No, otherwise I will see this figure the whole time. I will walk with that image and I will sleep with that. It goes with me everywhere so it is best to not see”* (translation).

All of these participants, except for one, changed their decision after delivery and asked to view their stillborn. When asked why they had changed their minds, they commented that they were curious to see what the baby they had just pushed out looked like as they had felt the baby against their legs and in some instances, moving.

In most cases the participants asked to see their baby right after delivery. The baby was wrapped in a sheet there in their hospital room and presented to the participants and their partners (if present). Those participants who only made this decision a few hours after delivery were treated differently. Their baby was washed and wrapped in a blanket. They were then taken to a private viewing room where they were allowed to spend as much time with their stillborn as needed. This viewing room was also used if other family members wanted to view the baby and say their goodbyes.

Even though the participants decided to view their child, some kept their distance. They only felt comfortable touching the baby's hand and looking at the baby. Very few felt they wanted to hold their baby close to their bodies as their baby was so small and they wanted to limit bonding. Both participants who described holding their baby close to their chest, seemed to find it more difficult to cope with their loss as this made their bond with their baby stronger. P29M, the male partner of P29F, got overwhelmed with strong emotions when he spoke about his loss and holding his baby close to his chest. P29F describes how coping with their loss has been worse for her husband as he held the baby and she did not:

*“Kyk, ek het haar glad nie teen my gehou nie, because I thought, dit is waar die bond begin. Your heart. So hy (P29M) het dit gehad en ek dink dit is hoekom dit soveel erger vir hom is. Because hy het daai movement gehad. Hy het daai movement gehad en sy hart het haar*

*gevoel. So ek het haar so gehad (illustreer hoe sy baba weg gehou het van haar lyf) die hele tyd, because I felt uncomfortable. So ek het haar basically neer gelê en haar bekyk.”*

*“Look I did not hold her against me, because I thought, that is where the bond starts. Your heart. So he (P29M) had that and I think that is why it is much worse for him. Because he had that movement. He had that movement and his heart felt her. So I had her like this (illustrates holding baby away from body with arms) the whole time, because I felt uncomfortable. So I basically laid her down and looked at her” (translation).*

Commonly the participants described seeing their stillborn as a good thing and many found closure in seeing the features of DS on their stillborn. Their reasons for wanting to see their stillborn was to put a face to the baby they felt moving inside them and also to not have any regrets and wondering about what the baby will look like. P24, a 36 year old woman, who initially did not want to see her stillborn, recalls:

*“Ek het vir myself gesê ek wil haar nie sien nie, maar toe die dokter kom en vra of ons seker is ons wil haar nie sien nie... Het ek gesê, ek dink ek wil haar sien, want andersins gaan ek konstant wonder hoe sy sou gelyk het. Maar sy het so normal gelyk, jy sou nooit gesê het sy is was nie normal nie... die kleinste oortjies, die kleinste handjies, dit was regtig die mooiste gesiggie wat ek al in my lewe gesien het. En ek moet sê, dit is waar ek vrede gevind het.”*

*“I told myself I did not want to see her, but when the doctor came to ask us if we are sure we don't want to see her... I said I think I want to see her, because otherwise I am constantly going to wonder what she would have looked like. But she looked so normal, you would not have said she wasn't normal... The smallest ears, the smallest hands, it was really the most beautiful face that I have ever seen in my life. And I have to say that is where I found peace” (translation).*

However, for some of the participants who could not see a problem in their baby it led to doubt in their decision and frustration as the baby looked perfect in their eyes. One of these participants, P18, said that even though she found this frustrating she reminded herself that her baby's problems were on the inside which gave her peace over her decision. P18, recalls: *“When I looked at baby, for me, there was nothing wrong. The child looked completely normal. Uhm, that was frustrating for me, because like they told me, the way they described what the child was going to look like, the baby did not look like that for me. But okay there were other complications and things so I have accepted it (becomes tearful)... But okay the problems were inside the child. Everything was inside, the urine pipe that was narrowed, the pipe was filled with water. But the child, according to them he was going to have a big head and things but it wasn't like that (translation).* Another participant, P23, regretted her decision to have a

TOP as she was unable to see any features of DS in her baby which caused her to believe she should have sought a second opinion.

Another factor which added to the trauma of seeing their stillborn, was that in some cases the baby exhibited signs of life for up to an hour after delivery. The participants were caught by surprise as they had expected the baby to be completely lifeless. Despite describing being initially frightened and shocked by this movement, they felt it made their bond with their child stronger and they were still content with their decision to view their stillborn. P1, explains:

*“Hy het genies, ja, end it het hom nader aan my gebring. Toe hy genies het en teen my been geskop het.”*

*“He sneezed, yes, and that brought me closer to him. When he sneezed and kicked against my leg” (translation).*

The only couple, P30, who did not view their stillborn was the couple who had an early second trimester TOP at 15 weeks of pregnancy, so this was not an option as the fetus was still too small. The female participant, P30F, mentioned that even if she had the option she would not have wanted to see her baby. As this was an early TOP she did not want to do anything that would make her bond with the child. At the time of the TOP she also did not want to know what the gender of her baby was.

### **b) Ceremonies of closure**

The participants performed certain actions as a way of finding closure over the loss of their baby. A few of the participants described having a moment of silence with their families upon their return home as a method of bidding farewell to their stillborn. Others described having a short memorial or funeral service with close family members. None of the participants asked to take their stillborn home as they preferred the hospital doing the cremation. Therefore, they did not have a casket at these services. One participant did however mention using a photograph of her stillborn to create a leaflet for the memorial service.

Additionally, a few participants who decided to take photographs of their stillborn, described destroying these photographs as a means of getting closure. They had initially taken these photographs as a means of remembering their baby or to show it to the family, especially their partners if he could not come to the hospital to see their baby. Once they had dealt with their loss many decided to rather delete these photographs. Their reasons for deleting these photos were mainly because they did not want this constant reminder of what happened. They felt looking at these photos of their stillborn brought back the painful and traumatic experience of the TOP procedure and their loss. They described feeling some sort of relief after deleting or

destroying the photographs of their baby. It was an action they took in order to position their minds to move on from their grief. P18, a 36 year old woman, recalls:

*“Hy (man) was nou nie baie ingenome gewees met die hele situasie dat ek ‘n foto geneem het daarvan nie, want hy sê dan word ek elke slag herinner aan die kind en hy wou gehad het ek moes dit delete het na ‘n maand. Ek het dit gedelete, uhm, hoe kan ek sê, ek het dit gedelete toe ek voel my gestel reg is, toe delete ek dit. Toe alles reg gevoel het.”*

*“He (husband) was not very happy with the idea that I took a photo, because he said then I will be reminded of the child every time I look at it and he wanted me to delete it after a month. I did delete it, uhm, how can I say, I did delete it when I felt I was ready to delete it. When everything felt right” (translation).*

### **c) Remembrance**

The participants treated this baby as part of their family and therefore many decided to have something to remember the baby by. Even though they had made peace with their loss, they felt it was important to honour the baby’s memory and to not forget that the baby was part of their lives. One way of remembering the baby was to give the baby a name. The majority of the participants named their child and referred to the baby as the little person he or she was meant to be. Others decided to keep memoires like an ultrasound photograph or some of the clothes that they had bought for the baby. The few participants who kept the photograph of their stillborn saw this as a keepsake as well. One participant’s (P1) family had a particularly unique way of remembering their baby as they had named their new car (which they bought shortly after their loss) after their baby. P1, explains:

*“Ons het ‘n kar gekoop en toe het hulle (haar kinders) die kar die naam gegee wat ons die baby sou noem (glimlag terwyl sy vertel van die kar se naam)”.*

*“We bought a car and then they (her children) named the car the name we had given to the baby (participant smiles while she tells the interviewer about the car’s name)” (translation).*

### **d) Needing a change in environment**

When having to deal with the grief after the TOP, a few participants found it easier to change either their work or move to a different town or province. For most of these participants the reason for this move was to have a fresh start. They wanted to forget about the trauma that they had gone through and did not want to be surrounded by anyone or anything that reminded them of this ordeal. This move was especially helpful for two participants who moved closer to their partners or parents. They felt this move allowed them to be closer to their support system. They also saw this as an opportunity to rebuild their relationship with their partners, as going through this traumatic experience while living far away from their partners caused additional strain. P23, a 43 year old woman whose partner and family initially lived in a different

province, commented: *“I am happy this side (different province) as it’s easy to meet my mom and my son. And I am also happily married now and my husband is also starting a business and things are looking good”*

One particular participant, P24, who worked at a playschool, decided that she did not want to work at the playschool anymore after going through the TOP. She felt she did not want to be surrounded by so many of the children and their parents at the playschool as all of them were asking her about the baby. However, she continued working as an au pair for a few weeks, but felt that in a way she was acting like this child was her child. P24 recalls:

*“Ek het my heel eenkant toe gehou van alles af en ek wil nie regtig met kinders omring wees nie, ek het net die behoefte gehad om babatjies op te tel... En later aan voel dit vir my ek moet myself distansieer van alles. Toe sê ek vir [employer] ek kan nie maak asof haar kind my kind is nie. Toe stuur sy vir my vir twee weke huis toe.”*

*“I kept to myself and did not want to be surrounded by children. I did however have this longing to pick up babies... Later on it felt that I had to distance myself from everything and I told (employer) that I cannot act like her child is my child, because it is not my child, it is her child. She then sent me home for two weeks”* (translation). After these two weeks this participant returned to work as an au pair, but still does not want to be surrounded by a big group of children at the playschool. Her employer commented on how she could see how this experience had changed the way the participant related to working with children.

#### **e) Hearing struggles of other parents**

Some found peace over their decision to have a TOP in speaking to other parents who either went through a similar experience or who were raising a child with a disability. Hearing the experiences of how others were struggling with their child reinforced their decision to have a TOP. P1, a 41 year old woman, explains:

*“Ons gaan kuier gereeld vir gestremde kinders in ons area end an gesels ons ‘n bietjie met hulle ouers. Ons het dit gedoen om ons te help om vrede te maak met wat met on sook gebeur het. En dit is baie moeilik vir daai ouers om na hulle baba te kyk. Hulle moet by hulle kind 24hr wees en so. Dit het ons baie gehelp, om uit te gaan end an sien ons dalk ‘n gestremde kind e dan gesels ons met die ouers en vra hoe hulle cope as ouers. End it was ‘n moeilike besluit vir ons, maar ons het eintlik die beste besluit vir ons gemaak.”*

*“We visit a lot of disabled children that live in our area, then we speak a little bit with their parents. We did that to help us get closure on what would have happened to us as well. And it is very difficult for those parents to take care of their baby. They have to be with their child 24hrs and so. It helped us a lot, going out and then maybe we see a disabled child and we*

*speak to the parents to ask how they are coping as parents. And it was a difficult decision for us, but we actually made the best decision for us” (translation).*

#### **f) Support**

Having support from their partner, family, employers and HCPs played a significant role in the participants’ ability to come to terms with their loss after TOP. Those participants who felt supported seemed to gain control over their emotions easier and quicker in comparison to those who did not feel supported.

In particular, those participants who were in supportive relationships seemed to deal a lot better with their loss than those who were not. P1, a 41 year old woman who requested TOP and had a very supportive partner, recalls:

*“Ons het baie daaroor gesels. Daar was ‘n bekommernis, maar my man was baie kalm. Dit was net ek wat nou so daai negatief gedinges het om te weet alles gaan nie fine wees nie. Maar hy het my altyd sterk gemaak om te sê alles is fine.”*

*“We spoke about it a lot. There was a concern, but my husband was always calm. It was just me that was negative and felt like things were not going to be fine. But he made me strong by telling me everything will be fine” (translation).*

In addition, if the families were around to offer support to the women or couples, it also enhanced their ability to cope with their loss after the TOP. P29M, the male partner of a 30 year old woman who requested a TOP, reflects:

*“Wat wonderlik was, is my ouers en my skoonouers, hulle het nie twee keer gedink om alles net so te los by die huis en optegekom het onmiddelik om ons te ondersteun. Dit was huge vir ons. Ek het net gedink, joh, ek moet nou huis skoonmaak, ek is nie baie goed daarin nie. Ek moet nou wasgoed was ek moet nou alles daai goete doen. En my ma hulle was daar gewees om daai te doen.”*

*“What was wonderful is my parents and my parents-in-law, they did not think twice to leave everything at home to come and support us. It was huge for us. I still thought, joh, I still have to go clean the house when we get home (from the hospital) and I am not very good at it. I still have to do the laundry and do all of those things. And my mother was there to do all of those things” (translation).*

Interestingly, the majority of the participants who had a TOP described the support from their employers as playing a role in their ability to cope with having a TOP. Those participants who had good working and personal relationships with their employers, described this relationship as a good source of support. Their employers were empathetic towards their situation and

allowed them enough time off work. In contrast those participants, especially the male participants, who did not have support from their employers and were not allowed to have an extended period of leave, described this as adding to the trauma of their loss.

Lastly, the participants also described appreciating the support they received from the HCPs after the delivery of their stillborn. They appreciated the opportunity to speak about their loss and any additional concerns regarding their decision to have a TOP before returning home. They found immense benefit from these appointments as it helped them find peace and certainty over their decision to have a TOP. P29M, continues to reflect:

*“God het voorsien dat ons vir jou (genetiese raadgewer) en die dokter wat vir ons gehelp ontmoet. En so, medies gesproke, het ons alles wat ons moes gehoor het, gehoor. So ons kan nie sê, kan ons maar ‘n tweede of ‘n derde opinie kry nie. Al ons vrae was beantwoord - meer as ons vrae was beantwoord.”*

*“God provided so that we can meet you (genetic counsellor) and the doctor that helped us. And so, medically speaking we heard everything that we were supposed to. So we cannot say that we need a second or third opinion. All our questions were answered – more than our questions were answered (translation)”*. This particular participant and his partner emphasised that the support from the genetic counsellor was integral in their journey to finding closure after they had had a TOP. P29M, commented that without this support, he did not think they would have been able to deal with their loss:

*“Kyk, as ons dalk by ‘n hospitaal was waar daar nie sulke counsellors gewees het nie, dan was ons miskien nou in ‘n hospitaal gewees. En in ander omstandighede gewees het, maar daai hulp wat daar was van Tygerberg was. Die feit dat daar so ‘n persoon was op personeel, het vir ons so baie trauma gespaar. En dit sou miskien meer op ons huwelik gewees het as ons dit nie gehad het nie soos ons dit gekry het nie.”*

*“Look, if we were maybe at a hospital where there wasn't counsellors like that (genetic counsellors), then we maybe would have been hospitalised now (due to grief) or we would have been in a different space, but that support was there from Tygerberg. The fact that they had a person like that as staff, spared us a lot of trauma. And it also may have been heavier on our marriage if we did not have the support we received” (translation).*

In contrast those participants who did not see a social worker or genetic counsellor before being discharged from the hospital commented that they would have appreciated a follow-up appointment to return to the hospital to receive this support at a more convenient time. They added that while they were in hospital, the support from the HCPs in making their decision regarding TOP was great, but afterwards they received no support. P18, a 36 year old woman who underwent TOP and did not receive any follow-up counselling, explains:

*“Ek meen, miskien na die tyd as alles klaar is (die TOP procedure), ‘n bietjie hulp en ondersteuning gee. Ek meen voor die tyd was dit ook om alles uit te kry. Maar nadat dit gebeur het, sodat dit ook ‘n bietjie kan uit, want op daai oomblik is jy alleen en jy weet nie wat... jy weet nie met wie jy kan praat en wat, ek meen jy is deurmekaar. Jy is in tranes. Jy weet nie wat om te maak nie... (begin huil).”*

*“I mean, maybe after everything (the TOP procedure) is over, it would help to give a bit of help and support. I mean beforehand (the support) was there to get everything (emotions) out, but after it happened it (emotions) also need to get out, because at that moment you are alone and you don’t know what... you don’t know who you can speak to and what, I mean you are confused. You are in tears. You don’t know what to do... (starts crying)” (translation).*

## **5.6. THEME 6: SATISFACTION WITH DECISION REGARDING TOP**

Those participants who were faced with having to make a decision regarding TOP after receiving a positive PND of DS, were asked to comment on their level of satisfaction with their decision. They were also asked to elaborate on whether their level of satisfaction with their decision had changed after the outcome of the pregnancy.

### **5.6.1. Satisfaction with Decision to Decline TOP**

All the participants who chose to not have a TOP after receiving a PND of DS, described being satisfied with their decision. Those participants who had strong personal or religious beliefs against having a TOP, described feeling content with their decision as they would not have been able to live with the guilt if they had elected to have a TOP. P25, a 38 year old woman, who initially considered having a TOP, but changed her mind, explains:

*“Maar ek is bly, ek sê vir die Here dankie dat my ma op my pad gekom het, en ek sê dankie dat ek nie vir babatjie laat uithaal het nie. Want...vir die res van my lewe sou ek vir myself verwyf het oor ek vir babatjie laat uithaal het.”*

*“But I am happy, I thank God that my mother helped me change my mind, and I say thank you that I did not have the baby taken out, because ... for the rest of my life I would have resented myself because I had baby taken out” (translation).* This particular participant lost her baby shortly after birth and added that not even this experience made her regret her decision.

Additionally, those participants who had babies with serious health problems, who found the regular hospital visits traumatic and feared that their baby was going to die, still felt it was the right decision to continue with their pregnancies as they were giving their babies a fighting chance in life. These participants also described feeling love towards their baby with DS and not being able to imagine their lives without him/her. Some commented that they were satisfied

with their decision to continue their pregnancy as they would have missed out on all the joy and meaning their baby with DS has brought to their lives.

Overall the participants mostly described their baby with DS as having a positive impact on their interpersonal relationships and therefore this enhanced their satisfaction with their decision to continue with the pregnancy. Even the two participants who split up from their partners due to their decision to continue with the pregnancy, still remained content with their decision. They expressed that their relationship with their baby with DS was of higher importance to them than their relationship with their partners.

The participants who decided to continue with their pregnancy after receiving a positive diagnosis of DS did not seem to feel that their baby had any negative impact on their work and social life. This also contributed to their overall satisfaction with their decision to continue with their pregnancy.

### **5.6.2. Satisfaction with Decision to Have TOP**

Most of the participants described feeling satisfied with their decision to have a TOP after receiving a PND of DS. However, some of these participants admitted having days where they felt a bit ambivalent. These feelings of ambivalence were usually brought on by witnessing other parents with their children or meeting a high functioning individual with DS. On the days these participants felt ambivalent they described thinking through their initial arguments and reminding themselves why they made the decision in the first instance in order to feel content with their decision again.

One particular participant, P30, really struggled with feelings of regret over her decision to have a TOP after meeting a high functioning teenager with DS and reading about the achievements of other individuals with DS. During this participant's interview, she was extremely emotional and the recorder had to be stopped five minutes into the interview. As the interviewer is a genetic counsellor, she felt that it would be un-ethical not to address the participant's emotions and feelings of regret. After exploring this issue further it was established that the participant's main reason for her regret was because she felt that her baby with DS was going to be healthy and high functioning, which sadly would not have been the case given all the comorbidities that were detected on the ultrasound scan (see table 4.2, p.60). After the interviewer gave more information regarding her own baby's condition and congenital abnormalities, this participant felt content with her decision to have a TOP. After understanding the seriousness of her baby's problems, she felt that she made the right

decision as she would not have been able to cope with her child suffering and possibly passing away shortly after birth. P30F, explains:

*“Ek dink ek is nou meer gemaklik daarmee, jy het my meer vrede gegee nadat jy verduidelik het oor die hartjie en die gat. Soos ek gesê het, hulle moes vir ons meer inligting gegee het, hulle moes meer in diepte verduidelik het... Nou dat ek meer inligting het, weet ek dit was die regte besluit”.*

*“I think I am more comfortable with it now, you have made me feel at peace after giving me the facts about the heart and the hole. Like I said, they should have given us more detail, they should have gone more in depth... Now that I have more information, I know that it was the right decision”* (translation and edited).

Those participants who had strong religious beliefs seemed to also struggle a bit more with ambivalence than the others. Two participants stated that their strong religious beliefs contributed to their feeling of regret over their decision to have a TOP. P30F, felt that her religious beliefs also contributed to her feeling of regret in combination with meeting a high functioning individual with DS as described above. As she had a TOP shortly after hearing she was pregnant and receiving the PND result of DS, she described feeling that everything happened too quickly, that she did not have enough time to reconcile her religious beliefs with her decision to have a TOP. Additionally, P23, a 43 year old woman with strong Christian beliefs, expressed regret over having a TOP. During the initial interview she frequently repeated the words “*God forgive me.*” After the TOP procedure she had multiple miscarriages and felt that this was God’s way of punishing her for not seeking a second opinion and going ahead with the TOP. This participant did not want to have a follow-up interview as this experience was too traumatic for her and she was dealing with a lot of regrets. She had also moved to a different province after the delivery in order to be closer to her family for additional support. The interviewer offered support from a counsellor, but the participant felt she did not want to make use of these services.

When the participants were asked to comment on what contributed to their feeling of satisfaction over their decision to have a TOP, they mentioned that the support from their partners and family played the most significant role. They also felt seeing other parents struggle with their baby with DS and hearing about other children with DS suffering, contributed to them feeling satisfied with their decision. They found peace in knowing that they had prevented this suffering for themselves and their unborn baby. Lastly, they also commented that having other people in their social circles back up their decision, led to a higher level of satisfaction.

## CHAPTER 6: DISCUSSION AND CONCLUSIONS

### 6.1. DISCUSSION

The aim of the current study was to gain a deeper understanding of how women or couples, who attend the prenatal clinic at TBH, experience and make their decisions regarding the option of PND for DS and TOP. This deeper understanding is seen as valuable in order to improve their satisfaction with the decisions these women or couples make in order to limit the negative long-term impact it may have on their emotional and social wellbeing. The findings of the current study is discussed below and where possible, compared to the existing literature on the topic.

