Exploring the decision making process of women offered termination of pregnancy for a serious congenital abnormality

by

Malebo Felicia Malope
MLPMAL005

SUBMITTED TO THE UNIVERSITY OF CAPETOWN
In partial fulfillment of the requirements for the degree

MSc (Med) Genetic Counselling

Date of submission
25 August 2017

Supervisor:
Dr. Tina-Marié Wessels

Co-supervisors:
Dr. Karen Fieggen
Dr. Chantel Stewart

Division of Human Genetics
Department of Pathology
Faculty of Health sciences
University of Cape Town

The financial assistance of the National Research Foundation (NRF) towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at, are those of the author and are not necessarily to be attributed to the NRF.
The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.
Declaration

I, Malebo Felicia Malope hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:  

Signed

Date: 20/08/2017
Abstract

**Background:** A weekly pregnancy counselling clinic is held in conjunction with foetal medicine experts at Groote Schuur Hospital for women with pregnancies complicated by foetal anomalies. In cases with poor prognoses, termination of pregnancy (TOP) may be offered. The women receive genetic counselling where the ultrasound findings, invasive testing and TOP options are discussed. Decision-making is the focus of these sessions. The experiences and decision-making processes of the women in this clinic are poorly understood, therefore this project aims to explore these women’s experiences and what factors influence their decision-making regarding TOP.

**Methods:** Qualitative research, drawing on principles of phenomenology was used as the study design. The sample for this study is women who had a prenatal diagnosis of a serious congenital abnormality and were offered TOP. The women were identified using the Division of Human Genetics pregnancy counselling database at the University of Cape Town in South Africa. Semi-structured face-to-face interviews with open-ended questions were used to collect the data and close-ended questions were used to obtain the demographic data. The interviews were recorded and transcribed verbatim. The data were analysed using a thematic data analysis approach. A total of 12 women were interviewed.

**Results:** Five themes were identified in this study. These include “Health care services”, “Home”, “Being a woman”, “Finding meaning”, and “The aftermath”. The healthcare services impacted the manner in which the women made sense of the ultrasound findings. Support (or lack of) from family and the community impacted on their decision-making. Stigma attached to having a child with a disability and/or stigma against TOP and partner relationships played a role. The women questioned their role as a woman and obligations of child-bearing. Finding meaning for the event was important and this process continued until after the delivery or after the child was born. Following the event having a burial and giving away the child’s clothes were found to play a significant role in their adjustment.

**Discussion and Conclusion:** The decision-making process was multifaceted and unique to each woman. They consulted their families, partners and community but in the end they made the final decision. The women considered a multitude of factors but it seems that there may be one deciding factor. This in depth exploration of the women’s experiences has provided valuable insight into the decision-making process, which can be used to improve the services offered to patients.
Dedication

I dedicate this minor dissertation to my mother, Anea Charity Malope and my grandmother Lucia Lasea Malope for encouraging me to follow my dreams and for always reminding me that:

“ke ngwana magana go hloiswa madumelwa go retwa!”
Acknowledgements

I would like to express my gratitude to the following individuals whose contributions have been invaluable:

Above all, I would like to thank God, without whom, none of this would have been possible.

I would like to thank the women who took part in this study. Your willingness to tell your story, which is not an easy to tell, is greatly appreciated.

To my supervisor, Dr. Tina- Marié Wessels, thank you for all your support and guidance and for always being available to assist. Thank you for your feedback and recommendations.

To my co-supervisors:

Dr. Karen Fieggen, thank you for always availing yourself and willingness to assist. All your recommendations and feedback were of great value. Your positivity encouraged me to keep going.

Dr. Chantel Stewart, Thank you for your contributions in this study.

I would like to thank my research assistant Kelly Barrow, isiXhosa translators, Nolubabalo Tyam and Khutala Mnisi, and editor, Loretta Mujuru, for all your assistance.

My fellow students, Kalinka Popel, Nicole van der Merwe and Clair Engelbracht thank you for your support and encouragement.