#### 6.1.1. Being at High Risk for Down Syndrome

In order to gain a better understanding of the decision-making processes it is important to first understand more about the participants' experiences of the events that led up to being offered PND and subsequently TOP. Prior to being offered PND, the participants' must face the difficult news of their pregnancy being at high risk for DS. All of the participants described this news as "*traumatic*" and "*difficult to hear*". Many of the participants expressed grief over the potential loss of their expected healthy baby. In some instances this news of their baby potentially having DS was so traumatic that they did not want to return for a follow-up interview as they could not bear being reminded of this experience.

There is a core theme of the participants expressing initial feelings of anxiety about their baby being disabled, however, most described being able to resolve these feelings and were able to enjoy the remainder of their pregnancies. Some participants did, however, express these feelings of anxiety returning shortly before giving birth. This was even true for those participants who had PND and were reassured that the baby did not have DS. A systematic review of the literature by Green *et al.* (2004) suggested that some women who screen high risk for DS are not entirely reassured by the negative PND result as they felt this higher risk for a chromosomal condition, makes the risk of other adverse outcomes more likely. As most of these participants screened high risk due to soft-markers or congenital abnormalities detected on the ultrasound scans, this also contributed to the residual feelings of anxiety. These residual feelings were finally put to rest once the participants saw their baby and got told that their baby is healthy.

Once the participants heard about their high risk of DS, they often expressed feelings of self-blame and guilt. These feelings appeared when the participants tried to find logical

explanations for why their baby was at high risk of DS. Unfortunately all of their explanations were related to something they had done which gave rise to feelings of self-blame and guilt. One possible explanation the participants came up with, was that the high risk was due to their AMA. Society proclaims that women who are older have babies with DS, because of their age. In a way this explanation makes medical sense as women older than 35 years are at an increased risk of having a baby with DS, however, not all of these women will definitely give birth to a baby with DS as there are other mechanisms involved in causing this condition. This is similar to the findings reported by Aune and Möller (2012). In addition to this, the more religious participants offered an explanation of being punished by a higher power for their initial thoughts of not wanting the pregnancy. For the majority of the participants the pregnancy was unplanned and therefore some had initial negative feelings towards their pregnancy and even considered having a TOP. Some added feeling they were being punished for certain past behaviours of drinking alcohol and smoking cigarettes. This notion of self-blame and guilt over their high risk status, is similar to the findings reported by Heyman *et al.*, (2006). These feelings were addressed during the genetic counselling sessions and the participants described appreciating the reassurance that they had not caused this high risk for DS.

Similar to what has been previously reported in the literature, the participants also seemed to treat this pregnancy as a “tentative pregnancy” (Rothman, 1994; Åhman, Runestam and Sarkadi, 2010). This period of a “tentative pregnancy”, lasted past the usual opinion of keeping a pregnancy secret during the first trimester due to the high risk of having a natural spontaneous abortion. Many, specifically those who had PND, decided not to disclose the news of their pregnancy until late in their second trimester, until they were certain that the baby did not have DS or that they were going to continue the pregnancy. They felt keeping their pregnancy a secret would enable them to cope better if they decided to have a TOP, as they would then not have to offer others an explanation on what happened to their pregnancy. In contrast, those participants who declined PND felt comfortable disclosing the news of their pregnancy, but decided to withhold the information about the high risk of DS, as they did not want to worry their friends or families.

In order for the participants to be capable of making a sound decision regarding PND and to enjoy the remainder of their pregnancy, they needed to find a way to cope with their high risk status. The various coping strategies used included remaining positive vs preparing for the worst, social isolation, remaining occupied and support. There was an interesting contrast in mind-sets between the participants, some chose to remain positive and others chose to rather expect the worst. The participants who remained positive did so as they felt stress is not good for the baby and that if they believe in positive things, good things will happen. This continuing

hope that the baby will be normal has been previously described by Somereth and Sundby (2010). In comparison, those participants who expected the worst dealt much better with a PND result of DS than those who remained positive.

Some participants described isolating themselves for a period of between one week and two months as a way of dealing with the possibility of their baby having DS. Of these participants, those participants who had PND and received a negative result for DS, expressed the shortest period of social isolation as they were able to easily return to interacting socially once they received the result. The longest period of social isolation was described amongst those participants who received a PND of DS and subsequently requested a TOP. Another avoidance coping strategy described, was keeping themselves occupied with things unrelated to the pregnancy. These things mostly included work-related tasks, daily household activities and hobbies. Lastly, support from the participants' religion, partners, family, friends, employers and HCPs were all seen as essential in coping with their high risk status. Social withdrawal, self-distraction in order to avoid anxiety and seeking support as coping strategies have all previously been described by Lafarge, Mitchel and Fox (2013).

Lafarge, Mitchel and Fox (2013) did however note that avoidance coping strategies like social withdrawal and self-distraction may become maladaptive if used long term. As these individuals make use of active denial and disengagement from the event, it may have a long term negative impact as they never fully deal with the trauma of the event and the impact it has on their lives. This means that these feelings may accumulate to a point where it will have a major impact on the individuals' psychological state. However, these strategies were described as valuable coping strategies when used for a short period of time as it allows the individuals' time to gain control over their emotions in order to strengthen them to deal with the trauma. Fortunately, this seemed to be the case for the participants in the current study. This finding does however highlight the importance of the awareness of the HCPs of these coping strategies to identify when patients use them in a maladaptive rather than an adaptive way.

## **6.1.2. Decision-Making Processes in Prenatal Setting**

### **6.1.2.1. Experience of making decisions regarding PND and TOP**

The participants seemed to find the decision regarding PND easier to make than the decision regarding TOP. Once the participants were able to consult with their important referents and establish what was more important for them, to know whether their baby had DS or to keep their pregnancy safe from the possible procedure-related risks, they were able to easily make this decision without any feelings of ambivalence. This is in contrast to what has been reported

in the literature in two US studies by Chevalier Sapp *et al.*, (2010) and Moyer *et al.*, (1999). The reason for this contrast could possibly be attributed to the women and couples in the current study expressing a less negative attitude towards the option of PND in comparison to those participants in the two US studies. The only negative aspects the participants in the current study highlighted, were the procedure related risks of miscarriage and possible transference of HIV. The women included in the US studies had added concerns about PND medicalising or interfering with the natural process of pregnancy. As the US women had more negative aspects to weigh up against the positive aspects, it possibly increased their level of ambivalence.

All of the participants described the decision regarding TOP as an extremely difficult one to make and leading to a high level of ambivalence. A possible reason why they found this decision more difficult in comparison with their decision regarding PND, could be due to the more direct life or death implications their decision would have. As previously described by McCoyd (2007) and Gaille (2007), the decision regarding TOP is complicated by the element of having to choose between giving life to a child with a disability or becoming bereaved over the loss of a baby, neither one leading to their desired outcome of a healthy normal baby. What added to the difficulty in making this decision amongst the majority of the participants in the current study, was the added time pressure due to their advanced gestational age. Almost all of the participants, except one, were already in the late second trimester of pregnancy (past 22 weeks) and had limited time to make the decision in order to still qualify for a TOP before the permitted gestational age of 24 weeks.

The participants found the genetic counselling sessions helpful in containing their negative emotions and assisting them in their decision-making processes. This illustrates that the genetic counsellor or medical geneticists fulfilled their role during these sessions as previously described by Hodgson *et al.* (2010). However, some participants noted that they did not find any benefit from the initial counselling session, while still feeling overwhelmed by the shock of hearing of the high risk of DS. Due to their emotional states they were unable to comprehend the information they were given at that time. They did however add that once they had returned for a follow-up appointment after having gained control over their emotions and being able to process the information, they found these sessions helpful. This supports previous studies which reported that an individual's emotional state has a major impact on their ability to process information and highlights the importance of timing these genetic counselling sessions appropriately (Booth and Siegler, 2006; Beilock and DeCaro, 2007; Durand *et al.*, 2009).

### **6.1.2.2. Self-reported factors influencing decisions in the prenatal setting**

The findings of the current study specified several factors which played a role in the decision-making processes within the prenatal setting. Many of these factors are similar to those previously reported in the literature. Also, the factors playing a role in the decision-making process regarding TOP is largely similar to those which play a role in making the decision regarding PND. The findings also illustrated that the women and couples found it easier to make their decision regarding PND, once they had established how they felt about having a TOP for DS if the diagnosis was confirmed. The findings also indicated that for some of the participants who were uncertain about whether they would want a TOP, the decision to have a PND was important in order for them to gain more information before establishing how they would feel about having a TOP. This suggests that the decision-making processes regarding PND for DS and TOP interact with each other and should be seen as one entity, rather than two separate processes. In practice, if a participant seems to struggle to make the decision regarding PND, it may be helpful to lead them to focus on their feelings towards TOP before making their decision. The opposite is also true for those participants who struggle to make the decision regarding TOP. This supports the findings previously reported in the literature by Durand *et al.* (2009), Markens, Browner and Press (1999), Liamputtong Rice and Naksook (1999), Rauch *et al.* (2005) and Pivetti and Melotti (2013).

The factors which played a role in both the PND and TOP decision-making processes were the perceived severity of DS, available support in raising a child with DS, finances, the participants' personal values and religious beliefs as well as their partner's opinion. The participants seemed to base their perception of the severity of DS on the information they were presented with during their genetic counselling appointment, the stories told in their communities or their past interactions with individuals with DS. Those participants who did not perceive DS as a serious life limiting condition, were less likely to be in favour of having a TOP and therefore less likely to opt for PND. In contrast, those participants who perceived DS to be a severely disabling condition which would lead to a poor quality of life, had a favourable attitude towards having a TOP and therefore opted for PND. This finding is supported by previous studies conducted by Yau and Zayts (2014) and Choi, Van Riper and Thoyre (2012).

Another factor which contributed to some of the participants' decision regarding TOP was the perceived overall health of the baby due to the soft-markers and congenital abnormalities detected on the ultrasound scan. Those participants who were expecting babies with serious additional congenital abnormalities, most often cardiac defects, would likely have been given a poor prognosis of life expectancy during their genetic counselling session. Those participants with less serious abnormalities would have been informed that their babies would

require regular hospital visits and in some cases, surgical intervention. The participants who opted for a TOP after receiving a positive diagnosis of DS, often expressed making this decision as they felt that they would not be able to attend the regular hospital visits as they either did not have the finances or easy access to transport. Some participants added that it was better to end the pregnancy than losing the baby after birth. They felt spending time and bonding with their child after birth would add to their grief. Related to this was making the decision in order to prevent suffering. These participants frequently described opting for a TOP out of love for their child as they wanted to spare the child a life of suffering. They expressed that it is the parents' duty to protect their children from pain and suffering. They added that they were not only sparing their children the suffering, but also themselves and their families the pain of seeing the child suffer. These findings support those reported by Korenromp *et al.* (2007), Ahmed *et al.* (2008), Gaille (2016) and Reed, Berrier and Reed (2017).

A major determining factor in the participants' decisions regarding PND and TOP was whether they would have support in raising a child with DS. As most of the participants in this cohort was of AMA, their parents were either deceased or of an age where they needed assistance in performing their daily tasks. This led to a diminished support system in raising a child with DS for many of the participants. Those participants who did not have a good support network in raising a child with special needs, were more likely to be in favour of a TOP and therefore more likely to request PND. The opposite was also true as those participants who felt they would have adequate support in raising their child with DS, were less likely to opt for PND and they would not consider a TOP. This finding is similar to the findings reported by Choi, Van Riper and Thoyre (2012) and Pivetti and Melotti (2013).

In addition to relational support, available financial support also seemed to influence the participants' attitudes towards TOP and subsequently PND. Some of the participants who were part of single income households, felt they were too financially constrained to raise a child with DS. This was even truer in those few cases where the participant was single or where the female participant (in the couples) was the breadwinner. These participants were in favour of TOP and therefore opted for PND, and those who received a positive result opted for TOP. These participants also described taking their other children's future in consideration when making this decision, as having to spend money on the care of their child with DS would mean that there would be less money available to provide for their other children's needs including their education. The concern of their other children feeling neglected due to all the attention their sibling with DS will need, was also raised by some of the participants. In contrast, those participants who did not have any other children to care for, were more likely

to continue with their pregnancy after receiving a PND of DS. These findings are similar to those reported by Hurford *et al.* (2013).

The participants' personal values and religious beliefs were often the main deciding factor for not undergoing PND or TOP. If they had strong values and religious beliefs against TOP then they were unlikely to have PND. They felt that having PND was unnecessary as this additional information would not lead to any benefit for them or their unborn child. In fact, it could possibly cause harm as they would be placing their pregnancy at risk of miscarriage. This supports the findings reported by Tsianakas and Liamputtong (2002) and Yau and Zayts (2014).

Interestingly, in the current study, those participants who had strong personal and religious beliefs against TOP, who were able to morally distinguish between having a TOP for personal and social reasons and having a TOP for medical reasons, still opted for a TOP after a PND of DS. They felt it was morally acceptable as this was not a reason made out of selfishness, but out of love to protect their child against suffering. These participants often described praying and consulting a religious leader about their decision, and if they found peace in having the TOP, then they went forward with the procedure. In contrast, those participants who did not feel it was religiously acceptable to have a TOP, described praying to God to help them accept whatever the outcome of the pregnancy might be. Those who gave birth to a child with DS, added praying for strength to raise their child. This supports the finding previously reported by Skotko (2005), Kuppermann *et al.* (2006) and Balkan *et al.* (2010).

The participants described the opinion of their partner as valuable when considering both PND and TOP. Previous studies have also indicated that the woman's partner is seen as the most important referent when having to make decisions within the prenatal setting (Kenen *et al.*, 2000; Ahmed *et al.* 2008). Some participants felt they needed their partner's consent before undergoing PND, as they feared they would be blamed if they had a procedure related miscarriage if they made this decision without consulting their partners. Some participants also described including their partners as a sign of respect. They felt it was not only their baby, but also their partner's, so the decision should be made together. Even though the decisions were made together, the participants often described the woman's decision as carrying a heavier weight as she was the one who would be implicated the most. They explained that the woman is the one carrying the baby and therefore she is the one who would have to go through the PND and TOP procedures. She is also the one that would have to explain to her social circles why she is not pregnant anymore in the case of TOP. Those participants who made a decision in agreement with their partners felt more at ease with their decision as they knew they would have their partner's support regardless of the outcome of the pregnancy. These findings were

also reported by Kenen *et al.* (2000), Andersson, Christensson and Gemzell-Danielsson (2014) and Gaille (2016). The implications of not making the decision with the support of their partners were illustrated by two participants who decided to continue with their pregnancy after receiving a PND of DS, despite their partners' wishes. This led to a lot of additional strain on these relationships and eventually led to the break-up of both.

In addition to their partner's support, some of the participants who received a PND of DS, described finding value in consulting their families before making the final decision regarding TOP. Those who opted for a TOP, felt more at ease with their decision, once they knew they had the support of their families and that they would not be judged for their decision. The same was true for the participants who decided to continue with the pregnancy. This supports the findings previously reported in the literature that women and couples valued the input from their family members before making their final decision regarding TOP (Markens, Browner and Press, 1999; Van den Berg *et al.*, 2008; Chevalier Sapp *et al.*, 2010; Pivetti and Melotti, 2013) However, in contrast to the previously reported studies, the participants did not seem to place such a high value on their family's opinion when having to make the decision regarding PND and this was not listed as a factor they considered before making the decision. This could once again be related to the previous description of the participants finding the decision regarding PND as easier to make in comparison to their decision regarding TOP. As the TOP was a more difficult decision, they possibly felt that they needed the input from more important referents in their lives.

The participants also mentioned a few factors specifically pertaining to their decision regarding PND, including the PND procedure related risks, family structure, risk perception as well as the perceived benefit of testing. As previously discussed, the PND procedure related risks were major determining factors when considering the testing. A factor specific to the SA context, was the fear of transferring HIV to the baby during the PND procedure. This supports the findings previously reported by Bee *et al.* (2013). The two participants who were HIV positive, both declined PND, despite understanding their risk of transference being low. They felt any risk was too high. They added it would be worse for them to have a baby with HIV in comparison to having a baby with DS. They explained that they would blame themselves and feel guilty if their babies had to have HIV as their HIV status would be the cause. With DS, they felt it would be easier for them to accept as they knew it was not something that they had caused.

The participants who were concerned about the risk of miscarriage were also more likely to decline PND. These participants described their existing family structure and obstetric history

as contributing to their fear of miscarriage. Those participants who had no children or who had experienced previous pregnancy losses were less likely to opt for PND. Additionally, those participants who had children of the same gender, and who were expecting a child of the opposite gender, were less likely to opt for PND. All of these above-mentioned participants declined PND as they felt it would be worse for them to lose the baby in comparison to raising a child with DS. In contrast those participants who had other children or in whom the pregnancy was unplanned, were more likely to opt for PND. These participants expressed not being concerned about the risk of miscarriage as they felt it would be worse raising a child with DS. These findings are similar to those reported by Cederholm, Axelsson and Sjöden, (1999), Kuppermann *et al.* (2000), Tsianakas and Liamputtong (2002), Durand *et al.* (2009). As the fear of miscarriage was such an important factor in deciding about PND, it is important to note that one participant who requested PND, did not recall ever being told about this risk. This participant signed a consent form stating that she had been informed about this risk which raises some concern about whether she truly gave informed consent. It is important for all HCPs offering genetic counselling to ensure that the patients understand the information given and the risks involved in having PND, before they sign the consent forms. The reason for this participant not being able to recall this information could be attributed to her high level of emotional distress during the genetic counselling session. It may also be due to the large quantity of information the women are presented with during these sessions, which makes the chances high that they might not hear some of the information or find it difficult to recall at a later stage.

Previous studies have indicated that the belief that the PND procedure will cause fetal injury led to many women deciding against PND (Cederholm, Axelsson and Sjöden, 1999; Tsianakas and Liamputtong, 2002). However, this was not reported as a concern amongst the participants of the current study. From the researcher's experience, a possible explanation could be that usually during the genetic counselling sessions at TBH, the genetic counsellors or medical geneticists place emphasis on explaining that the needle inserted to perform the PND procedures does not touch the fetus and does not cause any physical harm.

All of the participants in the current study screened a risk of 1 in 100 or above for DS, which falls into the high risk category. Overall the participants seemed to understand that they were at a high risk for DS, however the actual risk figure did not seem to be the determining factor when deciding about PND. Many of the participants who declined PND, did so as they chose to remain hopeful that their baby would not have DS despite understanding the risk of DS was high. Also those participants who were highly distraught about the news of the high risk of DS, was unable to comprehend their risk figure and therefore did not take this into consideration

when making their decision. These findings support the findings reported by (Booth and Siegler, 2006; Beilock and Decaro, 2007; Durand *et al.*, 2009).

Additionally, the participants' perception of their risk for DS, was influenced by their understanding of the ultrasound findings. There was a major misconception about soft-markers amongst the participants, with the majority seeming to perceive the soft-markers as more severe than they actually were. This misconception often led to an increase in anxiety as many believed it indicated the baby had DS and therefore all of these participants requested PND. This misinterpretation of screening tests for DS has been previously reported in the literature by West and Bramwell (2006) and Heyman *et al.* (2006). This misconception once again highlights the complexity of communicating risk information. This raises the concern of ineffective communication between the participants and the ultrasonographer, fetal medicine specialist or genetic specialist who provided them with an explanation of the ultrasound findings and how this influenced their risk of DS. This misunderstanding may also be attributed to each HCP involved in their care, providing them inconsistent explanations of the ultrasound findings. This finding also relates to the finding reported by Michie, Smith and Marteau (1999) that HCPs do not seem to give adequate explanations regarding the soft-markers looked for during the fetal anomaly scans. Previous literature has also provided evidence that an individual's decisions are influenced by the way the information is presented to them by the HCP and their understanding of this information (Michie, Smith and Marteau, 1999). Therefore, it is important to check the patients' level of understanding of the information they were presented with when assisting them in making their decisions regarding PND and TOP.

Lastly the participants' perceived benefit of PND testing also influenced their decision-making processes. Those participants who perceived the test as leading to some kind of benefit either for their unborn baby or themselves, requested PND. One such benefit was to possibly reduce the anxiety caused by the uncertainty of not knowing whether the baby had DS or not. This finding supports the findings reported by Durand *et al.* (2009), Pivetti and Mellotti (2013) and Ternby *et al.* (2016). Similar to what was reported by Durand *et al.* (2009), the participants in the current study also reported either opting for PND in order to have the choice of TOP if the PND result showed DS or to prepare themselves for the arrival of a baby with DS.

### **6.1.3. Impact of Decisions regarding PND and TOP**

Some of the participants who decided against PND, and all of the participants who decided against TOP after receiving a positive PND result for DS, were faced with the challenges associated with raising a child with DS. Those participants who requested PND were impacted by having this procedure and either receiving a negative or positive PND result for DS. Those

participants who received a positive PND result for DS and decided to have a TOP, were faced with the trauma of having the procedure as well as coping with their loss. The findings related to the impact of these decisions will be summarised and discussed below.

### **6.1.3.1. Impact of raising a child with DS**

A small number of participants who declined PND, gave birth to a baby with DS. These participants did not find the news surprising, as they described having prepared themselves for this possible outcome when they were told about the high risk for DS while still being pregnant. The participants who received a PND result of DS described experiencing emotions of shock, intense grief or sadness upon hearing this news. Most of the participants described this news as unexpected.

Having a baby with DS had a major impact on the emotional state of the participants. This was especially true for those participants who experienced additional complications related to the pregnancy or the baby's health. Some of the babies were born prematurely and the participants described this event in itself as traumatic. Some of the babies were born with a serious cardiac condition and had to stay in the hospital for a prolonged period and these conditions required surgical repair. These participants described feeling worried and anxious about the health of their babies and fearing that they were going to pass away. They also found the constant hospital visits mentally and physically exhausting. This supports the findings reported by Scott (2011). One participant seemed to be struggling more than the other participants as her baby received an unexpected diagnosis of Hirschsprung disease as well. She felt she had not been prepared for this on top of the DS, even though these conditions are commonly associated with each other. Therefore, this highlights that the HCPs who provide genetic counselling should prepare these parents for additional health complications related to DS, which will not necessarily be picked up on the ultrasound scans.

The participants gave two opposing descriptions of the impact their baby had on their interpersonal relationships. They all mentioned their baby strengthening their relationships with their family members and some reported that it strengthened their relationship with their partners as well. This is in agreement with the findings reported by Hickerton *et al.* (2012). In contrast, there have been reports where raising a child with special needs caused a bigger divide and eventual splitting up of couples (Rothman, 1994; Fanos and Mackintosh, 2000). This was true for two of the participants who received a postnatal diagnosis of DS. In one instance the baby with DS was the direct cause of the break-up and in the other the couple had problems before the baby was born. The latter couple lost their baby with DS, which fuelled the eventual break-up of their relationship. Both of these participants also did not

include their partners in their decision to continue with the pregnancy, which also contributed to their problems. This once again highlights the importance of promoting shared decision-making with their partners.

Having a baby with DS seemed to have very little impact on the participants' work and social life. The reason for this was that none of the participants were employed and also none of these participants disclosed their baby's diagnoses to their wider social circles. One of the younger participants did however comment how having a baby with DS had ended her dream of going to study further. The participants also described mainly interacting with their families who knew the diagnosis and accepted their baby. Only one of the participants, a participant who received a PND of DS, reported that having a baby with DS had a major impact on her social life. She expressed that having a baby with DS, made her less social as she realised that staying home with her children and family was more important than partying with her friends. Mostly the participants felt that despite the challenges associated with raising a child with DS, overall the baby had a positive impact on their interpersonal relationships and daily lives. They found satisfaction in raising their child with DS and described this baby giving them a sense of purpose and joy in life. These findings support the findings previously reported by Skotko, Levine and Goldstein (2011) and Scott (2011).

#### **6.1.3.2. Impact of having PND**

Those participants who had the PND procedure were content with how the procedure was performed by the fetal medicine specialists. However, the level of pain experienced during this procedure seemed to be related to the participants' level of anxiety. Those participants who expressed a higher level of anxiety due to their high risk status for DS or their fear of the needle used to perform the procedure, seemed to describe the procedure as painful. These participants also described experiencing a numbing feeling around the area where the needle was inserted. This numbing feeling seemed to last between a few days and a few weeks after the procedure. In comparison those participants who were less anxious described the procedure as "*quick and painless*". This finding is similar to the findings reported by previous studies investigating the impact of anxiety on the experience of certain medical procedures. They also concluded that those patients who experience high levels of anxiety shortly before undergoing the procedure, experience more pain during and after the procedure (Kokanali *et al.*, 2014; Tokmak, Kokanali and Irfan, 2015).

The waiting period for the PND results was approximately two weeks and most of the participants described this as a stressful period in their lives. What contributed to this stress

was the fear of having a procedure-related miscarriage. These findings are similar to the findings reported by Lou *et al.* (2015).

The participants who received a negative PND result for DS, described feeling some relief from their anxiety, which supports the findings reported by Marteau *et al.* (1992) and Lou *et al.* 2015. However, as previously described by Baillie *et al.* (2000) some residual feelings of anxiety remained due to their doubt in the accuracy of the testing or their belief that something else might be wrong with the baby which was not tested for. As most of these participants screened high risk due to soft-markers or congenital abnormalities detected on the ultrasound scans, this also contributed to the residual feelings of anxiety. These residual feelings were finally put to rest once the participants saw their baby and got told that their baby is healthy.

In those participants who received a positive PND result for DS, these feelings of anxiety were replaced with feelings of grief. These participants were content with how these results were delivered to them and expressed gratitude towards the genetic counsellor or medical geneticist who delivered this news. They felt supported by these HCPs which helped them to cope with the news and enabled them to make further decisions regarding the pregnancy. This is similar to what has been reported by Hodgson *et al.* (2010).

### **6.1.3.3. Impact of having TOP**

All of the participants who requested a TOP, apart from one, had a late second trimester medical TOP. All of the participants described this procedure as traumatic and having a major impact on their emotional wellbeing, interpersonal relationships and daily lives. Most of these participants seemed to have been so traumatised by this event that they did not want to return to TBH when having their follow-up interviews. This is explained by Condon (1986) that when a person returns to the place in which the original trauma occurred, there is likely to be some degree of physical, emotional and psychological distress. It does however need to be noted that the one participant who had an early second trimester TOP found it slightly less traumatic. This was ascribed to her having bonded less with the baby at the time of the TOP as she had not yet felt the baby move. This supports the findings reported by Somerseth and Sundby (2010) and highlights the importance of women booking earlier for their ultrasound scans in order to be presented with the option of PND for DS and TOP sooner.

Certain other aspects were described as contributing to the trauma of the TOP process. Similarly to what has been reported in a review study by Choi, Van Riper and Thoyre (2012), the first aspect was the waiting period in the hospital. The participants were separated from the support of their families during this period which enhanced their trauma. This was

especially true for those participants who lived far away from the hospital as their period in the hospital was extended as they could not go home after making the decision to have a TOP. Many of these participants also declined counselling by the social worker as they did not want to remain in the hospital to wait for the social worker which complicated their ability to cope with their loss. Those participants who received counselling after the TOP procedure, described coping better with their loss than those who did not. The participants who did not receive support after having the TOP, highlighted that they would have appreciated having this additional support from the HCPs at a later stage. These findings are similar to the findings reported by Hodgson *et al.* (2016) and Andersson, Christensson and Gamzell-Danielsson (2014), which highlighted the importance of the HCPs role in the patient's road to recovery after TOP.

The second aspect was the labour pains experienced during the procedure. These pains were described as more severe in comparison to the pains experienced during a natural labour. Usually the pain experienced during labour is overruled by the joy of giving birth to a healthy baby. Therefore, the grief of giving birth to a stillborn baby added to the participants' negative experience of the labour pains. This supports the findings reported by Hodgson *et al.* (2010) and Andersson, Christensson and Gamzell-Danielsson (2014). These participants did however appreciate how quickly the labour process was over.

The third and final aspect was the treatment and behaviour of the nursing staff in the labour ward during the TOP process. Many of the participants described the nurses as being insensitive and uncaring. Some of the participants expressed feeling as though they were left to their own devices and that the nurses did not acknowledge their loss. They added to the trauma by treating their stillborn baby as an object rather than a person. The majority of these participants described making the decision to have a TOP out of love for their baby and therefore wanted their stillborn to be treated respectfully. This is similar to findings reported by Somerseth and Sundby (2010) who emphasised the important role midwives played in the women's ability to accept and process the TOP procedure.

The participants described having a TOP had a major impact on their emotional well-being. The participants frequently described experiencing intense grief over their loss which is similar to the findings reported by McCoyd (2007). Previous studies have indicated that women who made the decision to have a TOP of a desired pregnancy after the discovery of a fetal anomaly, experience grief that mirrors that of a spontaneous pregnancy loss (McCoyd, 2007). This grief is often defined as disenfranchised, as often this grief cannot be openly acknowledged or publicly mourned or socially supported due to the nature of the loss and their role in making

the decision to have a TOP (Condon, 1986). As they chose this loss they often hide the full truth and do not feel entitled to their grief (McCoyd, 2007). As this grief is not acknowledged, the women often feel alone in their mourning as no one else is missing the baby as their interaction with the baby was limited (Cacciatore, 2013). What complicates the mourning of a pregnancy loss is that often the loss is only perceived as real by the parents and not the rest of society. This discrepancy has been noted to cause the parents relying solely on themselves in order to resolve their grief. When an individual fails to receive support or adequate acknowledgement of their loss, it leads to additional emotional and psychiatric distress (Malacrida, 1999).

The participants described the trauma caused by the loss of an expected healthy baby and having to deliver a stillborn as something they would never be able to forget. Some participants who were interviewed almost a year after the event, still became tearful when speaking about this event. This finding supports the findings previously reported in the literature (Sandelowski and Barroso, 2005; Korenromp *et al.*, 2007; McCoyd, 2007). Despite this trauma the participants were able to continue with their day-to-day lives, however certain events were described as triggers and brought these emotions to the surface. These events included specific days like the expected due date of their baby or special family days like Christmas. This specific trigger has been previously described by Maguire *et al.* (2015). Other triggers described in the current study were meeting a child with DS or seeing a parent bonding with their child with DS.

The participants commonly described being cautious when speaking to others about their decision to have a TOP as they feared being judged or stigmatised due to their decision. The participants preferred offering an alternative explanation for their loss by stating that they had a miscarriage or the baby was ill and passed away *in utero*. These alternative explanations allowed them to get the support needed while dealing with their grief, without having to face any judgment. This supports the findings reported by Robinson (2014), McCoyd (2007) and France *et al.* (2013). Another reason for non-disclosure was protecting their family members, especially their children, from the upset which is similar to the findings reported by France *et al.* (2013). For this reason selective language was used when speaking about their loss in order to limit the trauma. The participants often explained the baby as having gone to heaven when explaining the loss to their younger children.

Those participants who requested a TOP despite their strong religious beliefs described praying for peace and forgiveness over their decision. They often justified their decision as they acted out of love for their child and not out of their own selfishness. Once they were able

to find reconciliation between their decision and their religion, the latter became a major source of support. Those who struggled to reconcile their beliefs with their decision, expressed regret over their decision to have a TOP. Anderson (2007) have previously noted that individuals coped better when making decisions in line with their ethical, religious and moral values.

The literature has reported some contradicting results on the impact of pregnancy loss on the couple's relationship and relationships with their families. Some studies reported that this loss leads to an increased risk of marriage dissolution and others that it increased cohesion and intimacy between couple's and family relationships (Hutti, 2005; Shrettler, Hill and Cacciatore, 2012). In the current study, the trauma of the loss of their baby mostly seemed to have drawn the couples and their families closer together. The only exception was one couple, who already had problems prior to the pregnancy. The trauma caused by the loss of their pregnancy enhanced their problems and eventually led to them breaking up.

Having received a PND of DS and undergoing a TOP, seemed to have caused fear amongst the participants in having another baby. Most decided to not have another baby as the experience had been too traumatic and they did not want to go through a similar experience again. This supports the findings previously reported by Ndjapa-Ndamkou, Govender and Moodley (2013). In contrast those participants who had no other children or no children with their current partner were anxious to recover in order to be able to try for the next baby. This finding is similar to the findings reported by Fisher (2008). However, despite these participants wanting another baby, they admitted that their next pregnancy will be stressful as they will be worried about the recurrence of DS.

#### **6.1.3.4. Coping after TOP**

The following themes were identified when the participants described their strategies of coping with their loss after TOP. The first being viewing their stillborn. All of the participants who had a late second trimester TOP, opted to view their stillborn. Those participants who could identify the features of DS on their stillborn found reassurance in their decision to have a TOP. The opposite was true for those who could not see any problems with their baby as this led to a feeling of regret. Most of the participants chose to limit bonding with their baby by keeping the stillborn at arm's length. Those who decided to hold their baby close, seemed to find it more difficult to get over their loss which is similar to what has been reported in the literature by Green and Statham (1996) and Hughes, Turton and Evans (1999). Some added that they found this experience slightly traumatic as their baby exhibited some signs of life. This was unexpected, but still did not make the participants regret their decision to view the stillborn.

Overall the participants described seeing and examining their stillborn as helpful. It was seen as a method of dealing with their grief and finding closure as it promoted the realisation and confirmation of their loss. They used this opportunity to bid farewell to their child and some even decided to have a memorial or funeral service for their stillborn. This is similar to the findings reported by Lafarge, Mitchel and Fox (2013) and Andersson (2014). Similarly to what has been reported in the literature, there were opposing viewpoints as some participants found it helpful to view their stillborn, while others experienced it as distressful (Sommerseth and Sundby, 2010). Therefore, the experience of viewing the stillborn seems to be subjective and unpredictable. It may be helpful discussing the possible implications with the women or couples before they deliver their stillborn. This may enhance their ability to make an informed decision before being overwhelmed with the strong emotions of grief that most women and couples experience after the delivery of the stillborn.

The participants also described using other ceremonies of closure. This included destroying the photographs they took of their stillborn. Some participants felt they needed to destroy the photographs as they felt holding on to these photographs prolonged their period of grief as it kept reminding them of their loss. Others felt keeping these photographs as a reminder of their stillborn was important. Similarly to what has been reported in the literature, taking photographs was a healthy way of coping for these women and couples as it enabled them to remember their baby and to speak about their loss (Lafarge, Mitchel and Fox, 2013). Other keepsakes as things to remember their child by, included ultrasound pictures or an item of clothing. Many participants also decided to name their child and often spoke about their little one as being part of the family. This remembrance was a way of acknowledging the baby existed. Lafarge, Mitchel and Fox (2013) and Andersson (2014) reported similar findings and explained that this form of acknowledgment and speaking about their baby was helpful as it allowed them the opportunity to process their memories and experiences after TOP.

After undergoing the TOP, some of the participants were unable to return to their previous home and work environment. They needed to either move house or find a different working situation in order to be able to cope with their loss. This was seen as an opportunity to start over. This finding is in contrast to the finding reported by Lafarge, Mitchel and Fox (2013) that women found returning to their normal work-life routine as helpful in overcoming their grief and finding closure.

The current study found that women or couples who opted for TOP generally found it helpful to speak to parents of children with disabilities, including DS. They found reassurance that they made the right decision when hearing how these parents were challenged by raising their

child with special needs. They also found the support from their partner, family, friends and the HCPs critical in dealing with their loss. Similarly to what has been reported in the literature, those participants who had supportive partners and families coped well with their loss (Hodgson *et al.*, 2016; Fisher, 2008 and Andersson, 2014). The participants in the current study added their employers as an important source of support. Those participants who had supportive employers seemed to cope better. Some participants mentioned that they struggled to deal with their grief as their employers did not want to give them the necessary time off work to deal with their emotions.

#### **6.1.4. Satisfaction with Decisions regarding PND and TOP**

Overall there was a feeling of satisfaction amongst the participants over their decisions regarding PND and TOP. Most often their decisions were in line with their religious beliefs and personal values.

Similarly to the findings reported by Tsianakas and Liamputtong (2002), all of the participants expressed satisfaction over their decision to have PND, regardless of the outcome of either the pregnancy or the PND test result. Those participants who declined PND and gave birth to a normal healthy baby were content with their decision as they would have unnecessarily placed their healthy baby at risk if they had the PND procedure. The only time these participants expressed feelings of ambivalence was during the pregnancy when additional complications related to the pregnancy or their own health was picked up. Those participants who declined PND and gave birth to a baby with DS were also content with their decision as they described their baby with DS as mostly having had a positive impact on their interpersonal relationships and daily lives.

Those participants who requested PND and received confirmation that the baby did not have DS, were satisfied with their decision to request PND as it offered them relief from the anxiety caused by not knowing. Those who received a PND result confirming DS, also expressed being content with their decision. These participants described being grateful for having the PND result, as it allowed them the opportunity to either opt for a TOP or prepare for the arrival of their baby with DS. This supports the findings previously reported by Hedrick (2005).

Similar to what has been reported by Choi, Van Riper and Thoyre (2012), all the participants, except one, were able to achieve an overall feeling of satisfaction with their decision to either continue with their pregnancy or have a TOP after receiving a PND of DS. All those participants who decided to continue with their pregnancies, expressed feelings of content with their decision, despite the challenges associated with raising a child with DS. These participants

felt that the sense of purpose and joy their child brought to their lives overshadowed the negative experiences. This is similar to the findings reported by Hodapp *et al.* (2001) and Norton *et al.* (2016).

Despite the trauma and the impact of having a TOP, most of the participants were able to find closure and were satisfied with their decision to have a TOP. However, some of these participants admitted having moments where they felt ambivalent about their decision. These feelings were usually brought on when they saw other parents bonding with their children. Witnessing this often made them wonder if they should have continued with the pregnancy. This has been reported by Robinson (2014). However, the participants described quickly overcoming these ambivalent feelings by reminding themselves about their initial arguments on why they made the decision in the first place.

The only two participants who expressed feelings of regret over their decision were those who were unable to reconcile their decision with their religious beliefs. One of these participants was able to find reconciliation after being interviewed for the study and being offered additional information on how her baby would have suffered post-delivery. She then felt content with her decision as she could justify it as unselfish and protecting her baby from suffering. Unfortunately the other remains regretful and feels she is being punished for her choice as she has had several miscarriages following the procedure. This participant also exhibited a high level of doubt in her decision to have a TOP and her partner was not available to support her in making this decision. All of these factors have been reported by Korenromp *et al.* (2009) as predictors of regret and long-lasting maladjustment after the TOP procedure.

## **6.2. COMPARISON WITH PREVIOUSLY REPORTED PROPOSED DECISION-MAKING MODELS**

The decision-making processes described by the participants largely matched the proposed decision-making theories and models presented in sections 3.2 (p.29) and 3.3 (p.34). As originally defined by the HBM and further elaborated on by Van den Berg *et al.* (2008) in their hypothesised prenatal screening behaviour model, the participants also reported the perceived risk of having a child with DS and the perceived severity of DS to play a role in their decision-making. Those participants who perceived the risk of DS as high and felt that DS was a serious life-limiting condition were more likely to opt for PND and subsequently TOP in the case of a PND of DS. In addition, the participants' perceived severity of DS was indirectly related to their experiences and interactions with individuals with DS as well as their

understanding of the information about DS they were presented with during the genetic counselling session.

As proposed by Van den Berg *et al.* (2008) the participants in the current study similarly reported child-related anxiety as playing a major role. This relates to the risk-as-feelings hypothesis as proposed by Loewenstein *et al.* (2001). Loewenstein *et al.* (2001) stated that individuals are mostly motivated to participate in a particular action when motivated by emotions such as worry, fear and anxiety. All the participants who were highly anxious and worried about the health of their baby and their baby having DS had PND testing. The level of anxiety the participant's experienced seemed to be related to their understanding of the results of their prenatal screening test (ultrasound scan looking for soft-makers for DS). Many of the participants who mistook the soft-makers for DS as serious abnormalities, had an increased level of anxiety and therefore they were more likely to opt for PND. Additionally, if the participants believed that their baby would have serious health complications and DS, which would lead to a poor quality of life for the child, then these participants were more likely to opt for TOP. In contrast to the proposed model by Van den Berg *et al.* (2008) the participants in the current study did not mention response efficacy as directly affecting their decision-making process. However, it did seem to have an impact on the residual levels of anxiety after receiving a normal PND result. Those participants who doubted the accuracy of the PND result, remained slightly anxious.

Their attitude towards TOP was one of the most prominent factors listed by the participants as influencing their decision regarding PND, which is in agreement with the proposed model of Van den Berg *et al.* (2008). Those participants who had a favourable attitude towards TOP were more likely to opt for PND than those who were not. The participants added the perceived burden and available support in raising a child with DS as influencing their attitude towards TOP. Those participants who perceived a high personal, family and financial burden were more likely to be in favour of TOP if the baby had DS and therefore opted for PND. Similarly, those participants who felt they would not have enough support to cope with raising a child with DS, had a favourable attitude towards TOP and subsequently opted for PND. Even though Van den Berg *et al.* (2008) did not include the TPB's notion of PBC in their model, as they described undergoing prenatal testing as a behaviour that will only be performed once, PBC does seem to impact the decision-making process regarding TOP. In this instance the behaviour is seen as the act of raising a child with DS and PBC refers to the individual's ability to raise a child with DS. Therefore, the above-mentioned perceived burden of raising a child with DS and support in raising a child with DS indirectly relates to PBC. Those participants who felt they would not be able to raise a child with DS, were more likely to opt for TOP. The

participants described the internal factors inhibiting their ability to raise a child with DS as their personalities and emotions. They felt they would not have the right personality traits which is required to raise a child with DS, like patience and resilience. They added that they would not be emotionally strong enough to endure seeing their child suffer and possibly losing their child after birth. The external factors were related to being dependent on others for help in raising the child with DS and the availability of this support as well as the barriers related to accessing the needed health care services (finances and transport issues). If the participants had many of these external factors inhibiting their ability to raise a child with DS, they would opt for a TOP.

Other personal factors which influenced their attitude towards TOP were: their personal moral values, obstetric history, number of children and the gender of their children. Those participants who had strong moral beliefs against TOP were less likely to opt for PND. Related to the factor of parity included in the model proposed by Muller and Cameron (2015), the participants of the current study who were childless and experienced multiple pregnancy losses were more conflicted in making the decision regarding PND and TOP. Those who were anxious about experiencing another loss seemed to decline PND due to the procedure-related miscarriage risk. These participants were also less likely to have a favourable attitude towards TOP. Interestingly the participants in the current study who only had children of the same gender, declined PND and TOP when they were expecting a child of the opposite gender. In the current study the participants also described the added risk of HIV transfer during the PND procedure as influencing their decision to decline PND.

Subjective norm, as defined by the TPB and incorporated in the models by Van den Berg *et al.* (2008) and Muller and Cameron (2015), were one of the most influential factors in the decision-making processes reported by the participants in the current study. The interpersonal relationships with the participants' partners, HCPs as well as families were essential in making the decision regarding PND and TOP. In agreement with the model proposed by Muller and Cameron (2015), most of the participants chose a decision in line with these key people's preferences in order to maintain harmonious relationships. When these relationships were maintained they seemed to be more content with their decisions. It is important to note that even though the participants preferred making a shared decision and preferred making a choice all parties were content with, it was not the most important factor in their decision-making processes. If there was disagreement, they were unlikely to comply with their partner's decision if it was not in line with their own religious beliefs and personal values. They would then choose the option they felt most comfortable with, even if it led to the disharmony in the relationship.