National research Foundation (NRF) for funding this course.

To Mama (Anea Malope) and Sesi (Lucia Malope), thank you for your daily calls, love, care guidance, support and encouragement.

To Mamogolo (Babatyi Malope-Kgokong) than you for your guidance.

To the rest of my family, thank you for your love and support.

Tatenda Mujuru thank you for your support, care encouragement and help when I needed.
Table of Contents

Declaration ............................................................................................................................ i
Abstract ................................................................................................................................ ii
Dedication ........................................................................................................................... iii
Acknowledgements ............................................................................................................. iv
List of terms and abbreviations ......................................................................................... viii
List of tables and figures ..................................................................................................... ix

Chapter 1: Background and Literature Review ..................................................................... 1

Congenital Abnormalities and causes ................................................................................. 1
Epidemiology ........................................................................................................................ 2
University of Cape Town Internal Data ........................................................................... 3
Genetic counselling in a prenatal context .......................................................................... 4
   Termination of pregnancy ............................................................................................. 7
Decision-making .................................................................................................................. 8
   Factors affecting decision making .............................................................................. 8
   Finding meaning ....................................................................................................... 14
Rationale for the Study ..................................................................................................... 14
Aims and Objectives ......................................................................................................... 16
   Aim ............................................................................................................................. 16
   Objectives ................................................................................................................ 16

Chapter 2: Methodology ..................................................................................................... 17

Introduction ...................................................................................................................... 17
Study Design ..................................................................................................................... 17
Study Population .............................................................................................................. 18
   Inclusion Criteria .................................................................................................... 18
   Exclusion Criteria ................................................................................................. 18
Participant Recruitment ................................................................................................ 18
   Participant Identification ......................................................................................... 18
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Recruitment</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Description of participants</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Research Setting</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Data Collection</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Data Analysis</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>Research Trustworthiness</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Ethical Considerations</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Ethical Approval</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Informed Consent</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Privacy and Confidentiality</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Risks/harm and benefits</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Chapter 3: Results</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Participant Demographics and Pregnancy Information</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Themes</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>Theme 1: Health care service</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Theme 2: Home</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Theme 3: Being a Woman</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>Theme 4: Finding Meaning</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Theme 5: After the birth</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td>Reasons for Decision</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>Chapter 4: Discussion and Conclusion</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>Participant Demographics and Patient Information</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>Deciding Factors</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Health Care Services</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>Home</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>Being a Woman</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>Finding Meaning</td>
<td>77</td>
</tr>
</tbody>
</table>
## List of terms and abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>CA</td>
<td>Congenital Abnormalities</td>
</tr>
<tr>
<td>CHD</td>
<td>Congenital Heart Defects</td>
</tr>
<tr>
<td>DTOP</td>
<td>Declined Termination of Pregnancy</td>
</tr>
<tr>
<td>FAS</td>
<td>Foetal Alcohol Syndrome</td>
</tr>
<tr>
<td>FMU</td>
<td>Foetal Medicine Unit</td>
</tr>
<tr>
<td>GSH</td>
<td>Groote Schuur Hospital</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IUD</td>
<td>Intrauterine Death</td>
</tr>
<tr>
<td>LB</td>
<td>Surviving Live-Born</td>
</tr>
<tr>
<td>LTOP</td>
<td>Late termination of Pregnancy</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother to Child Transmission</td>
</tr>
<tr>
<td>NND</td>
<td>Neonatal Death</td>
</tr>
<tr>
<td>PCC</td>
<td>Pregnancy Counselling Clinic</td>
</tr>
<tr>
<td>SA</td>
<td>South Africa</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>TOP</td>
<td>Termination of Pregnancy</td>
</tr>
<tr>
<td>UCT</td>
<td>University of Cape Town</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
List of tables and figures

Tables:

Table 1: Demographic Information
Table 2: Pregnancy Information
Table 3: Decision to the offer of TOP and the deciding factors
Table 4: Most difficult aspects for each participant