Included in subjective norms was the added systems perspective proposed by Lawson and Pierson (2010). The decisions made by the participants seemed to not only be influenced by their interpersonal relationships with their partners, families and physicians but also by the relationship with their fetus. Those participants who were further along in their pregnancies and were more bonded with their fetuses, found it more difficult to make the decision regarding TOP. In contrast, those participants who were earlier in their pregnancy, and who were treating it as a “tentative pregnancy”, found it easier to make the decision regarding TOP as they were less bonded and would not have to face questions from their social circles regarding the loss of the pregnancy.

Additionally, the systems perspective proposed by Lawson and Pierson (2010) adds the notion of the women or couples making a decision within a larger embedded societal context. In the current study the participants did not seem to place a lot of weight on the medical and legal norms as they did not report feeling any pressure regarding this in making the decision regarding PND and TOP. They were however influenced by the norms and the perceived beliefs of certain members in their close social circles. They often included the opinion of their employers and friends in their decisions regarding PND and TOP. If the members in their close social circles would accept their decision to have PND or TOP, they were more likely to opt for these procedures. The participants raised finding immense benefit in hearing stories from their friends or from other couples in similar situations. In particular, those participants who opted for a TOP, described hearing what other people had gone through raising a child with DS, made them feel more at ease to make the decision to have a TOP. The participants also expressed finding it helpful in knowing that they had the social acceptance of either having a TOP or raising a child with DS.

The last factors related to subjective norms were added by the conceptual model of decision-making in the prenatal setting of Anderson (2007). Anderson (2007) added that individuals use several different personal styles of thinking. The participants in the current study seemed to employ the ethical and practical thinking styles as defined by Anderson (2007). The participants in the current study reported placing a heavy weight on making decisions in line with their religious and personal moral values. Those participants whose religious beliefs or moral values were against TOP, were more likely to decline TOP. This could possibly be related to the fear of being judged by their fellow believers or society if they decide to end the life of their fetus. Reconciling their decisions with their beliefs and values were essential in gaining decision-satisfaction. Those who did not make decisions in line with their values,

experienced ambivalence over their decisions and some even described regretting their decisions.

Muller and Cameron (2015) also mentioned condition coherence and perceived benefit of testing as key factors in the decision making process of the participants. Condition coherence seemed to resonate in the decision-making processes of the participants in the current study, as those participants who had a good understanding of DS and the information they were given, seemed to be less conflicted with their decisions. Furthermore those participants who perceived the test as beneficial, either in order to reduce their level of anxiety, to prepare themselves for a child with DS or to enable them to undergo a TOP, all requested PND.

Overall the decisions the participants made were in line with the rational choice models. All the participants described weighing-up different options and outcomes and then choosing the one they believed had the maximum benefit with the least amount of risk. For example, those participants who felt it would be worse for them to have a baby with DS, than having a miscarriage due to the PND procedure, opted for the PND procedure. For them the benefit of having the option of TOP and not having to face the challenges of raising a child with DS, far outweighed the risk of having a miscarriage. As mentioned by the rational choice models, the weight each of the options and outcomes carried was subjective and based on each participants subjective experience. As the current study was of qualitative nature, the exact weight each of these factors carried cannot be commented on.

Both the decisions regarding PND and TOP were highly subjective and seen as an individualised process. Each woman or couple interpreted their situation uniquely and placed a different weight on each factor. Therefore, two individuals in a similar situation will not necessarily make the same decisions. Certain trends were noticed in the current study with regards to which factors seemed to be more influential than the others. The factors that seemed to carry a heavier weight for most of the participants who declined PND was their unfavourable attitude towards TOP, fear of miscarriage and fear of transferring HIV (in the case of an HIV positive mother). In turn the deciding factors for the participants who requested TOP seemed to be their level of anxiety and their favourable attitude towards TOP if the baby had DS. The factors that seemed to carry the heaviest weight for those participants who declined TOP was their moral values and religious beliefs as well as having sufficient support in raising their child with DS. Those participants who requested TOP mainly did so as they perceived DS as a severe, life-limiting condition and they felt morally and ethically compelled to protect their child from a life of suffering. Even though all the participants valued the input from their partners, families and other important referents within their social circles, their

opinions were not the final decision-making factor. All other reported factors also seemed to play a secondary role

### **6.3. PROPOSED GUIDELINES TO SUPPORT DECISION-MAKING REGARDING PND FOR DS AND TOP WITHIN SA CONTEXT**

After comparison with the available literature and theories or models on decision-making within the prenatal setting, the researcher proposes Figure 6.1 (p.172) as a decision-making guideline regarding PND for DS and TOP within the SA context. Figure 6.1. (p.172) is based on all the factors reported by the participants as influencing their decision regarding PND for DS and TOP. It also presents the decision regarding TOP as directly impacting the decision regarding PND. All the factors listed in Figure 6.1 (p.172) need to be considered by the HCPs when aiding women or couples in their decision-making processes regarding PND and TOP in the SA prenatal clinic setting.

This guideline is however not be used as a model or theory as further research is needed to confirm these finding. It also needs to be noted, that the researcher did not perceive any obvious associations between the decision-making process and the participants' age, ethnicity, socioeconomic status and educational level, however these factors could not be properly assessed due to the qualitative nature of the study. A quantitative study is needed to assess the influence of these factors. Further quantitative research is also needed in order to establish the weight of each of the factors, presented in Figure 6.1 (p.172), on the final decision each individual makes.

Figure 6.1 highlights the following differences when comparing the findings of the current study to the findings previously reported in the literature as illustrated by Figure 3.5 (p.49):

1. The decision regarding TOP often precedes the decision regarding PND for DS. The participants often first explored their feelings regarding having a TOP if their baby had DS in order to assist them in making their decision regarding having a PND for DS.
2. The participants' understanding of the soft-markers impacted their level of anxiety. If they perceived the soft-markers as severe this increased their anxiety and had a direct impact on their decision to have PND for DS. This study highlights the importance of ensuring that the women or couples understands this information when assisting them with their decision-making process.
3. The procedure-related risks which impacted the decision regarding PND were only listed as the fear of miscarriage and their HIV risk. The HIV risk factor is unique to the SA context. In contrast to what has been previously reported, the participants in the current study were

not concerned about fetal injury as it was emphasised during their genetic counselling appointment that the procedure does not cause bodily harm to their fetus.

4. The perceived health of the baby was highlighted to influence their decision regarding TOP. If the baby had a serious congenital abnormality, the participants frequently mentioned that this was their reason for opting for the TOP and not the confirmed DS. In contrast, there were a few participants who mentioned that they would have kept their baby if their baby only had the congenital abnormality detected on the ultrasound scan and not DS.
5. Religious beliefs were noted as an important factor when making the decision regarding PND for DS and TOP. This study added a unique insight into how the participants reconciled their decisions with their religious beliefs.
6. Personal moral values were emphasised as a determining factor when deciding whether a TOP for DS was acceptable or not.
7. A unique interpersonal relationship highlighted by the findings in the current study, was the women or couples' relationship with their employers. They often described seeking advice and support from their employers when making their final decision regarding PND for DS and TOP. For those participants who had opted for a TOP, the understanding and support from their employers promoted their adaptation after the procedure.
8. Previous literature has reported the number of children as influencing the decision-making processes within the prenatal setting. The current study highlighted that it not only the number of children, but also the gender of the previous children influences these decisions.

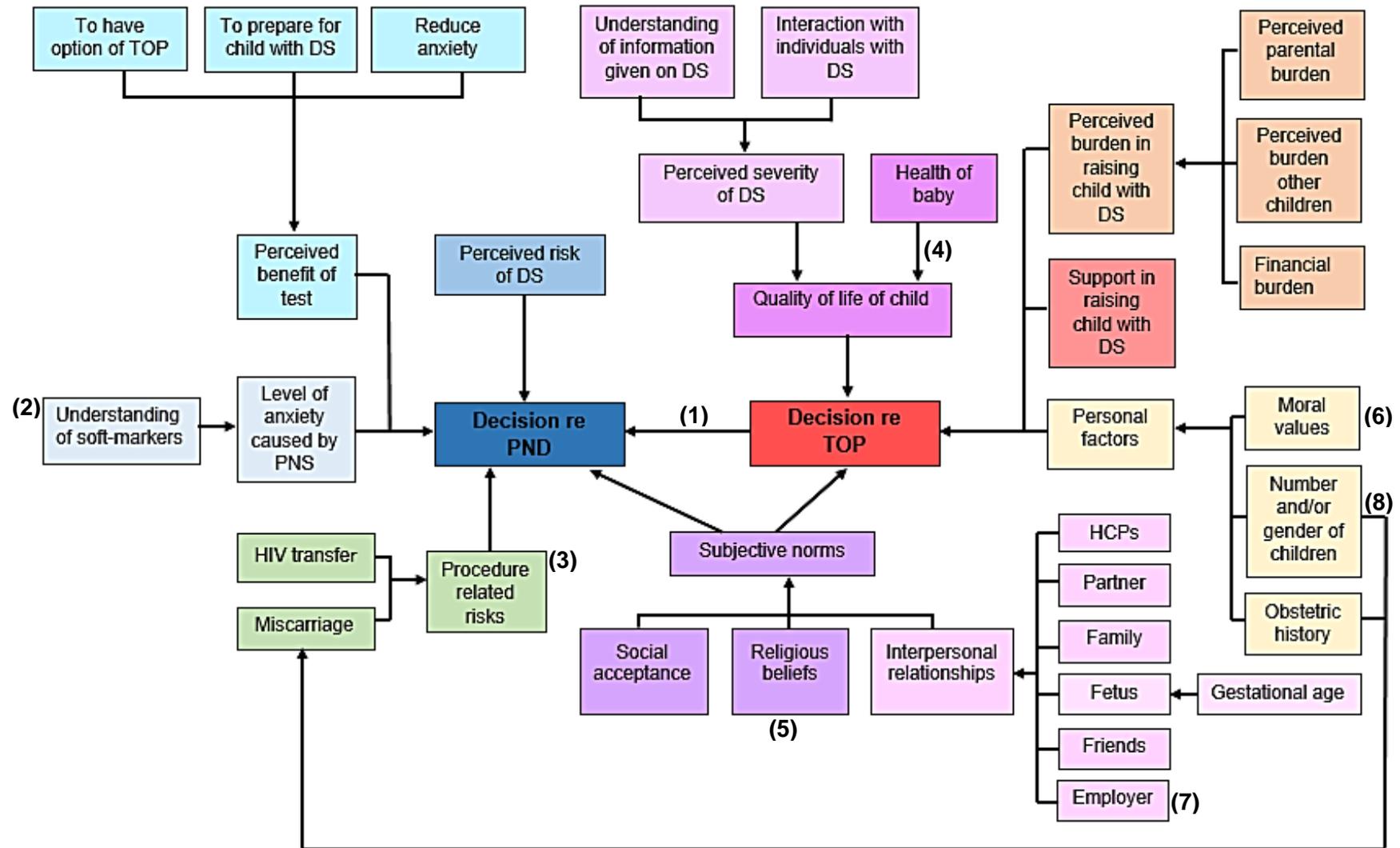


Figure 6.1: Proposed decision-making guideline regarding PND for DS and TOP within the SA context

The findings of the current study also indicated certain factors which led to increased ambivalence amongst the participants when making their decisions. In some instances this doubt led to eventual regret in their final decision regarding PND and/or TOP. In addition to this there were also some factors which seemed to lead to a prolonged period of grief and trauma after the TOP. These factors are listed in Table 6.1 (p.173). It is suggested that the HCPs who offer genetic counselling to these participants take note of the factors and address them during the counselling sessions in order to improve the decision-satisfaction amongst the women or couples, as well as promote the adaptation after TOP amongst those who opt for this procedure.

**Table 6.1: Factors influencing decision satisfaction with decision regarding PND for DS and TOP, as well as trauma of having TOP**

|  |   |
|--|---|
| <b>Factors influencing satisfaction with decision regarding PND for DS and TOP</b> | High level of emotional distress<br>Initial high ambivalence<br>Unsupportive partner<br>Making decision conflicting with religious beliefs<br>Making decision conflicting with moral values   |
| <b>Factors adding to the trauma of having TOP</b>                                  | Advanced gestational age<br>Lack of support<br>Strong religious beliefs against TOP<br>Waiting period in hospital<br>Unexpected movement of stillborn<br>Holding stillborn close to chest<br>Being unable to identify DS features on stillborn<br>Attitudes of nursing staff in labour ward |

#### **6.4. RECOMMENDATIONS FOR IMPROVED PRACTICE**

The following recommendations are made in order to improve the genetic counselling and support the women and their partners receive in the prenatal clinics.

##### ***a) Presentation of information***

It is advised that the women and their partners who attend these clinics should receive standardised and consistent information from all the HCPs involved in their care, especially when explaining the soft-markers detected on their ultrasound scans and how this influences their risk of DS. It is important to check that these women and their partners have an adequate understanding of this information in order to enhance the quality of the decisions they make.

Timing is also essential when giving this information to the patients. If a patient seems too distressed, allow them time to compose themselves or to return to the hospital on a different day.

In turn, the information regarding the health of their fetus based on the ultrasound findings should be individualised. If it seems that their baby will have DS and a serious comorbidity, like a cardiac defect, the patients need to be informed of the severity of this condition. The standardised information provided when explaining DS does not present the couples with the worst case scenarios if their babies have a lot of serious health conditions related to the DS. This recommendation was suggested by the participants of this study, who mentioned that the more severe cases of DS should be presented. Many of the participants found peace with their decision to have a TOP, in knowing that their baby would have suffered and possibly passed away after birth. Another recommendation is sharing the stories of other women or couples who made similar decisions. The participants in the current study noted that they found immense benefit from hearing how others coped after their decision. This was especially true for those who had a TOP.

Lastly, it is important to offer the women who are HIV positive with a clear explanation of their risk of HIV transference during the PND procedure. It may be helpful to explain that this risk is lower than their risk of transferring HIV during the birthing process and that having the PND procedure does not add much to this final risk. It also needs to be made clear that being on antiretroviral treatment and having an undetectable viral load, significantly reduces this risk (Maiques *et al.*, 2003; Bee *et al.*, 2013).

#### ***b) Explore psychological stressors of patient prior to making the decision***

It has been indicated that the women who are under a lot of pressure due to other stressors in their lives, find it more difficult to make the decision regarding PND and TOP. Therefore, it is recommended to explore their psychological state and what other stressors they have in their lives prior to assisting them with the decision regarding PND or TOP. If the counsellor addresses the other psychological stressors in the patient's life prior to making the decision, it is believed to increase their satisfaction with their decisions as well as their adaptation after the outcome of the pregnancy.

Also, for those women who accept PND, it is important to try and contain their anxiety levels as increased anxiety has been found to lead to a more painful experience during and after this procedure. It may also be helpful to warn the women who remain anxious, despite efforts to

reduce these levels that this procedure might be painful and the area where the needle will be inserted might be numb for a day or two.

**c) *Encourage shared decision-making***

It is recommended that the women include their partners in making their decisions regarding PND or TOP. The relationships with the partners are particularly important and it has been noted that making a decision with the support of their partners improves their satisfaction with their decisions. If the partners are not available or if there are some concerns that the women are in abusive relationships, the women should be encouraged to seek advice from an alternative important referent in their lives, like a family member, friend, employer or religious leader.

**d) *Provide ongoing support to women or couples who declined PND***

The current study illustrated that hearing that there is a high risk for DS during a pregnancy causes high levels of anxiety. It is important to follow-up with these women and couples even if they decline PND. It is important to ensure that they were able to effectively cope with this news and that they have been able to happily continue with their pregnancy. If it is noted that these women or couples are experiencing prolonged anxiety or serious psychological comorbidities (like depression) due to this news, they need to be referred to the appropriate counselling services.

**e) *Prepare women better for TOP procedure***

In order to help with the adaptation of the couples after the TOP procedure it is important to properly prepare them for this process in order to limit added trauma. It is recommended to prepare the women for the waiting period in the hospital. This waiting period was described as adding trauma to their experience of the TOP process, therefore if they know that they may be in hospital for a few days while awaiting the delivery of their stillborn, they could potentially put certain things in place to help them cope.

One suggestion could be making sure their partners, families or friends will be able to come visit them regularly. If they do not have a nearby support system it may be helpful to refer them to a social worker, nurse or genetic counsellor who can do regular check-ins. These women could possibly also benefit from being introduced to other women in the hospital wards going through the TOP procedure for a similar reason, as a form of peer support. It may also be helpful for them to bring something along to distract them from the thought of the TOP procedure and that they have to deliver a stillborn baby. Suggestions would bring along

something to read, like a book or magazine. It may also be advised for the women to do journaling or colouring in as these activities have been found to relieve emotional distress.

During the genetic counselling session it is recommended to prepare the women and/or couples for the delivery of the stillborn. It is important to inform them that they will be presented with the choice of whether they want to see their stillborn baby or not. It is also important to prepare the women that the stillborn baby may exhibit some movements for a few hours after delivery. In some instances these movements are just reflexes and not actual signs of life. The women also need to be prepared that they may feel the stillborn move against them during the birthing process. The women and/or couples may also benefit from a warning that seeing and holding their stillborn baby may prolong their grieving process as it may increase bonding with their baby. It is also advised to prepare the women and/or couples that they may not be able to identify the features of DS on their stillborn as the baby is still underdeveloped.

***f) Provide better support during and after the TOP procedure***

The HCPs working with these women should ensure to either offer the women and their partners' adequate support during and after the TOP procedure or make sure they are referred to HCPs who could offer support. The nursing staff in the labour wards may benefit from additional training or a workshop on how to support women in the wards who are undergoing a TOP for a FA, including DS. The staff members need to be trained on how to be compassionate and offer adequate support. They need to be aware that they should treat the stillborn with the same respect as a live-born baby. A special sticker may be added to their folders in order to indicate their reasons for being in the ward and to highlight their need for additional support.

It is recommended that all the women who have undergone a TOP for DS should be offered a follow-up appointment with a genetic counsellor or social worker before being discharged from the hospital. The participants of the current study were not provided with adequate support after the TOP procedure. Many did not want to wait for a social worker in the ward, but were also not given any follow-up appointments to speak about their trauma. This is important as many of these women were left to their own devices and would have immensely benefitted from additional support in order to address any concerns and questions they had after the procedure.

***g) Encourage patients to speak about their experiences***

The participants in the current study mentioned speaking about their experiences regarding undergoing TOP as helpful in dealing with their grief. They either spoke to their partners, close

family members, close friends or HCPs. Therefore, this practice should be encouraged in all women or couples who undergo a TOP for DS.

#### ***h) Increase public awareness of DS and PND options***

If the public understands DS and the cause thereof, it may limit the stigma associated with this condition. Many of the women and couples feared the stigma and judgment they would receive due to the belief that their age had caused the DS. If the patients also have prior knowledge of DS it may reduce the shock they experience when hearing about their risks. If the emotional trauma is reduced, it will in turn lead to a better understanding of the information they are presented with to enhance decision-making.

Additionally, if the women are aware of the risks of DS and the PND options available, they may present at the clinics at an earlier gestation of the pregnancy. This will allow them more time to make their decisions regarding PND and TOP, if appropriate. An earlier diagnosis of DS has also been reported to be less traumatic as the patients are less bonded with their fetuses. This is especially true for women who undergo a TOP at an earlier gestation.

#### ***i) Increase awareness of AMA pregnancy***

It may be helpful to increase the awareness that women above the age of 40 years can still achieve a successful pregnancy. Many of the participants who were of AMA mentioned the pregnancy being unplanned as they did not think they could still fall pregnant at their age. Hopefully with an increased awareness of this possibility, the number of AMA women falling pregnant unexpectedly will reduce.

#### ***j) Improve referral pathway from day clinics***

The day clinics need to be informed of the available prenatal screening and diagnostic tests for DS. They also need to be informed of the appropriate referral pathways in order for these women to get the proper care. This may also improve the referral of these women to the tertiary institutions who perform the prenatal tests for DS at an earlier gestation.

## **6.5. STUDY STRENGTHS AND LIMITATIONS**

The current study had a number of strengths and limitations. The strengths of the study are listed below.

- The study design is seen as a strength due to its unique nature and it being the first of its kind conducted within the SA context. The study design allowed for the exploration of a relatively unexplored research area.

- The qualitative nature of the study was a strength as it gave a voice to the participants and the unique longitudinal design allowed insight into how the decision-making processes develop. It also allowed the researcher to be able to compare the emotional and social impacts between those participants who declined PND, requested PND, declined TOP and requested TOP.
- The depth of the information gathered is seen as a strength. The use of semi-structured interviews allowed for more depth and richness of data. A qualitative questionnaire study would have limited the depth of the data gathered.
- The researcher is an experienced qualitative researcher who has been on several research training courses and has been involved in conducting several qualitative studies. The researcher was able to build good rapport with the participants which improved the quality of the data gathered.

The following study limitations were identified:

- The small number of participants can be seen as a limitation by some as it limits the extent to which the findings can be generalised. However, this is not an important issue for a qualitative study as these approaches are not aimed at providing information that is widely generalisable but rather information that provides an in-depth understanding of a specific situation or phenomenon. However, since validity of the study was a priority, the researcher invites the readers of the research to make their own connections between the elements of the study and their own experiences. For those HCPs working in a similar prenatal clinic context in SA, the findings may be applied as the HCP sees fit, based on their own experiences.
- The Xhosa speaking participants' were not interviewed by a Xhosa speaking researcher and therefore had to express themselves in their second language. The richness of the data would possibly have been enhanced by linguistically and ethnically matching the participants and the interviewers.
- The retrospective accounts of the participants' experiences were subject to their memory and perception of the original situation. Therefore, errors could have occurred in their recollection thereof which limits the accuracy of the true experience. This was not seen as an insurmountable obstacle as the manner in which the experiences stood out in their memory were also psychologically revealing (Giorgi and Giorgi, 2008).