Figures:

Figure 1: Summary of the themes and domains
Figure 2: The decision making process
Chapter 1: Background and Literature Review

This chapter is comprised of the literature review, the study rationale and the aims and objectives of the thesis

Introduction

Congenital abnormalities (CAs) are common worldwide and have a significant impact on the health and wellbeing of affected children, their families and their communities. Many CAs are associated with a shortened lifespan and lead to long term disabilities, causing financial and psychosocial burdens. A pregnancy diagnosed with a serious foetal abnormality inevitably causes stress for the women and their partners particularly when faced with having to make a decision about termination of pregnancy (TOP). The decision making process is affected by various factors such as personal, family, social and cultural beliefs. Factors that influence a woman when deciding whether or not to terminate her pregnancy in the setting of a serious congenital abnormality in South Africa are not fully understood. This study aims to address that question by gathering in depth qualitative data from a sample of women who have attended the pregnancy counselling clinic at Groote Schuur Hospital in Cape Town. In this literature review, background information on congenital abnormalities including epidemiology and causes and more specifically information on the congenital abnormalities seen at the University of Cape Town pregnancy counselling clinic will be discussed. Genetic counselling in the context of congenital abnormalities including the factors that influence decision making regarding TOP for a pregnancy affected with a serious congenital abnormality will also be discussed.

Congenital Abnormalities and causes

Congenital abnormalities or disorders are structural or functional anomalies that are present at birth (World Health Organisation (WHO), 2017). The severity of the abnormality is determined by the organs involved and the type of malformation in the foetus. Causes of CAs include environmental and, teratogen exposure as well as genetic abnormalities and multifactorial environmental and genetic contributions. One South African study found the causes of these abnormalities may be genetic or multifactorial in 80.5% of cases and due to teratogen exposure in 19.5% (Christianson et al., 2006). However for some CAs, the aetiology is unknown (WHO, 2015). The cause of CAs can be divided into pre-conception
and post-conception effects. Pre-conception causes of CAs are genetic in origin and can be due to chromosomal abnormalities, single gene and multifactorial disorders (Malherbe et al., 2016). The most common life-limiting abnormalities that are caused by a chromosomal abnormality and are compatible with life, are trisomy 13 and 18 which are conditions that affect multiple organ systems (Turnpenny & Ellard, 2011). Post-conception causes are those that occur after conception, including teratogen exposure (alcohol and drugs), maternal illness and infections (diabetes mellitus, rubella), toxin exposure and environmental causes such as intrauterine constraint or amniotic bands (Malherbe et al., 2016).