## 6.6. RECOMMENDATIONS FOR FURTHER RESEARCH

It is important to note that due to the sensitive nature of this research topic and the ethical implications thereof, the researcher recommends that future research regarding this topic

rather be conducted quantitatively or as a review of the existing literature. The following recommendations are made for topics of further research based on the available literature and research findings of the current study.

- A quantitative study measuring the correlations between the factors presented in Figure 6.1 (p.172) as well as the weight each of these factors carry in the final decision regarding PND for DS and TOP.
- A study focusing on the presentation of risk information by the obstetricians and ultrasonographers in comparison to the information presented during the genetic counselling sessions. This study will be helpful in order to establish the differences in explanations given to the patients, which in turn may be helpful in providing standardised information.
- A study focusing on the male partners' experiences regarding decision-making within the prenatal setting. There is a paucity of literature available on the male partner's experiences as traditionally the men were not as involved in the pregnancies and were unlikely to attend the hospital visits. As shared decision making is encouraged, it would be useful to investigate whether the factors men report as influencing their decisions are similar to those reported by women.
- A longitudinal study focusing on the long-term impact of having a TOP for DS. It may be helpful understanding the duration of the period of grief the women experience over their loss and the coping strategies they use. This information will also enable HCPs to provide adequate support in order to promote adaptation.
- A study focusing on the understanding and experiences of decision-making regarding PND for DS and TOP within the private sector of SA. From the researcher's experiences of working in both the private and public sector hospitals, she has noticed a large discrepancy between the supportive services offered. The women in the private sector, are rarely given appropriate genetic counselling or offered support after the TOP procedure.
- A study focusing on the Black African women or couples who need to make the decision regarding PND for DS and TOP. This study will be helpful to assess the role cultural differences play in the decision-making process. This study may also identify the role of language barriers in the prenatal clinics as most of the genetic counsellors in SA are either Afrikaans or English speaking.
- A further investigation into the impact of HIV status on the decision-making process regarding PND for DS as the current study only included two HIV positive participants. Therefore, the finding that HIV status plays a role in the decision-making process needs to be confirmed by a larger study.

## 6.7. CONCLUSIONS

The findings of this study illustrates the real difficulty of the decision-making processes within the prenatal setting as well as the impact each of these decisions have on the wellbeing and daily lives of these women or couples. The news of the pregnancy being at high risk of DS is anxiety-provoking and therefore these women and/or couples need adequate support in dealing with this anxiety in order to promote their ability to make decisions regarding the further management of their pregnancy.

The decision-making processes regarding PND for DS and TOP is complex and numerous factors seemed to influence the women/couples decisions. The participants described the decision regarding PND as easier to make than the decision regarding TOP. The factors influencing both their decision regarding PND and TOP were the perceived severity of DS, risk perception of DS, available support in raising a child with DS, finances, partner's opinion, family structure and personal values and religious beliefs. Additional factors involved in the decision-making processes regarding PND was the procedure related risks of miscarriage and HIV transference as well as the perceived benefit of testing. In the decision regarding TOP it was also important for the participants to consult with their families. They also considered the health of the baby (based on the ultrasound findings) when making the decision regarding TOP and many described making the decision to have PND in order to prevent suffering for the child and themselves. Overall the participants seemed to report feeling satisfied with the decisions they had made. Making shared decisions and making decisions in line with their personal beliefs and values, seemed to enhance their level of satisfaction with their final decisions.

Due to the complexity of the nature of these decisions, it is critical to recognise the level of expertise and skills required by the counsellors offering genetic counselling to these women and/or couples who screen high risk for DS. It is important to offer women and couples with clear and accurate information regarding their risks for DS as well as what the PND and TOP procedures entail. The HCPs should allow these women to make autonomous, informed decisions and should treat their decisions with respect and non-judgement. Each woman or couple's individuality needs to be respected and no presuppositions should be made by the counsellor on which decisions they will make.

Those women/couples who decline PND require additional support in managing their anxiety throughout their pregnancy as this might have a long term negative impact on their psychological well-being and pregnancy experience. The women/couples experienced benefit

from having PND in that it led to some reduction in the anxiety they experienced, if the result indicated that the baby did not have DS. In those who received a PND, it was seen as beneficial as it either allowed them the option of having a TOP or preparing themselves for the arrival of a baby with DS. Those participants who opted to continue with the pregnancy described the joy and purpose they gained from having a child with DS as overshadowing the challenges they were faced with. Those participants who opted for a TOP described this procedure as having a major impact on their emotional well-being, interpersonal relationships and daily lives. For these participants who had a TOP it was important to receive adequate social and professional support in order to overcome the grief of their loss of pregnancy.

The findings of this study adds to the literature as it is the first study of its kind to be conducted in the SA context. This study identified decision-making factors specific to the SA context especially the risk of HIV transference and understanding of the explanation provided regarding the soft-markers detected during the ultrasound scan. It also illustrated that the women/couples in the study context were more likely to make ethical and moral decisions and not necessarily decisions based on the facts of the risk information. The information provided in the current study will hopefully lead to an increased understanding which will in turn, improve the decisional support these women and/or couples are offered while having to make a decision regarding PND for DS and TOP. Providing adequate decisional support is going to become more and more essential in the future as technology advances and the access to PND for DS increases. The findings of this study was integrated into a practice guideline which is aimed at shaping how services are delivered in the prenatal setting in SA in the future. This guideline is also aimed at helping the HCPs, providing genetic counselling, guide women and couples in their decision-making processes in order to enhance their level of satisfaction with the decisions they make.

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# APPENDICES

## APPENDIX A: TOPIC GUIDES USED FOR IN-DEPTH INTERVIEWS

### Topic Guide 1: Initial interview

1. Describe how you have experienced your current pregnancy thus far?
  - Planning of pregnancy
  - Being told about news for the first time
  - Reactions of partner and family members
  - Negative experiences
  - Positive experiences
  
2. Tell me how you experienced being told about the risk of having a baby with Down syndrome?
  - Understanding of information given
  - Counselling given
  - Psychological impact
  - Concerns and fears
  
3. Please explain how you experienced the decision-making process regarding prenatal testing for Down syndrome?
  - Emotional responses
  - Information provided
  - Interpersonal relationships influencing decision (partner, family, friends and community)
  - Other factors influencing decision: society, cultural, moral, ethical and religious
  - Difficulties in making decision (ambivalence, time pressure)
  - Differences in opinion (partner, family, friends)
  
4. What would change your mind regarding your decision to go/not go for prenatal testing for Down syndrome?

**Topic Guide 2: Second interview with participants who requested prenatal diagnostic testing**

1. Describe how you have been since we last met and how you experienced waiting for the results?
  - Feelings towards pregnancy
  - Thoughts
  - Regrets
  - Emotional experiences
  - Impact on partner and family
  - Sources of support
  
2. Describe how you experienced the news of the prenatal test results?
  - Emotional impact – shock, grief, fear, relief, happiness
  - Impact on partner and family
  - Conveyed in acceptable/unacceptable manner
  
3. How do you feel about your decision to have prenatal testing done?
  - Satisfied or unsatisfied
  - Regrets
  - Pleased

**Only for participants who received a negative result for Down syndrome (after birth)**

4. Described how you experienced the birth of baby?
  - Worried
  - Examined baby for features of condition
  - Excited
  
5. Do you have any recommendations on how to improve the decision-making process for other women/couples in a similar situation?

**Only for participants who received positive result for Down syndrome**

6. Please explain how you experienced the decision-making process regarding termination of pregnancy for Down syndrome?
  - Awareness of TOP process
  - Factors influencing decision – psychosocial, contextual
  - Interpersonal relationships influencing decision – partner, family, friends
  - Satisfaction with decision
  - Factors that will change decision

**Topic Guide 3: Final interview with participants who declined PND**

1. Explain how you have experienced the remainder of the pregnancy since our last meeting?
  - Worry about risk
  - Reconsidering decision not to test
  - Emotional impact of being at increased risk
  - Sources of support
  
2. How have you experienced baby after the delivery?
  - How is baby? Normal or baby with Down syndrome
  - Interactions with baby
  - Interactions of partner and family with baby
  - Reactions of others
  - Emotional impact
  
3. Now that baby is born, describe how you feel about your decision not to have prenatal testing done?
  - Happy
  - Satisfied or unsatisfied
  - Regrets
  
4. Do you have any recommendations on how to improve the decision-making process for other women/couples in a similar situation?

**Topic Guide 4: Final interview with participants who requested TOP**

1. Please share your experience regarding stopping the pregnancy?
  - Procedure of TOP
  - Waiting period in hospital
  - Emotional impact
  - Reactions of partner and family
  - Impact on daily life
  
2. Explain how you felt after baby was delivered?
  - Viewing of baby
  - Partner/family viewing baby
  - Emotional impact
  - Still satisfied with decision
  - Regrets
  
3. Describe how your decision has impacted your daily life and relationships?
  - Work
  - Partner
  - Family
  - Friends
  - Community
  - Emotional impact
  
4. Describe how you cope with the decision you made to stop the pregnancy?
  - Ceremonies of closure - burials, photos, memory box
  - Sources of support
  
5. Please share what your future plans are regarding pregnancies after this experience?
  
6. Do you have any recommendations on how to improve the decision-making process for other women/couples in a similar situation?

**Topic Guide 5: Final interview with participants who declined TOP**

1. Explain what your experiences have been since you were told that your baby has Down syndrome?
  - Remainder of pregnancy
  - Reactions of family and friends to news of diagnosis
  - Reactions of family and friends towards decision to keep baby
  - Emotional impact - grief process
  - Feelings about decision - regret, content, happy, fear
  
2. Describe what your experiences have been since your baby has been born?
  - Seeing baby for first time
  - Partners reaction towards baby
  - Health implications
  - Coping with baby
  - Reactions of family and friends towards baby
  
3. Now that baby is born, describe how you feel about your decision to keep baby?
  - Positive or negative
  - Satisfied or unsatisfied
  - Regrets
  
4. Do you have any recommendations on how to improve the decision-making process for other women/couples in a similar situation?

## APPENDIX B: COPY OF CONSENT FORMS FOR PARTICIPATION IN RESEARCH STUDY

*Afrikaans Version:*

### **DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM**

**Titel van navorsingnavorsingsprojek:** “Om besluitneming oor voorgeboortetoetsing vir Down sindroom en terminasie van swangerskap te verstaan.”

**Hoofnavorsers:** Me Chantelle Scott

**Kontaknommers:** 021 938 9788/ 084 501 3576

**Navorsingsprojekleiers:** Dr Donald Skinner en Dr Michael Urban

U word uigenooi om deel te neem aan die navorsingsprojek “om besluitneming oor voorgeboortetoetsing vir Down sindroom en terminasie van swangerskap te verstaan.” Ek, Me Chantelle Scott, gaan hierdie navorsingsprojek uitvoer. Ek is ‘n Genetiese Raadgewer en PhD student van die Departement Molekulêre Biologie en Menslike Genetika by die Universiteit van Stellenbosch.

Hierdie navorsingsprojek is deur die Gesondheidsnavorsingsetiekkomitee (GNEK) van die Universiteit van Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Vat asb u tyd om deur hierdie dokument te lees, wat vir u sal verduidelik waaroor die navorsingsprojek gaan en wat van u verwag sal word indien u sou besluit om deel te neem. Voel vry om enige vrae te vrae oor enige dele van die navorsingsprojek wat u nie verstaan nie. Hou asb ook in gedagte dat u op geen manier forseer word om deel te wees van die navorsingsprojek nie. Dit is heeltemal u besluit en

u besluit sal aanvaar en gerespekteer word. U besluit sal geen invloed hê op die sorg wat u sal ontvang by die hospitaal tydens u swangerskap nie.

#### Hoekom word hierdie navorsingsprojek gedoen?

Hierdie navorsingsprojek word gedoen om te probeer verstaan hoe vroue of paartjies wat die voorgeboortekliniek by Tygerberg hospitaal bywoon, dit ervaar om die besluit te maak of hulle voorgeboortetoetse wil ondergaan om te sien of die baba Down sindroom het of nie. Ek wil graag ook bepaal hoe vroue of paartjies dit ervaar om die besluit te maak of hulle die swangerskap wil stop indien die baba Down sindroom het. Ek sal graag inligting wil versamel oor die emosies waardeur vroue en paartjies gaan, die faktore wat 'n rol speel en belangrik is wanneer hulle hierdie besluite maak en hoe hierdie besluite hulle familie en gemeenskap beïnvloed. Hierdie inligting is belangrik sodat ons die vroue en paartjies kan ondersteun deur hulle te help om goeie besluite te maak waarmee hulle gemaklik voel. Dit is belangrik om goeie besluite te maak sodat dit nie later lei tot negatiewe gevoelens en emosies nie.

#### Hoe gaan hierdie navorsingsprojek gedoen word en wat gaan van my verwag word?

- Ek gaan onderhoude voer met 33 individue of paartjies wat die voorgeboortekliniek by Tygerberg hospitaal bywoon.
- As u besluit om deel te neem sal u gevra word om 'n paar onderhoude te doen. Hierdie onderhoude sal gedoen word nadat u besluit het of u 'n voorgeboortetoets wil ondergaan, nadat u u resultate ontvang het, nadat u besluit het of u die swangerskap wil stop as die baba Down sindroom het en laastens twee maande nadat die baba gebore is of twee maande nadat u die swangerskap gestop het. Dit sal van u verwag word om deel te neem aan minstens 2 onderhoude en 'n maksimum van 3. Ek sal die onderhoude met u voer en elke onderhoud sal tussen 1 en 2 ure van u tyd vat. U kan besluit waar u die gemaklikste voel om die onderhoud te doen, by die hospitaal of huis, of u kan 'n plek voorstel indien nie een van hierdie vir u sal pas nie.
- Tydens die onderhoude sal u gevra word om u stories te deel van hoe u die swangerskap ervaar en hoe dit gevoel het toe u uitgevind het u het 'n verhoogde kans vir 'n baba met Down sindroom. Ek gaan ook vir u vra oor hoe u u besluit gemaak het om voorgeboortetoetse te ondergaan of nie. As u die toets gehad het gaan ek vir u vra om u ervaring te deel toe u die toetsresultate ontvang het. As u baba Down sindroom het, gaan ek vir u vra hoe u u besluit gemaak het om die swangerskap te stop of om die baba te behou. Ek wil ook weet hoe u na die tyd by die huis aangepas het met u

besluit en hoe hierdie besluite u laat voel het en die impak wat dit op u daaglikse lewe, familie en vriende gehad het.

- Met u toestemming, sal ek die onderhoude digitaal wil opneem. Dit sal dit makliker maak om te onthou wat tydens die onderhoude gesê is, want elke stukkie inligting is baie belangrik.

#### Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?

Daar is geen ernstige risiko's indien u sal besluit om deel te neem nie. Die enigste bekommernis is, dat u dalk slegte gevoelens soos hartseer en angstigheid mag ervaar wanneer u uitgevra word oor u ervarings. Indien nodig, sal 'n geleentheid vir u geskep word om 'n genetiese raadgewer, maatskaplikewerker of sielkundige te gaan sien. Die tyd wat dit vir u vat om deel te neem aan die navorsingsprojek kan gesien word as ongerieflik so hou in gedagte dat u sal moet bereid wees om tyd te maak op meer as een dag as u wil deelneem.

#### Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?

Daar is geen direkte voordele vir u indien u sou deelneem nie, maar met u help, hoop ons om ander vroue en paartjies, wat deur dieselfde proses van besluitneming oor voorgeboortetoetse en stop van die swangerskap vir Down sindroom gaan, te help. Ons wil hierdie vroue en paartjies help sodat hulle nie later spyt is oor hulle besluit nie en dan 'n klomp negatiewe gevoelens ervaar nie.

#### Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?

U gaan nie enige betaling ontvang vir u deelname nie, maar u sal wel vergoed word as u deelname lei toe enige onkoste soos vervoerkoste om by die hospitaal of plek van die onderhoud uit te kom.

#### Hoe gaan my persoonlike inligting beskerm word?

- Die inligting wat u met my deel tydens u onderhoud sal vertroulik gehou word.
- Die opnames van die onderhoude sal vernietig word nadat die navorsingsprojek voltooi is en ek al die inligting opskryf het. Die opnames en sal gesluit word in my kantoor by die Universiteit van

Stellenbosch se mediese skool. Dit sal ook gestoor word op 'n sleutelwoordbeskernde rekenaar totdat ek die navorsingsprojek voltooi en opskryf het.

- U naam sal verwyder word van alle dokumente om die inligting vertroulik te maak en seker te maak dat niemand weet wie die persoon was wat die inligting gedeel het nie.
- Die inligting sal voorgedra word by vergaderings en gepubliseer word sodat die inligting nuttig kan wees vir ander, maar geen name of ander persoonlike inligting sal genoem word nie.

Mag ek besluit om nie meer deel te wees van die navorsingsprojek nie en wat is my regte as 'n deelnemer?

U hoef nie deel te neem aan die navorsingsprojek as u nie wil nie. Indien u besluit om deel te neem, mag u later u besluit verander. U mag enige tyd onttrek uit hierdie navorsingsprojek. U besluit sal gerespekteer word en u sal geensins gepenaliseer word nie. Indien ek voel dat dit beter is vir u om nie meer deel te wees van die navorsingsprojek nie, sal ek u vriendelik versoek om die navorsingsprojek te verlaat.

Vir wie kan ek kontak indien ek enige vrae het oor die navorsingsprojek?

Ek sal met graagte enige vrae wat u het rondom hierdie navorsingsprojek beantwoord. Indien u enige verdere vrae het oor hierdie navorsingsprojek, kan u vir my, Me Chantelle Scott, kontak by 021 938 9788 of 084 501 3576. Indien u enige vrae het oor u regte as deelnemer aan die navorsingsprojek, kan u die Gesondheidsnavorsingsetiëkomitee van die Universiteit van Stellenbosch kontak by 021 938 9207.

## Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, \_\_\_\_\_, om deel te neem aan 'n navorsingsprojek getiteld "*Understanding decision-making regarding prenatal testing for Down syndrome and termination of pregnancy: An Interpretive Phenomenological study*".

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek vrywillig is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorsingsprojekdokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.
- Ek vir die navorser toestemming gee om die onderhoude digitaal op band te neem

Geteken te (*plek*) \_\_\_\_\_ op (*datum*) \_\_\_\_\_.

\_\_\_\_\_  
Handtekening/ Vingerafdruk van Deelnemer

\_\_\_\_\_  
Handtekening van Getuie

## Verklaring deur navorsers

Ek (*naam*) \_\_\_\_\_ verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan \_\_\_\_\_, in 'n taal waarmee hy/sy gemaklik is.
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te (*plek*) \_\_\_\_\_ op (*datum*) \_\_\_\_\_.

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Handtekening van Navorsers

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Handtekening van Getuie

*English Version:*

## **INFORMATION SHEET AND CONSENT FORM FOR PARTICIPATION IN A RESEARCH STUDY**

**Title of Research Study:** Understanding decision-making regarding prenatal testing for Down syndrome and termination of pregnancy: An Interpretive Phenomenological study

**Principal Investigator:** Ms Chantelle Scott

**Contact Numbers:** 021 938 9788/ 084 501 3576

**Supervisors:** Dr Donald Skinner and Dr Michael Urban

You are invited to participate in the study "*Understanding decision-making regarding prenatal testing for Down syndrome and termination of pregnancy: An Interpretive Phenomenological study.*" The study is being carried out by me, Ms Chantelle Scott. I am a Genetic Counsellor and PhD student of the Division of Molecular Biology and Human Genetics at Stellenbosch University.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

Please take some time to read the information explaining the details of this study as well as what will be expected of you if you agree to participate. Please feel free to ask any questions about any part of this study that you do not understand. Please also keep in mind that you are in no way being forced to participate. It is completely your decision and whatever you decide will be respected. Your decision will not have any influence on the care you will be receiving at the hospital during your pregnancy.

### Why is this study being done?

This study is being done to try and understand how women or couples who attend the prenatal clinic at Tygerberg Hospital experience having to decide whether they would like to have prenatal diagnostic testing for Down syndrome. I am also trying to see how women or couples experience having to decide whether they would want to stop the pregnancy if the baby has Down syndrome. I would like to gather information on the emotions the women and couples go through, the things that are important for them when making these decisions as well as how it influences their families and their experience when they go back home. This information is important so that we can support women and couples to help them make good decisions that they feel comfortable and satisfied with. It is important to make good decisions so that it does not lead to negative feelings and emotions.

### How will the study be done and what will I be asked to do?

- I will be interviewing 33 individuals who attend the prenatal clinic at Tygerberg Hospital.
- If you agree to participate, you will be asked to do a few face-to-face interviews. These interviews will be done after you have decided whether you want prenatal testing, after you have received your test results, after you have decided if you want to stop the pregnancy if the baby has Down syndrome and lastly two months after your baby is born or you two months after you have stopped the pregnancy. You will be expected to participate in a maximum of 3 and minimum of 2 interviews. I will be interviewing you and each interview will up between 1 and 2 hours of your time. You can decide whether you feel more comfortable to do the interview at the hospital or at home, or you can suggest a place if neither of these suit you.
- During the interviews you will be asked to tell your stories on how you are experiencing your pregnancy as well as being told that you have a chance of having a baby with Down syndrome. I will also ask you to describe how you made your decision to have prenatal testing or to not. If you had prenatal testing I will ask you to share your experience of receiving the test results. If your baby has Down syndrome I will ask you to tell me about how you made your decision to stop the pregnancy or keep the baby. I would also like to know how you coped having to make these difficult decisions and how your decisions made you feel and how they have impacted on your daily life, family and friends.
- With your permission I would like to record the interviews. This will make it easier for me to remember what was said during the interview as every bit of information is very important.

### What are the risks or inconveniences for me if I participate in the study?

There are no major risks or inconveniences if you decide to participate in the study. The only concern is that you might experience negative feelings, like sadness, anxiety and anger, when you are asked to share your experiences. As sensitive topics will be discussed which might lead to a bad emotional reaction, there will be an opportunity for you to go see a Genetic counsellor, social worker or psychologist. The time it will take for you to participate in this study might also be seen as an inconvenience so please keep in mind that you will have to be willing to make time on more than one day to be able to participate.

### What are the benefits for me if I participate in the study?

There are no direct benefits to you for participating in this study, but with your help, we hope to be able to help other women and couples who are going through the same process of making decisions of whether they want prenatal testing and whether they want to stop the pregnancy if the baby has Down syndrome. We want to help these women and couples so that they don't regret their decisions later and then experience a lot of negative feelings.

### Will I be paid to participate?

You will not receive any money for participating; however you will receive money if you had to pay for transport to the hospital or to get to the place where you are going to be interviewed.

### How will my personal information be protected?

- The information you share with me during the interviews will be kept confidential.
- The recordings of the interviews will be destroyed after the study has been completed and I have written up all the findings. The recordings will be locked away in my office at Stellenbosch University's Medical School and stored on a password protected computer until I have completed the study and successfully published the findings.
- Your name will be removed from all the documents to make the information anonymous and to make sure no one knows who the person is who gave me the information.
- The information will be presented at meetings and published so that the information can be useful to others, but no names or other personal information will be presented.

May I stop being in the study and what are my rights as a participant?

You do not have to be in this study if you do not want to. If you agree to participate in this study, but later change your mind, you are allowed to withdraw at any time. Your decision will be respected and you will not be penalised for withdrawing. If I feel that it is better for you to not participate anymore, I will kindly ask you to leave the study.

Who do I contact if I have any questions about the study?

I will be happy to answer any questions you have about this study. If you have any further questions about this study, you may contact me, Ms Chantelle Scott, at 021 938 9788 or 084 501 3576. If you have any questions concerning your rights as a participant in this study, you may contact the Stellenbosch University Health Research Ethics Committee at 021 938 9207.

**Declaration by participant**

By signing below, I, \_\_\_\_\_ (*full name of participant*) agree to take part in a research study entitled *Understanding decision-making regarding prenatal testing for Down syndrome and termination of pregnancy: An Interpretive Phenomenological study*.

I declare that:

- I have read or had read to me this information and consent form and it was explained to me in a language with which I understand.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I understand that I may choose to leave the study at any time and will not be penalised.
- I understand that I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests.
- I understand that all personal identifiers, like my name, will be removed from the study documents and I give the researcher permission to publish the findings of this study.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_.

\_\_\_\_\_

**Signature/ Thumb print of Participant**

\_\_\_\_\_

**Signature of Witness**

By signing below, I, \_\_\_\_\_ (*full name of participant*) give the researcher permission to audio-record the interviews.

Signed at (*place*) \_\_\_\_\_ on (*date*) \_\_\_\_\_.

\_\_\_\_\_

**Signature/Thumb print of Participant**

\_\_\_\_\_

**Signature of Witness**

**Declaration by the Investigator**

I \_\_\_\_\_, declare that I have explained the

*(Print researcher name)*

information given in this document to \_\_\_\_\_.

*(Print participant name)*

He/She was encouraged and given ample time to ask me questions. Conversation was

conducted in Afrikaans/English/Xhosa/Other language \_\_\_\_\_

*(Print language)*

and no translator was used.

Signed at \_\_\_\_\_ on \_\_\_\_\_

*(Place)*

*(Date)*

\_\_\_\_\_  
**Signature of Investigator**

\_\_\_\_\_  
**Signature of Witness**

## APPENDIX C: EXTRACT FROM TWO INTERVIEW TRANSCRIPTS

### **TRANSCRIPT: INTERVIEW 1: PARTICIPANT 5: AMA WOMAN: REQUESTED PND**

The participant was a 40 year old Xhosa lady. She had a 1 in 41 chance of having a baby with Down syndrome due to an absent nasal bone and advanced maternal age. She was counselled by a Medical Geneticist regarding her risk and prenatal testing on 31 December 2013. She was offered a CVS at this stage and accepted as she would definitely terminate a child with Down syndrome. On 2 January 2014 she returned for the procedure. The test failed and the participant had to return for an amniocentesis on Tuesday, 28 January 2014. While she was waiting to have testing done, I explained the aims and objectives of my study to her and invited her to participate. She was very happy to help and the interview was done after she signed the consent form.

The interview was done in a large counselling room at the Ultrasound unit at Tygerberg Hospital on Tuesday, 28 January 2014. The interview lasted for 54 minutes and 35 seconds and was done in English. The participant was outspoken and expressive which didn't leave much work for me. I built good rapport with her.

It was an easy interview to do and I think it went very well. At times I wanted to interrupt due to my nature of wanting to counsel and reassure. I did do it for the first few minutes, but then controlled myself and stopped interrupting. I just let the participant speak. We were however interrupted by one of the doctors as she was looking for a room. This was a brief interruption and did not really affect the interview too much.

I was a bit stressed in doing the interview at first, but very quickly relaxed as the participant spoke freely. I struggled to pick up on all the queues as she was giving me a lot of information at once.

Interviewer (I)

Participant 5 (P5)

I: Okay. So as I have said, just a normal conversation, okay. Uhm so the first question I just want to ask. Yes, because I didn't do the previous counselling so I haven't spoken to you about the pregnancy and how it has been so far. So if you can just tell me a little bit about your experience of being pregnant.

P5: Uhm to be pregnant, first thing, children is a gift from God so everyone must be happy to hear the news but there is a complication in the pregnancy. Depends how, how is it. Depends you do drugs or you drink alcohol or you are stressful. So all those things they affect the baby. But me I was happy to be pregnant, because my first child was, I was 31 to have the first children. And the second born I was 38, 37. So I thought myself I'm finish, I'm not going to have another baby. I couldn't with difficulties to raise the children. Especially when you are not working. It's only one person working. So, uhm.

I: So when you heard about this one were you happy, because you thought...

P5: After in October, November, September my father did have a stroke and I was not right. I was not right since then and everything changed at my house and my husband. I was a funny person who wants to stay alone, who don't want to go anywhere. You see. Even one day my husband come from work and say: "[participant name] are you okay?" And I say: "No, I don't know." And I start to cry. "I don't know what's wrong with me." Then he said: "Maybe it's your father?" Then I say: "No, I don't think it's that, because I saw my father and I feel better, but there is something inside but I don't know what it is. Something on my heart." I feel like crying. I feel like I don't want to see anyone, I wish to be alone here at home. Even I was harsh to my little kids even when they call me I am "what?" Even I don't want to hear a noise you see and then he asked me don't you think you are pregnant? I say no. This is my last thing on my mind. He say okay. And then I thought hey I don't like what I am like. I'm a playful person who likes to laugh, but now I'm always indoors, I don't want to talk to others. You see even if someone came to my house and knock I just keep quiet and then if my baby go to school and the other one to crèche. They going to come back from school then I am still on the bed. I didn't do nothing in the house. And then at last no man there is something wrong. I must go to... Oh my husband phoned you must go to the clinic ne. And I say no. And on the Month end he says [participant name] you must go. I say no I don't feel like, but till on the 27th I told myself no I must wake up the 27th December. When I go to the clinic. I did feel sick before I told myself I got Gal, you know Gal? I took freshner tablets. And then I tried to get out of there, but even I did that, there is something that I feel to vomit. But nothing came out. Eh, I wonder what is going on. I never thought that I'd, there is something inside. I go to the clinic and then when I go there. It is my turn to the doctor. Doctor "what is the problem?" I say I don't know what my problem is. I am here to get help so that you can examine me and see what is wrong. He say: "You are here to get test? Pregnancy test or?" I say you can give me all the tests you want. Then he say okay you must go to the loo to check that you are pregnant. When I go there the assistants they check my urine and I keep on speaking to the assistants. Eh I'm stressed because what if I'm pregnant? At a 40 year old. Ha huh uh I don't think I can. And the answer is they laugh and they look at me. Yoh at a 40 year you are! And then I was shocked. No, you are joking. They said come see. When I had a look Yuh. (Big sigh and few seconds of silence)

I: And how did that feel?

P5: (Carries on with story) Positive. Heh? They say yes. I go to the Doctor, the Doctor, here is your results. So you are pregnant. I say ja, they said so, they said so, I am. So I don't know. They say I must go to the booking room. When I go there, they say I must go, I am late for the bookings. I must go do the HIV test so long. And then I must come back on the 30th of December. So I go to do HIV and everything was fine. They ask me, pap smear, I did my pap smear on 2010 and it was fine. My blood test it was, everything was fine you see. And then. On the, when I come back home I broke the news because my husband was curious. What did they say. Yuh I am pregnant. He say Yuh. And I am 13 weeks which is almost three weeks, three months. He say Yuh [participant name]. He just say yuh [participant name]. And after I get that news, yoh, I wasn't feeling well. Because when I look at my children, they are still young. I'm not working, it's their father who is working. (Sigh). So what am I going to, okay I am pregnant, it's fine, nothing I can do. But I'm not okay you see. I stay Saturday, Sunday, Monday I go early. I wake up early and I was the first one on the pregnancy ja. Then I go to the nurse or sister, Haibo mama how far are you? When is your

last period. I say I don't know because I was like I go this month and this month I don't so I'm not sure when. I can say August. When he checks he says no it's not August, because suppose the baby is moving now. So then they put me on the scan on the heartbeat, they hear the heartbeat. Yes there is a beat but how far? You don't know? I don't know either the sister said. And then he ask the the the other doctor with the scan and then I go to the scan. The scan show that I am 13 weeks. And then he will show me here's your baby. Here's the head, hand, legs. Here's the heart. And then I was happy. There is a living thing inside of me. And then the sister says I must book here (Tygerberg), because you are not for us. But because of your age you must go to Tygerberg. They write everything they took the blood, those bottles of blood. They phone, they make an appointment for me on the 31st. And they say no they say you must go there tomorrow on the 31st. I say no problem. And they say to me the others I make them appointment but they don't go. When someone got a problem, now they came to us. So you are not going to allow that and when I go home I tell everything to my husband and I was then I told them no I'm not going to Tygerberg, I saw mos there is a baby so why I'm going there. You see. And at night I thought no I must go there, what if, you see. And I came here. When I came here the Doctors they ask me you know why you are here. I say yes it's because of my age they said so. Nothing did they tell me. They say okay. They put me on the scan. Long time. They write, they look, they write. But I was concerned, because I look in your eye and I see there's something wrong. No matter what it is, but there is something not right. Okay then but they keep on coming and going. Looking and scanning. Coming, looking and scanning. And then she just left me there. And I was look on the other side now. Don't look at it, yes, there is something. And my heart start beating faster, because I wonder what is it. You see. Is it one leg, one arm, but he's okay even if, but what is it? And then after 2 minutes they came with the other lady, they looking, oh, and I hear her when she says I am not convinced at all. Oh, what is it? They just put that thing and say no. Wake up sisi and wipe your stomach. I wipe my stomach. They didn't tell me yet what is it, I still rub. And then I just sat there. And then she said to me. Your baby is fine, but we are not 100% sure. I say why, what is the problem? And then she said, we don't see the nasal bone. What is a nasal bone? I've got a book mos at the house. Pregnancy questions and answers, so I read all about Down syndrome if the baby can be Down syndrome or normal you see. Nasal bone, on my mind came, nasal bone, yoh, it might be huh-uh. They say no we are going to put you on the other scan so that we can be sure. I say okay fine. I go outside. They call me again, they put me say no sisi we don't see nasal bone is absent so there is a risk, a high risk of Down syndrome but you must make sure, because everything is there, only that. Yoh it was the worst day of my life.

I: So, that was this year?

P5: This year on the 31st.

I: Oh, was it on the 31st of December? Was that when you heard about the nose?

P5: Yes. I go outside and I was starting crying and my eyes was full of tears. Yoh. The other lady told me she's 43 and my baby they got the hole in the heart and the others they told me my baby is not going to grow. It's going to be like that person that's short but he's hold. They told me my baby has got two hearts. Yoh, can you just stop ladies, because mine they don't have this bone, so how does it look like. So I was, it was not me. Then they say you can wait here, we are going to organise a uh..

I: A counsellor?

P5: A counsellor. I say okay. And then the counsellor came, [Counsellor name]. [Participant name] you know why you are here? I say yes I know why I am here. Tell me how you feel? I told her, she saw me mos. I can see how you feel, but don't worry and the tears start to run down, because I don't think there is nothing can change mos, you see? And then they told me, we figured out that your baby doesn't have a nasal bone. You know what does that mean? I say yes I know, because I read a lot of books with the Down syndrome baby because that book I wrote, I read, it said, uhm, most normal babies within 11 weeks you can see the, the nasal bone, you see, because on that 11 weeks the baby develop everything, but most Down syndrome, most abnormal babies you can't see the nasal bone. So it depends to the mother if you want to go through a test like the CVS and the amnio-something if the mother want to make sure if the baby is Down syndrome or not you see. And then I told Mrs Hanekom ja I know how. You are like, you like to think, like you are a wise women you see.

I: Well read-up

P5: Ja, so I ask her so what else then. They told me you are going to have a test, but you must go to your partner first. And I say what I say my partner is going to say it's fine. I know that. So nothing that I want to discuss, because I want to make sure that my baby is fine you see. And then they give me options if we can find out that your baby is Down syndrome, that there is an extra chromosome or something. And I told them I'm a person, I'm a sensitive person and I know what a Down syndrome look like so financially I can't afford to be in and out of hospital. I still have a children and I don't have that much family support. It is me and my husband, my father is that one that I have to look after you see and I didn't go to my mother so no one like I can rely on if I can have a baby like this. Someone that can stay with me so they can look after my children. My mother-in-law passed away and she was the only person who was going to do that. No one else who can do that. They say hey [participant name] there is options, if you find out that the baby has the Down syndrome you can continue with the pregnancy or you can just terminate, it is illegal, it is legal to do that but it depends on you. And I told them, but if you want to just terminate, because you gave me the result mos that there is no nasal bone and to my knowledge, if the baby, if the baby has no nasal bone, there is a chance that you got a Down syndrome so what, why must I wait now? Because now you put me in a lot of pressure and I can't cope. You see. And then she say, ja, I understand, but you can't just terminate. You must choose the test you must do. So I say okay, I can do the test. And then he, she ask me, why, if I can ask, why you want just to terminate and I told her. First thing I didn't plan this pregnancy and I told myself that I am not going to have another baby. So it just happens, surprise to me. So you see. She say no you must, you must take a chance too. I say okay. I do the test on the second of, actually I did want to do a test on that day, the 31<sup>st</sup>, but then she go to the Doctor, the Doctor say no it's the 31<sup>st</sup> today and we are going to close early so she must come back on the second. And then I came on the second, they do the test. Oh first, on the 31<sup>st</sup> I go to broke the news at home. When I get home, yoh, it was just, I just enter the door and I cry and cry and cry and cry for about 4 or 5 minutes. And my husband ask, whats wrong, Thandi? What is it Thandi? I am not going to know if you don't talk. What is wrong? And even my two year old, mamma mamma what is wrong? I say no, I've got headache. He just hug me. Mamma, mamma, mamma don't be sad. Where am I going to start you see. And then I told my husband, yoh, they put me on the scan and they saw

the baby, but they say the baby is fine, but they don't, she or he, they don't have a nasal bone. What is that? I used to read for him that book, he says oh you like to read. Can you wait for this reading of yours. Do you remember the book one day I read for you? He say ja, ja. What do you remember? And then he told me that the healthy baby he got this thing but the abnormal one don't. So I say eh your baby, your baby it don't have this thing. He say what. I say yes he don't have a nasal bone. So I don't have a picture what it looks like you see. Serious, because the children are don't have it is not good at all. But it not stay there where I stay. I saw, I saw him at the mall, it's not good. Even his mother is not like he's, I don't know like normal, he's not free to go, even the children is not free to go in public.

I: Is that now the children that have a problem?

P5: Yeah, because they don't have this thing and the eyes are like you see. He was not confident enough, you see because all the persons look to him like you see so it is not nice. That thing it is not nice, it is serious. And then he started to cry. He say what are you going to do. I say I don't know, but they gave me option that I must do a test, if the test can tell me that there is a Down syndrome, I have to terminate. He say, why don't you just terminate. Why don't you just terminate. And I say I told them that why can't I just and then they gave me that option, no you must do test first, because the baby is fine. It is only this thing maybe it is just a minor thing not a... so I want to do, I want to run that test and then do it. And then I came on the 2<sup>nd</sup> to do the test so I wait. I count mos that I am going to get an answer on the 23<sup>rd</sup>, because it was three weeks, but I got shocked when I got private number. Hello, are you [participant name]. I say yes. Did you come to Tygerberg. Yoh. I say yes, what's wrong? They say [participant name], I'm sorry mam but the test result that we did on the 2<sup>nd</sup> it did not grow enough as we want to. I say so what does that mean? It means there is something wrong? No no no we don't know yet. But what we can do is you can just come and do another test. And I ask what if the test fail again? What is going to happen and the time is going and the baby's growing. And I don't want to feel the baby inside me. Why, maybe the answer is going to be like there is Downs, he or she is Down syndrome so I don't want it to hear this baby. So I say please can we do something. She says no [participant name] you must come on the 28<sup>th</sup> to do the test again. So make sure this test, the second test, is going to give us what we want. And then we can give you the answer and then after all we can do what we are supposed to do. So it was, it is not me, serious. The whole time since 31<sup>st</sup> January and I decide to go to church, because I was sitting at home doing nothing and ja I tell my friend. Hey my friend there is this thing and it is bothering me. So if maybe I can tell someone maybe. And then she say no [participant name] man nothing like that, you see, nothing like that. I say how can you say nothing like that but the doctor said you see? And then she said, no [participant name] man, can you come with me. You know the church they are called universal. Ja I did go there on Friday last week, the 24<sup>th</sup>. And then I pray there. I go to the pastor first for counselling. They say he's a counsellor and I told the problem why I'm here. And then they, he ask me do you know, do you believe? I said yes I did believe in Jesus and what I want is I want God to turn stone into bread. So this thing they say they can't see maybe they just can't you see. They can be there like miracle or they can just make something I don't know you see. So they say if you pray and believe, God can make things possible. And then we prayed, we sing, and prayed and I was crying, I was crying so I was crying. And then we go home and when I go home I feel like ja something is just (big sigh) you see. (means lifted off shoulders). But what is next. On the 28<sup>th</sup> I have to go and do the test so I have to wait for the results again. I go to the on a Sunday service to the same

church and then we praise, we preach, we praise, we preach and then when I pray I wish God You can do the miracle inside me I don't what You can do, but You can do something, because I've got life inside of me and there is a possible thing that they can be Down syndrome because they don't have that bone. So even if You can just build the bone, I don't know how, but if You can just build the bone inside that baby. I can be very happy. You see. So when I was praying like I ask God I feel something I see like something like He's scratching inside me. And I tell myself, maybe, maybe God build that thing that I just asked now so I don't know serious. Because I pray and I go to church every, because I make a chain and I pray for several days.

*Interrupted by doctor (30:00 – 30:19)*

So I make a chain of prayer for seven day. I ask what do You want me to do seriously. So I ask this thing so I ask from Friday. So I must pray for that seven Friday. So I am here today, I don't know.

I: Do you feel that going to church and praying made you feel better?

P5: Ja, I feel better since I go there.

I: And you said it was like a weight that lifted?

P5: Yes. Since I go there I feel like now I am a new person. I can go and smile and because I was all like I don't want to talk you see, but I got my times sometimes yoh. Like I am a bully in the house. I bully my husband. If I don't want to do something I don't want to. If I want something I want it by force you see.

I: As in now?

P5: As in right now. I am bully. And I don't want someone to ask me a question three times. Like even if I told you something that I wanted something and you didn't do I'll go, if you didn't do it I will just jump up and shout and then afterwards I go to bed and sleep. You see. I feel like sleeping the whole day like I don't feel like serious but now I am going to church and I feel at least I can stay with them now and talk. Laugh at least but it is just a small time I'm like that, a nice person. But most of the time and I wish to be away at home. And I come home just to go to bed and sleep. I don't want to sit with them and talk and they just. I don't know they make me, I don't know how. Especially my husband, I will pick up a fight quickly.

I: And how does he feel about all of this?

P5: You see he is not okay. Even he say you know if I was not working maybe the doctor, if I can talk to the doctor myself why you don't just you can't just terminate, because my wife is not my wife now the way I see you see. Because this thing it stress you big time and you can't hide I can see you are not [participant name] that I know. So it's not nice. I wish I can do this and over it that I can see. Even, my question is, okay the results came and tell me otherwise okay your baby is Down syndrome. I did say mos I am going to terminate yes if it is like that. What am I going to be like after?

I: After the?

P5: After the termination. What I'm going to be like. I don't know. It's my question I ask myself. How I am going to be like because I knew there was someone inside now you see I don't know. I don't know, serious.

I: From hearing you talking, do you think baby has Down syndrome?

P5: I don't think, but I want to, the doctors to be sure. Not like take the word on my mouth that no. I want them to do like a proper and tell me the truth. [Participant name] your baby is fine. [Participant name] your baby is not fine. You see. But every month I was they don't have the negative thoughts they always have the positive. The baby is fine. While you know deep deep deep inside you've got a, it might be. So I don't know.

I: So you feel you are more positive?

P5: I am more positive.

I: And your husband?

P5: My husband don't cope, I don't want to know.

I: Do you talk to each other now?

P5: Ja we talk. But there is time we can see we are serious.

I: And you said he is working the whole time, so that is why he doesn't come with you?

P5: Ja. He's working.

I: Uhm okay, just to ask a bit if I understood you correctly now, so the reason why you would want to have this test now, is because of the stress of not knowing. You want to know now for 100% if it is like that or not?

P5: Yes.

I: And if it is like that, you just think you don't have the finances to raise a baby with a problem and also you said you don't have support in raising a child with a problem?

P5: Yes. And the time that he or she is going to take. All that time. And what about the others?

I: The two other children?

P5: You see, they are still young. The girl is little, they are still growing. She is turning 10 and she still needs me. Even the small one still need me, so if I am going to have a children like that I don't know. It's going to be stressful you see.

I: And also because you said this wasn't a planned baby?

P5: Yes.

I: So you weren't even prepared to hear that you are pregnant in the first place?

P5: Serious, no you are joking. They said no come. When I go there ha, but when they do the test again they do a test mos on the 27<sup>th</sup> it was positive. When I go there on the 30<sup>th</sup> your urine everytime they must go, they call the others no is it me that don't see because I saw one line here. And I was starting to yes maybe it was a mistake that one, they say no I must come and wait for a couple of minutes. And then she call me which is oh it wasn't planned, even if it wasn't planned, if it was no problem I would accept you see.

I: So you say if baby has no problem, even though you didn't plan it, you would still accept it?

P5: Yes.

I: You would still want baby? If baby is normal and healthy and everything?

P5: Ja.

I: And your husband? Do you think he is also like that?

P5: (Laughs). Ja, my husband is so supportive but now, huh-uh. He say no [participant name] huh-uh. Because he know how I am. I don't know how to explain.

I: Is it just because how you are coping with it now, with the stress and being like a bully? Is it just that he doesn't like that?

P5: Ja, serious now, I am like a bully and I don't like to be like that.

I: Ja, obviously, because you said it is not like you.

P5: And I wish to go and stay far alone. No one can ask me nothing. I just want to be alone. I don't know to ask myself a question for who I don't have the answer to. Everyday I've got a question. How does this baby look like if he don't have this thing? How does it look like? And if I can give birth to a baby like that how am I going to look? What are my children going to react you see? They are going to feel mos alone, or they are going to feel like, I don't know how. You see. Because I didn't tell them there is something. I told them I am going to Tygerberg, then the daughter is asking why? No I've got an ear problem, you see?

I: Did the other doctors ask you why?

P5: No my daughter she ask why you go to the doctor mommy? I just lie no I've got an ear problem so I am going to. I don't want to tell her that there is a brother who you see?

I: Why don't you want to tell her?

P5: No, how? Because what if I told her, I told her that you are going to have a brother or sister. What if the results came otherwise? What am I going to tell her, you see? I don't want to break the news yet to them.

I: So that all depends on what this test says?

P5: So you see. Even at home my father didn't told yet. It's only me and my husband that knows that we are on this situation. So it is hard.

- I: I completely understand. Uhm I wanted to ask uhm because when you came here you obviously you said you had to hear that you were pregnant, and that wasn't planned. But you thought after they did the scan at the day hospital that everything was fine? And then you came here and we told you about the nasal bone. With us telling you that, did it change how you feel about baby? Did that change your feelings towards baby?
- P5: That I have a baby inside me. To tell you the truth. I don't you know mos when you are pregnant. You feel happy and you always. Mine, I always hide mine, because I don't want someone to see me that way. She is. You see. Because I am not proud or I am not happy because of this thing I hear you see. My stomach don't show if you can see. Because I always make sure that I don't wear tight things. But I make sure that I my stomach must always be like I am flat because I am not proud of serious.
- I: And that is because we said there might be a problem? So you don't want to tell people and then have to explain again.
- P5: You see when it's gone, why, what happened? You see so I am not, I don't know, I am not, I don't even feel nothing. Then you see to my baby boy I was always brushing within a three months or two months because I know there is someone here. Even I starve myself mos the whole day now. I don't want to eat. You see?
- I: So it has really had a big impact?
- P5: I don't want to eat. Serious. Because I can't swallow, because even if I eat I don't enjoy it. Why am I eating? I ask myself why am I eating? Why must I be healthy? Why I don't know how this baby look like why?
- I: Do you think if we had pictures to show you what children look like if they have an absent nasal bone, do you think that would help you a little bit?
- P5: (*Giggles*) I don't know, serious. Like if I can see them personally and then I see this one he got flat bone but is normal, I can be okay maybe if the result can come like this. Like now if the result can come and told me that [participant name], we don't see a Down syndrome baby. I will be glad. It's just a flat bone or it is just a flat something. I can be glad but please don't lie. You must tell me the straight answer you see.
- I: So if it is like that we must just tell you and not...
- P5: Ja, because that is what I told Doctor. Doctor don't hesitate to tell me. Just tell me straight. Because I like the straight talk. [Participant name] the baby is not fine. Just tell me and then I must see the next step you see.

**TRANSCRIPT: INTERVIEW 1: PARTICIPANT 23: AMA WOMAN: REQUESTED TOP**

The participant is a 43 year old Xhosa lady who initially attended the ultrasound clinic on 24 November 2014. During this visit she screened low risk for DS. Due to advanced maternal age she was still offered genetic counselling by a Genetic Counsellor and invasive prenatal testing. She declined testing at this stage.

She returned for her detailed scan on 20 January 2015. Ultrasound showed an echogenic focus and hypoplastic nasal bone. She now screened high risk and had a chance of 1 in 33. For DS. She was counselled by the same Genetic Counsellor and requested testing at this stage. She was informed of the test results on Tuesday, 27 January 2015. The test showed that the baby had DS (47,XX,+21). She was counselled with her sister present and decided to have a TOP. She was given mifepristone and was sent home. She was admitted to hospital for a TOP on Thursday, 29 January 2015.

She first returned to the ultrasound unit to wait for a bed to open up in the ward. I spoke to her about my study while she waited and she consented to participate. I gave her a diary and started the interview in the larger counselling room at the ultrasound unit, Tygerberg Hospital. She was then called to go to the ward and I stopped the interview and accompanied her to her private ward room in J4. Once she was settled we continued the interview. The interview was conducted in English and in total it lasted 59 minutes and 55 seconds.

The participant is intelligent and works as a lab technician so has good insight about the tests. She was honest and expressive. She was tearful during some parts of the interview, but her grief seemed appropriate.

It was a very good interview and I found it easy to speak to this participant. I felt empathetic towards her as she really has been through a lot. She also spent the whole morning waiting for a bed and was only admitted at 3pm. I was more upset about this than she was and told my colleagues that this was unacceptable. I had to calm down before doing the interview as I did not want my feelings to interfere.

Interviewer (I)

Participant 23 (P23)

I: So just to ask, you were seen by [Genetic counsellor name] for both times? The November one and I think you came back recently for another scan?

P23: Yes on the 20<sup>th</sup> of January I came back.

I: Okay, and what did they say?

P23: They on the 20<sup>th</sup> of January scan, it was to know the sex of the baby, and to see if there is any abnormalities which they found like a spot in the heart of the child and they noted that the nasal, the nasal cavity, I don't know if it's nasal, but the nasal defect indicates some thing about Down syndrome, but [Genetic counsellor name] said to me it might be because the child

takes after me, because I also have a flat nose. *Laughs*. And then that was a little hope for me you know and I was excited because it was a baby girl and and then that was when she persuaded me to do the test, like the amnio, the amnio...?

I: Amniocentesis.

P23: The amniocentesis ja so I thought I was concerned so I must do it. So I did it on the 20<sup>th</sup> of January and then she phoned me on Tuesday? Yes on Tuesday she phoned me to say the results are back. I was at work and I asked how was it and then she said no it is not good, I need to come immediately so my boss drove me hear. And then I met [Genetic counsellor name] and then she told me it tested. It's a, you know, it's a Down syndrome thing, child. And then they asked me what do I want to do, in fact they even asked me prior to this, what if, what would I do, so I told them no I won't keep the child, because its, I know it needs your attention, the child, you know, fully dependant on you know depending on the abnormalities of the child. But most of the time the child needs the mother or someone to depend on which I don't have time for that. Because you know what my son is at the university, I'm a single parent you see, I need to support him, I need to be working, I can't be out of work, because I need to look at the child. And I think at the same time if you know I don't think you, I don't want to say it's wrong to keep the child, but if you know in time, I think for the child also it is not the right thing, because what would you be keeping the child for. You know, when you know exactly what the child is going to be like, you know, the child might be retarded maybe you know, and doesn't actually progress like other children you know and it is a trauma to you, and you have to be at the hospital. There is no time for you, you always need to be there so that is why I came to this decision. It was not an easy decision. It really wasn't easy, because I was looking forward to a baby girl and you know I couldn't even sleep when I heard the news. I couldn't sleep you know. My sister had to be with me. Because it was not good, I feel so bad about this, because you know because I can feel the child is still kicking you know in my stomach and I must do this. Yoh. But because of, I mean we must, it's reality, I can't keep the child, because the child needs my attention and I don't have time for it you know so and I can't, it's you know. My mom is old, she is 62 years old and she's already looking after my sister's child who is 10 years old also needs attention so I can't you know ask her to do this for me. You know so that is why I came to the decision...

I: To stop?

P23: To stop the progress of the pregnancy.

I: Just to ask, you were saying that you are a single parent, is the father of the baby at all involved still?

P23: The father was supposed to be here for the scan, but he is at the Eastern Cape now, and he was supposed to be here on the 20<sup>th</sup> for the scan and then he didn't pitch. He didn't give no reason and he didn't phone. Only, he phone's only today after hearing from the daughter because I am chatting with his daughter who is 20 years old who after hearing what I went through went to the father and explained to him and then now he wants to come over, he wants to stop what we are doing, because he is coming tomorrow. So I said to him it is too late to care now, because he was supposed to be here when I made the decision to do this

and I had already taken the pill and for that matter he had already shown me that he you know, that he actually doesn't care, so this is entirely my decision. It is going to be my baby so I actually don't think that he cares.

I: And do you feel because he didn't show up he is not going to be around when baby is born?

P23: I think so. I think so and beside that you know there are other things that I've picked up from him you know that I don't think he is responsible, that he is going to be a responsible father because the daughter was with me from September to December and he wasn't taking care of her. I had to sit with a child that doesn't go to the saloon, you know she goes to the saloon, she is a young lady, she is beautiful, she needs to look nice you know. But to get money from him, that is a struggle, besides that my child, my child has been accepted to study at Walter Sisulu University and I didn't have enough money you know, because the registration was 5.2 which I am running less, I was running less than that amount and I asked him to make a loan to me, I even explained how I am going to pay it because I know he just got a lump sum from his workplace so I know that he does have it, he just told me no, I used it I don't have money, just like that. So picking up from these things that he does I don't think he will care actually about this baby.

I: And do you feel that he cares about you still?

P23: I don't think he does. I don't think he does because the last time we spoke was when I asked him for this money and then he sent me this one sentence to say bad news I don't have money. You know just like that. He didn't phone me. He didn't explain this is what I did with the money, this is why I don't have money, you know? Because he doesn't care.

I: And have you been together for a long time?

P23: No, maybe that is why I'm giving him credit because I am still learning what kind of a person he is because we just met in July last year.

I: Okay.

P23: So it is not very long, it is not very long but joh.

I: And the baby, was it a planned baby?

P23: This wasn't a planned baby, it just happened, I was just excited that it happened. It was not planned.

I: And was he at all excited about the baby?

P23: Yes, he was excited and he wanted it to be a boy.

I: Okay so he wanted a boy and you wanted it to be a girl?

P23: Yeah, he wanted a boy. He was calling me uhm boy's mother, he was calling me, because he wanted the child to be a boy so much, in fact he didn't even know the child was, he didn't ask after the scan what's the gender of the baby. He didn't ask you know, he only asked now after the daughter told him what was happening. So he doesn't actually care.

- I: And he lives in the Eastern Cape?
- P23: He is planning to relocate back to the Eastern Cape, because he's got a business there that he is running. He is wanting to pursue the business, ja, that is why he has resigned from his workplace.
- I: It's also like you have said, it is hard hey...
- P23: It's very hard...
- I: Having him there and going through this as a single mom. And your son, how is he taking this?
- P23: My son, my son, he doesn't know, I didn't tell him. He doesn't know that I was going to have a baby.
- I: So he doesn't know you are pregnant?
- P23: He is not here, he is in the Eastern Cape.
- I: Ja, you said, because he is studying there. What is he studying?
- P23: He is doing electrical engineering.
- I: Oh, that is great. And is he the only child that you have?
- P23: He is my only child.
- I: And you said you didn't tell him about the baby?
- P23: No, I didn't want to make him, because I had a problem before this child, in 2012 I was pregnant and 7 months the placenta ruptured and I lost the baby. So it was a very traumatic time for me, and even I didn't tell a lot of people about this one, because I was, you know, worried a little bit that something might happen, because with that one I was very healthy. Everything was fine, I even went to the fertility clinic because my gynae referred me there because of age. To the fertility clinic in Claremont, Kingsbury I think. Ja. Just to make sure that everything was fine, and everything was fine. They looked at the brain of the child you know this technology. So I was you know, very happy and then this thing happened with no explanation because there is no explanation for that. I had no high blood pressure, I was okay, so even my gynae couldn't explain that because it happened just 5 days after seeing him and confirmed that everything was fine. So I don't know.
- I: And did water just start coming out?
- P23: You know what, I felt bloated the previous night and I thought maybe because I was traveling from the Eastern Cape to hear, and when I travel I always get bloated, so the following, I was bloated the whole night man and I was uncomfortable, but there was no pain, and then the following morning I was preparing for work and then I went to the loo and when I stood up, joh the blood...
- I: It was just coming?

- P23: Heavy heavy, and the clots, it was heavy. And there was no pain. And I thought I don't know, I don't know if this child has made it. Because I mean this blood, so I managed to phone my gynae and I was there, he is at Cape Town Medi-Clinic and I phoned him, he said I must come immediately and when I went there he was ready by the maternity ward already with a c-scan. And then he scan and there was no heartbeat. So he even asked me what happened? I don't know what happened, I don't know what happened. And I was thinking to myself, I wonder if it was because I was driving. And someone told me no it has nothing to do with that. And he told me he doesn't know either.
- I: And when baby didn't have a heartbeat, did you still have to deliver baby?
- P23: No, they had to cut me, because I lost too much blood, I was already weak when I got there. So they had to operate.
- I: I am sorry to hear that.
- P23: Ja and that is why I was quiet about this pregnancy. I really didn't know, I didn't want everybody to, even my mom was you know a little upset about this. Uhm thinking of what happened...
- I: Previously.
- P23: Ja.
- I: And you said that was in 2012?
- P23: That was in 2012 yes.
- I: And also your mom was worried when she found out you were pregnant?
- P23: Yes, that I am pregnant now.
- I: So you told your mom, and your boss probably also knows, because she dropped you off. But it's like you said after what happened you didn't feel like sharing this with anyone because maybe it happens again.
- P23: Ja.
- I: And uhm just to ask, you said that you were happy in the beginning when you found out that you were pregnant. After you had that scan, that recent scan in January, when we told you about the dot in the heart and the nose, uhm after we told you that, did that change how you felt about baby?
- P23: I was still hoping, because you know my nose is also flat and short and I was thinking maybe the child is taking after me. And because [Genetic counsellor name] has told me no, the spot in the heart is not a life-threatening thing, people do live a long time with that thing. Some don't even know they have it, so I thought okay, maybe the heart, maybe the nose is from me, and never mind the heart it is not going to be. So when she phoned me, and told me it was bad, joh, because she did tell me no those two plus age, the thingy they are calling me...

*Nurse was calling participant to check her into the ward. Stopped the recorder after 15 minutes and 36 seconds and walked with the patient to the ward and her bed. Continued the interview after we were settled in her room.*

I: Okay, so if I remember correctly, uhm you were saying that you still had hope when [Genetic counsellor name] told you about baby because uhm you've also got a small nose. And when she told you, was it quite a shock when you heard? Was it unexpected?

P23: You know, I thought, I thought it was because I was thinking about it a lot and I was expecting it. And I even said to her it is fine I can come the following day for the results. But as soon as she dropped the phone you know, I just broke down and I thought, I couldn't do anything, I couldn't work, I couldn't concentrate and I was the only one in the lab. I work in the lab. And I had to phone my boss, you know, and I knew there was no one to replace me until 11 from the next shift. The next shift started at 11 so I knew I had to hang in there just a little until that person come at 11 o'clock. My boss said, in fact, I actually smsed her and told her what was happening and I have to be here as she said to me the following morning, but I couldn't cope, I couldn't, I was so anxious, I knew there was something wrong, she told me, but I had to come you know. And you know, because I thought maybe it is not that severe, maybe there is something that they can do to reverse the situation or whatever. So my boss took me here. And she told me no there is no cure for that thing. And I, I need to make a decision. And my sister was here already. We met here. My sister, my boss dropped me and I phoned my sister to come be with me, because I needed someone to support me. And my sister told me no it is your decision. She showed me if you keep it what would you be keeping the baby for, you know, and I had no answer, because I know my situation, I can't take care of that baby. So I made the, the same day I made the decision and I took the pill on the same day.

I: On the same day that she told you?

P23: Yes.

I: And did she tell you over the phone that the baby had Down syndrome?

P23: No, she didn't tell me over the phone. She just told me it is not good news. She was expecting to call me with good news, but no it is not.

I: Okay, it is not good news, but she didn't tell you what the news was?

P23: No.

I: And uhm so you told your boss? Is your boss very supportive because she took you, she brought you to the hospital so is she supportive in general?

P23: She is, she is a very supportive person. Shame, because as I am telling you now, the situation with the previous pregnancy was so bad. Everyone was so worried and because I didn't tell her anything. She just knew I was pregnant and I was keeping quiet about it. And now I'm telling her this thing, joh, she was also so sorry for me. She was feeling sad for me, you know, she had to drive all the way from where ever she was to come and fetch me to bring me here.

You know. Because she wasn't around there she had to drive from wherever she was to show that she was concerned. And we were talking about it on the way, the possibility, what was I going to do, you know. All these things and shame.

I: It is good to have a boss like that and she understands. And you have got your sister for support as well?

P23: Yes, I've got my sister, my two sisters they are very supportive, shame.

I: Okay, so you have got your two sisters that support you, and you've got, your mom? How is your mom?

P23: My mom I said please do not mention it to my mom, she is in the Eastern Cape, she is not here so I said to them please don't mention it to my mom. I will tell her when I am ready. I know she is not going to take it well. I know that she is going to want to be here. And I know that it is impossible to leave that 10 year old child there. You see. So she is going to want to be here you know, and she is old. So when I am ready and it is done I will tell her.

I: And your son, are you going to tell him as well?

P23: *Sighs*. My son I am going to have to tell him when I tell my mom. Because he is there with my mom. I will tell them together.

I: And uhm to go back, having the counselling with [Genetic counsellor name], did that help you at all?

P23: Yes, it did help me. It did help me see the bigger picture and not regretting my decision you know. Although I still have that thing, I even asked if they are sure about the results you know. I still have this thing that this is wrong. There is something to me that is telling me why are you doing this it is wrong to do this thing you know. But I know that it is right for my situation and my reasoning is not a selfish reason you know. Because I am doing it for the child that I don't want her to suffer and I am doing it for me to be able to support my son I have to be working. There is no way that I can just leave work, there is no other support my son is getting from anywhere else. I need to work you see. So God forgive me.

I: It is like you are saying, if you had, do you think if you had better support you maybe would have thought differently about baby?

P23: Of course, if I had like, you know, if I had money to take my child to the best place where I know she is going to get 24hr care and where I know that she is gonna be, you know, have someone...

I: Looking after...

P23: Looking after her you know. I know she is going to need that attention and I am not that person, I can't get someone, because that person needs to get paid and there is no one, I don't have that thing. I know that there are maybe institutions but even those need to be paid you know so.

- I: So it does sound like, what you are saying, is that you actually are thinking about baby. Because you are thinking who is going to look after her. So it is like you are saying it is not like, it is not a selfish decision.
- P23: It is not a selfish decision. It is not, because I have seen these children that are like that. I have seen them. Although they are not like my family but you feel this thing, when you look at that child you think gosh you know. You wish you could do something and you know.
- I: So you feel bad when you look at the other children?
- P23: Yes, I do. I do and that is why I think no.
- I: Because you said you don't want her to suffer and go through all of this.
- P23: No. I don't.
- I: And the other children that you have seen, how would you explain Down syndrome? How would it be different than other babies?
- P23: The children or at least the one, there's three, actually there is a couple in my are that has three kids and they are all of them. That is why I asked [Genetic counsellor name], that is there a possibility that I will have a normal child after this? Because you know I have seen these three kids and they are all you know. And she says no, it is just like something that happens once, it is not a thing. So I could try if I wanted to, but I don't because I am old. I am 42. And yoh I have looked at those kids and I have thought gosh, that one doesn't even talk. At least he can walk but it is not easy for you to communicate with him because he can't talk you know. And he wants to play like other children, but some of the other kids don't understand him. They make laughter of him. They, you know, it is not right, but they are kids, they don't know what that child is going through. And if you are looking at those kids you know, like recently I like locking my gate, so there was a friend that came in so I didn't lock my gate, so there was one of them. One of them came, so I couldn't see, because there was a car so I couldn't see, by the gate. But I know there is something at the gate and I am asking my friend, what is going on there, what is happening? Because I've got a brother, I don't want him to come into my yard, he's stout ne. So that is why I always lock. So I asked my friend can you see what is going on there at the gate. So she says no it is that child. Shame that one that doesn't speak. And that was after I shouted already. Hey, what are you doing? You know after I shouted. I didn't know it was him. And he screamed. He screamed you know and yoh I felt so bad, because he doesn't understand why am I screaming at him you know. And I couldn't see that it was him you know. I felt so bad. I felt so sad.
- I: But you didn't know.
- P23: Yoh I felt so sad. Because I heard, after I shouted I heard this scream. And then my friend said no it is that child from. So I went out the gate and he ran. Shame maybe he thought I was going to hit him or whatever.
- I: So it is like you say they are a little bit slow.

- P23: Ja.
- I: And from your understanding, do they walk and talk?
- P23: He walks, but no he can't talk. I don't know if he can hear, but he can't talk. But he plays with other kids. He plays with other kids. He is like a baby man, he is like a 3 year old but I think he is 9 or 10. And he comes into and he doesn't know if it's not right to come into everybody's house. To just go in. He goes in there and watches TV anyway. If he comes in here and he sees us sitting here, he will come in and watch TV. You know. And he doesn't know, and some people they don't like it and he doesn't know.
- I: Okay I see. And you felt after seeing them you can't deal with it. Deal with a baby that is similar?
- P23: No I can't.
- I: I can understand that.
- P23: I can't.
- I: When [Genetic counsellor name] spoke to you, did she tell you what is your chances to have a baby with Down syndrome?
- P23: Uhm, because of the age. I must always consider the age, because if I try now in two years and I am 45 years old which gives them a more risky thingy. You know. So that is why I said to her no I am going to close.
- I: Is that why you feel you are just getting older so it is not good?
- P23: Ja, ja, and the thing is I don't have luck with men so...
- I: You don't have luck with men?
- P23: Yes.
- I: Why are you saying that?
- P23: Because with my baby that I lost in 2012, I was engaged to be married to that guy, my fiancé, who I was seeing more than 12 years, but he was in the Eastern Cape. And then this thing happened.
- I: Was it after you lost baby?
- P23: No, you know I was 6 weeks pregnant when I got a call from the father of my child, the bigger child, and he knows about him you know. But he phoned late, like 10 o'clock to inquire if my son is still coming to the birthday party which he invited him to. And I was supposed to take my son there, but because I was in an accident and I didn't have a car I had to explain to him over the phone while he was inquiring if the child is still coming or not. So I told him no I was

involved with an accident and I just came out of the hospital and my boyfriend, ex-fiance, came over from PE for that accident. So when he woke up and I was busy talking to this man he asked me who is this, so I told him my son's father, he wants to know if he is coming. Then he asked why is he phoning, why is he not phoning him. Because he does not have a phone and I was the one who was supposed to drop him there.

I: Ja.

P23: So he was mad about that. He was mad about that that the father of my son was here in Cape Town while he is in the Eastern Cape. So he thought we had something, some connection or whatever, I cannot explain, and he told me no, he is not going to under some man's, he is not going to be a second choice and he is never going to be under my son's father. He was so insecure, he was a very insecure person.

I: That is also not good.

P23: Ja. And that is why he took his ring at that time. Yoh, he traumatised me. And he blames me for losing the baby. He said I did it. Like I did it. So that is why I say I don't have luck with men. And I was alone after that when we broke up until I met this one and look at what is happening now. No so.

I: Maybe it is just the wrong one's that you are picking?

P23: Yoh, I think it is time for me to just accept that I am a single woman.

I: We will see.

*Both start laughing.*

I: Maybe some time you meet this amazing man and then things change.

P23: The thing is I am old now. You know.

I: It doesn't matter, I see a lot of older mom's that are older than you.

P23: Really?

I: Yes, so that is not an excuse.

*Both laugh.*

P23: Even so if I meet someone that I don't think we will be thinking about kids, because we will both be old.

I: Ja, and he will probably also have is own children.

P23: Ja.

I: But you never know.

P23: Only God knows.

I: Yes. Okay, so you've actually been through quite a lot.

P23: A lot yes. Hmm a lot. A lot. And you know the reason why I am thinking so of my son and wanting to be there for him is because he was also involved with drugs hey. He was involved in drugs and now that he has finally come to his senses and wanting to do something with his life, I think I need to be there and support him. Yes I can support him this way, because I took him to the rehabs twice, and I have always been there for him. But I think he needs me more now, especially because of financial, he is not getting no finances from anywhere, so I have to be there.

I: And did you also study? Because you work in the lab?

P23: You know I got a learnership via Pathcare. They have a training academy there and they offer learnerships there and I did medical technology. I am a technician. I did chem path via Pathcare Academy and they employed me.

I: That's good.

P23: That is 7 years ago and I am still there.

I: But that is good.

P23: It is good. It is good. It is an achievement for me also, because I didn't have like a support system to go to varsity to do whatever you do after I matriculated but you know God is good.

I: And that you got this and that you can actually support your son is amazing. Uhm ja. To think of everything that you have been through and still managing this. Ja, what was I going to ask now? Uhm, everything that [Genetic counsellor name] told you about Down syndrome and the test, did you understand all the information at that stage?

P23: Yes, I did understand. And I try also to google things and read some information also. And I thought I still made the best decision for me and for the child.

I: Definitely. And I can understand. I can hear that you feel, that you are not doing this out of selfish reasons you are doing this because of the child. And the decision to have the test, because I know you said that [Genetic counsellor name] persuaded you to have the test. So what was the reasoning for doing the test in the end?

P23: The reasoning for doing the test was to catch whatever was there in time. You know, before the further stage of pregnancy where I have maybe connected already with the baby or, I am not saying that I am not connected with the baby now, but you know when you are so far and your hopes are so high, you know, no one is expecting to have something different than a healthy beautiful baby at 7, 8 months and that is why I thought okay, no I must do this thing. Besides the first time that they said about this test, the thing that I was worried about was that they said there were chances that you could have a miscarriage and that was why I didn't want to do that. And because my boyfriend, the father of my child was there with me, and he

said no. We are not going to do it you see. Now that he was not here and now, you know I know better than him medically wise and all these things. And I thought maybe I must make this decision by myself.

I: So you made the decision yourself?

P23: Yes, I made the decision by myself, he wasn't there.

I: And the reason is you felt you needed to know what was going on?

P23: Yes.

I: Okay and are you happy with that decision to have the test?

P23: Yes, I am very happy, because just imagine now, you know.

I: And were you happy about the way you were told about baby or would you have done it differently?

P23: You know, yes, she didn't tell me over the phone, which I appreciated. Which is my confidentiality is respected or whatever and she took me to a room you know. Nobody is going to hear about this you know, it is between, it was very confidential. And I like the way it was done, there was no other way I could have expected it, there is no other way that I could have done it. If they wanted they could've emailed the results to me, just like that. You know, but I had to come here.

I: Okay so it was good that she actually contacted you and spoke to you.

P23: You know I really appreciate what you did, because she said to me that I will make sure that I do for you you know and she actually did. She phoned. Because some doctors even like from here, when they see you, like for instance you've got protein in your urine and they ask you to do a 24hr urine, then you do a 24 hr urine. Then you see a different doctor and the doctor that ask you that, doesn't actually see you or know the result or make a follow-up. Maybe it is a load of patients that they see. So I really appreciate what she does, because I am not the only one that she sees, but she phoned me you know. So.

I: So it sounds like you like the fact that she actually cares and makes an effort?

P23: Yes.

I: And did it help having your sister with you?

P23: Oh it helped a great deal, it really helped. Because I was crying all the way. I only stopped when she came.

I: Hmm.

P23: You know, only when she came and told me everything was going to be fine, you know, the weirdest thing that she told me is that she had a dream about this you know, and she didn't want to upset me but she already told my mom about the dream. That early December she had a dream that I had this baby.

*Knock on the door and nurse enters. Nurse asks questions about patient so I stopped the recorder again until the nurse was done with the participant and left the room.*

I: Okay so what were we saying? Yes, your sister, we were saying that it was good to have your sister and that she had a dream?

P23: She had a dream and she said I had this baby. She went to visit me by my house and I had this baby and this baby was sitting there in a beautiful chair but the baby was wrapped in lots of like blankets and towels and stuff. And then when she wanted to see the baby I said no. I didn't want her to see. First of all, she was thinking hayi why didn't I tell them that I had a baby. Second of all she comes and excited about the baby and then I say no, look at the baby. And then when she eventually managed to take the blankets off and look at the baby, yoh, she found like a disabled thing. My baby had a very big head. The head was huge, humungous, and the hands were like so little. Like so little hands like fragile. Or fragile hands. And then she was thinking like why she didn't tell us about the baby, she was keeping it to herself. And then while she was standing there with the baby and the baby just grabbed her arm like that and holding on to her like you know, and then she was so scared. She woke up like it was a nightmare and then she told her boyfriend and my mother.

I: Your mother about it, but she never told you...?

P23: She never told me until that day.

I: Okay, and you said because she was here with you and she also helped you to make the decision to stop, because she asked you why would you want to keep baby.

P23: Ja, ja.

I: Okay. Uhm and that is good to have someone that actually asks you these things. Uhm so if I understand correctly, your reasons for making this decision is basically because of finances, because you need to support your son at this stage. Because he really needs you right now. And also with time, because you don't have the time to not go work and to look after baby. And the other thing is also that you said that you don't want to see baby struggling and that will also not be right for you. Is that, does that make sense to you what I am saying. Am I understanding you correctly?

P23: Yes, that is the reasons.

I: And then uhm in the end your sister really helped you to make this decision to stop.

P23: Yes, she supported me. She supported my decision.

I: Okay, so it was your sister, and your boss, did she also, because you said on your way here...

- P23: Yes, we were talking about it and she also said it is my decision but she supports it. If I say yes to this it is for me and she even went on to ask me where is the father of the child you know. I told her he is not here you know and I told her the real thing. And then she said no then it is entirely your decision because it looks like this is going to be your baby, financially and otherwise. So whatever decision I am making she is going to support.
- I: Okay, and that is also why you felt when you got here you didn't need to include him because of how he has been acting.
- P23: You know.
- I: And with the, did they explain to you, how they are going to stop the pregnancy?
- P23: Uhm, they said they were going to give me that pill that I took already which didn't do nothing to me. There is nothing coming out. *Laughs*.
- I: I can see that you are not in any pain at all.
- P23: And then uhm they said I am going to have to come in today and then they gave me to pills. I asked [Genetic counsellor name] so can't they cesar me. Can't they give me a cesar because haybo I am so scared. So she said no the cesar is risky, because the child is so small you know and it is not going to be difficult. The only thing that is going to be crap is like if they have to suck me, that placenta if there is something left out there, that is the only crap part. But I was thinking now if they cannot give me anaesthetic?
- I: If you are at all in pain you can have as much medication as you need.
- P23: Okay. So.
- I: But it is all going to depend on you and how things go. Uhm did she ask you if you wanted to see baby if baby comes out?
- P23: Yes, she did. And I said yes I want to see my baby. I want to see my baby and I want to hold her. And she explained to me, don't think if you are going to see that baby that you are going to see the abnormality on the baby. You are going to see a cute baby but you are not going to notice the you know. I said no I understand but I want to see the baby.
- I: You are basically just going to notice her tiny little nose. So she did warn you that you are not going to see anything on baby?
- P23: Because it is like in the brain?
- I: Yes it is on the inside. You can't see the problems that baby has, you can only see it on the blood test that we did.
- P23: Ja.
- I: Why do you want to see baby?

- P23: I don't know, I would like to make peace with what happened. Because if I don't see the baby I would think, I wonder how would she look like and all these wonder things that I will be thinking.
- I: Okay, so you feel it will help you make peace with it to actually see and hold baby.
- P23: Yes.
- I: Uhm, what was the other thing? Uhm so basically you feel that you are making the right decision at this stage?
- P23: Yes.
- I: Just to go back to the test, you said you originally did not want the test because of the miscarriage risk so what made you not worry about the miscarriage risk anymore?
- P23: The thing is there is mos now two, ne, there is this one where they can take from the uhm...
- I: The amniotic water?
- P23: The water, which they did, and there was this one which I was a little concerned about which they take...
- I: Where they take from the placenta?
- P23: No, the, from the cord, where they take blood from the cord. And that is the risky one. And I was a little bit, I was happy when they couldn't take from the placenta, ag the cord, because that is a little risky than the other one, but the results, I asked them if the results would give the same indication so they said yes. So I said no it is fine. The water then.
- I: Okay because they were doing the water one, you weren't as worried about the miscarriage.
- P23: No, I wasn't, because it was just to pull water, it was amnio, I was looking at the screen, there was nothing touching the baby, the needle did not touch the baby, because you know. But with the cord the needle had to go in there so.
- I: Okay, so that made you feel a little bit better...
- P23: Ja.
- I: That they did the water one and not the cord.
- P23: Little bit better ja. And I was going to ask them questions if they did the cord. I was going to be worried.
- I: So you weren't worried afterwards?
- P23: No especially when I got home and there was nothing. Nothing is happening to me except the little pain of the needle.

- I: Nothing else happened?
- P23: Nothing else. I wasn't even thinking of miscarrying after seeing, looking the way it was done. You know, because I don't think, it is not like you are taking 1L of water from the womb. They were just taking a little bit so I didn't think that it was going to affect the baby in any way.
- I: Okay so it is good that you weren't worried about that.
- P23: No, I wasn't worried about that.
- I: And you basically, how long did you wait for the test results? Was it one week or two weeks?
- P23: I think it was a week. That was the 20<sup>th</sup>.
- I: Ja, I think it was a week. And were you, did you stress in that week? Were you worried about this.
- P23: Hayi, huh-uh, because they told me it was a week I wasn't, I was thinking about this, but I didn't want to worry myself at the same time. I need to concentrate at work, I can't be thinking, I have to be there. So I just put it aside and maybe think about it when I go home you see. And praying, I was praying, I was praying all the way, I was praying every night and... *starts crying 09:26-09:43*. I was praying that it was a mistake you know. You know but then it wasn't. *Big sigh*. It's okay.
- I: You are going through a lot. And how do you feel now because you said you were praying about it a lot?
- P23: I prayed about it.
- I: You are not feeling angry or anything?
- P23: No. I can't feel angry. I can't feel angry because you know God decided. He is the one that makes decisions, and we cannot caution Him. We must just accept what is coming to us. And that is what I was praying for you know that whatever I am getting, I must just accept it. Because nobody, nobody prays, or expects to have an abnormal child. But it happens. I must just accept it you know. And you can't wish it for someone else and not you so you must, whatever I must just be strong.
- I: And you also said is that the reason why you are not feeling, like you said, it is not like you wanted to do this, in a way it feels wrong for you to stop. But for your situation this is the best decision.
- P23: Yes. *Tears still running down participants face*.
- I: Because it is not an easy thing.

- P23: *Big sigh.* It is not easy, yoh! It is not an easy thing. It is not an easy thing that is why most of the people that I have seen in the meeting room they are maybe coming for the same thing, they completely refuse to test, because now I see why. It is not easy. It is not easy.
- I: But you think it was a good decision in your case to do the test?
- P23: I still think it is a good decision that I did it.
- I: Even though they are not doing it, you still feel for you personally.
- P23: Yes, for me yes. Maybe they have a different perspective. Or they have, they have you know, they have different religions. You know maybe they respect their religion or whatever, culture wise they think it is not the right thing to do.
- I: But do you feel that you are not respecting your religion by doing this?
- P23: *Big sigh.* I feel so bad. I don't although I said to you at the back of my mind I think it is wrong thing to do, because I am killing a child you know, but now there is no other way of doing it, looking at my situation. You know. There's no, I can't, I need to support the child and I don't have means to do that.
- I: I can hear from what you have been saying that it is going to be very difficult for you. Uhm but do you think you are going to be able to live with this decision?
- P23: I have to. And that is why I didn't want to involve everyone. It helped to be on my own, making my decision. With him not being here. Because I didn't want something to sit on me and say you know he was saying no and I was saying yes you know. And that is why I made the decision at his absence. The thing is, he is not my husband first of all, and...
- I: He has not been around.
- P23: He's not been around. He has not been supportive at all.
- I: So you said it helps that you made this decision and there is no one saying no and making you feel bad for making a good decision for you.
- P23: Yes. And you know I was telling my one colleague on facebook, I was chatting to her, because I need to speak to somebody so I thought I would speak to her because she is a nurse by profession. She is there working together. So I am telling her this is what's happening and she says what do you mean by saying they are going to take the baby out. Are they going to kill the baby. Yoh, I felt so bad, because I know that she has got a disabled child. But I don't know what is the disability of the child, because she is new at work, in fact I don't like talk something so personal with her. So I don't know the disability of the child but I know in the back of my mind I thought okay that is why she is asking this because she is raising this child.

## APPENDIX D: CODEBOOK

### *Pregnancy Experience (PE)*

- Excitement
- Unplanned
- Named child
- Bought baby supplies
- Worse pains
- Happiness

### *Emotional reactions towards being at high risk for DS (HRDS)*

- Upsetting
- Why my baby?
- Worry
- Guilt
- Sadness
- Stress
- Punishment from God

### *Impact of being at high risk for DS (IHRDS)*

- Praying for miracle /good outcome
- Anxiety at birth (check to see if normal)
- Doubt in ultrasound findings
- Negative feeling towards pregnancy
- Preparing for the worst
- Thinking positive
- Tentative pregnancy

### *Factors influencing decision-making prenatal diagnostic testing (DPND)*

- Initial indecision
- Influence of partner
- Perception of soft-markers
- Risk perception of Down syndrome (RP Down syndrome)
- Risk perception of miscarriage (RP Miscarriage)
- Would not TOP
- Gender of baby
- Perception of Down syndrome
- Miscarriage risk
- Religion

- Baby healthy
- Compulsory test
- Acceptance of family
- Previous experience
- Number of children
- Obstetric history
- Impact on other children
- Finances
- Impact of disabled child on couple's relationship
- To be prepared
- Influence of information given
- Satisfaction

*Experience of PND procedure (PND Pro)*

- Fear of pain (of needle)
- Fear of miscarriage

*Waiting period for test result (WTR)*

- Anxiety
- Isolation
- Hopeful
- Tentative pregnancy

*Delivery of PND test result (TR)*

*Reactions towards receiving negative PND result (Neg TR)*

- Relieved
- Happy
- Thank God
- Excited about baby
- Less stressed
- Doubt in accuracy of test

*Reaction towards news of diagnosis (DR)*

- Sadness
- Guilt
- Grief

- Isolation
- Blaming
- Delayed acceptance
- Feeling down
- Difficult news

*Factors influencing decision-making termination of pregnancy (DTOP)*

- Age of parents
- Perceived teasing
- Perception of Down syndrome
- Finances
- Future of other children
- Number of other children
- Suffering
- Religion
- Partner's opinion
- Family's opinion
- Support in raising disabled child
- Lifetime dependency of child
- Difficulty attending regular hospital visits
- Test from God
- Satisfaction
- Belief that all future children will have Down syndrome

*TOP Process (TOP Pro)*

- Understanding of procedure
- Seeing stillborn

*TOP Impact (TI)*

- Perceived judgement
- Reconciling religious beliefs
- Fear about future pregnancy
- Changing workplace
- Changing living environment
- TOP stigma
- Impact on family relationships
- Impact on relationship with partner
- Emotional distress
- Seeing stillborn

*Coping with loss/Ceremonies of closure (CC)*

- Remembrance
- Finding meaning
- Destroying photos
- Memorial service
- Bids farewell to stillborn
- Finding peace

*Birth experience**Impact of keeping child with Down syndrome (IDS)*

- Family
- Relationship with partner
- Work
- Social life
- Emotional impact
- Health of baby

*Support (S)*

- Children
- Partner
- Sister-in-law
- Genetic counsellor
- Religion
- Uncle
- Friends
- Aunt
- Parents
- Family
- Mother
- Cousins
- Support Group

*Genetic counselling*

- Experience of genetic counselling session
- Timing of counselling session
- Understanding of information

*Advice to other women (A)*

- Trust God
- Share experience to help others
- Your choice
- Encouraging words
- Have the test
- Speak about concerns

## APPENDIX E: LETTER OF ETHICAL APPROVAL



UNIVERSITEIT·STELLENBOSCH·UNIVERSITY  
jou kennisvenoot • your knowledge partner

### Approval Notice New Application

17-Oct-2013  
Scott, Chantelle CJ

**Ethics Reference #: S13/09/169**

**Title: Understanding decision-making regarding prenatal diagnostic testing for Down syndrome and termination of pregnancy: An phenomenological study**

Dear Miss Chantelle Scott,

The **New Application** received on **25-Sep-2013**, was reviewed by Health Research Ethics Committee 2 via Committee Review procedures on **16-Oct-2013** and has been approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **16-Oct-2013 -16-Oct-2014**

**Present Committee Members:**

Rosenkranz, Bernd B  
Botha, Philip PR  
Barsdorf, Nicola  
Mills, Lize L  
Davids, Mertrude MA  
Fernandez, Pedro PW  
Kruger, Mariana M  
Rohland, Elvira EL  
Botha, Matthys MH  
De Roubaix, Malcolm JAM  
Moller, Marlo M  
Willett, Derrick DWE  
Edwards, C E

Please remember to use your **protocol number (S13/09/169)** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

**After Ethical Review:**

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372  
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

**Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Helene Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.  
For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

If you have any questions or need further assistance, please contact the HREC office at 0219389207.

**Included Documents:**

SYNOPSIS  
PROTOCOL FINAL  
DEC LETTER SKINNER  
APPLIC FORM  
DEC LETTER SCOTT  
CHECKL  
CV SCOTT  
CV SKINNER  
DEC LETTER URBAN  
PROTOCOL  
CV URBAN

Sincerely,

Mertrude Davids  
HREC Coordinator  
Health Research Ethics Committee 2