**Epidemiology**

Approximately 6% of neonates worldwide are born with a congenital abnormality (WHO, 2015) and 303,000 neonatal deaths each year are due to CAs (WHO, 2016). In South Africa, it is estimated that 150,000 neonates are born with a congenital abnormality each year (Department of Health, 2013). This means that 1 in 15 children in South Africa are born with a congenital abnormality (Malherbe, Christianson & Aldous, 2015). About 70% of all congenital abnormalities can be prevented, treated or improved with appropriate care, but only about 12% are identified at birth in South Africa. This indicates under-detection and under-reporting of CAs and is largely attributed to the lack of clinicians and facilities that specialise in CAs (Malherbe et al., 2016). It is estimated that congenital abnormalities account for about 7.7% of stillbirths in tertiary hospitals, and 2.5% in primary and secondary institutions. However this is thought to be an underestimation due to the lack of screening and diagnostic services in some of the centres (Malherbe et al., 2016). The lack of adequate attention given to CAs in South Africa is, in part, due to the shift in focus to the HIV, AIDS and TB epidemics. Prior to that, certain conditions considered to be of high priority were identified by a task team when policy guidelines for the management and prevention of Genetic Disorders and Disabilities were drawn up (Department of Health, 2001). These conditions include Down syndrome, neural tube defects, foetal alcohol syndrome (FAS), albinism, cleft-lip and palate, talipes equinovarus, and congenital infections. The recorded data of CAs across SA for the period 2006-2014 shows that 35.92% were common priority conditions. The largest single group of CA’s were neural tube defects (16.53%) which included anencephaly, encephalocele and spina bifida (Lebese, Aldous & Malherbe, 2016). There is a high prevalence of FAS in SA accounting for the high proportion (10-15%) of teratogenic CAs. However FAS is also
under-reported at 1.53% (Lebese, Aldous & Malherbe, 2016) as the foetal alcohol spectrum disorders rate, outlined by the Foundation for Alcohol-Related Research in three provinces in South African reported a rate of 29 to 290 per 1000 live births, depending on the area (Olivier, Curfs & Viljoen, 2016). Congenital heart defects (CHD) are under-reported in South Africa (Lebese, Aldous & Malherbe, 2016) as most are either undiagnosed or misdiagnosed. The prevalence of CHDs in South Africa is estimated at 5-22/1000 (Brown & Pepeta 2016). However less than 40% of children with CHD receive the care that they need (Hoosen et al., 2010). Due to under-reporting and lack of paediatric cardiologist services in some provinces in the country, CHDs are reported to cause 1.2% of childhood deaths of children under the age of 5 (Medical Research Council, 2010). About 85% of children with CHDs can live into adulthood if the cardiac defect is well managed (Warnes et al., 2001).

CAs can be identified prenatally or post-delivery and ideally should be promptly diagnosed as this will impact on the options available to the expectant parents and allow for optimal management of the pregnancy and child. Lebese, Aldous & Malherbe (2016) indicated in their study of the South African Department of Health’s national congenital defects surveillance system that the majority of neonates affected with a CA were live-born and were only identified post-delivery. In this same study, all the cases in which a CA was identified prenatally resulted in TOP. This could be bias as possibly only prenatally diagnosed CAs resulting in TOP were recorded. CAs identified subsequent to a stillbirth or spontaneous abortion accounted for 5.74% and 0.2% of the CAs, respectively (Lebese, Aldous & Malherbe, 2016).

**University of Cape Town Internal Data**

Patients with a pregnancy complicated by a congenital abnormality are usually referred for genetic counselling at the Groote Schuur Hospital (GSH) Foetal Medicine Unit (FMU). These data were captured onto the University of Cape Town (UCT) pregnancy counselling clinic (PCC) database. The data in the UCT PCC database was captured by the genetic counsellor or the clinician that counselled the patient and this information is accessible to the Human Genetics clinical team. In the UCT PCC database 4852 patients were seen and counselled by genetic counsellors and genetic clinicians at the clinic between December 2007 and July 2016. The indications for counselling were: abnormal first trimester nuchal translucency screen (n=384), positive maternal aneuploidy serum screen (n=83), second trimester ultrasound soft markers for aneuploidy (n=255), advanced
maternal age (AMA) (n=1814), congenital abnormality (n=1720), family history of genetic disorder (n=409), teratogen exposure (n=48), other reasons (n=98) and unrecorded (n=41). Invasive prenatal testing was offered to 3504 patients of which 1383 accepted testing, 1779 declined and 342 were recorded only as undecided. TOP was offered to patients according to the internal policy of the unit and the Choice of Termination of Pregnancy Act No. 92 of 1996, (1996). A total of 764 women were offered TOP (including fetocide when appropriate) of which 322 accepted and went through with termination of their pregnancy. Of the women who chose TOP, 293 were described as having based their decision on the severity of the congenital abnormality. Four of the pregnancies were exposed to teratogens (warfarin, roacutane and positive TORCH infection screens). For 402 of the patients who declined TOP, the pregnancy outcome was not recorded. In the remainder, 25 of the pregnancies resulted in intrauterine death (IUD); six in an early neonatal death (NND); nine were live-born and survived the neonatal period. Of the 764 women who received counselling for a congenital abnormality and had genetic testing, 37 were found to have trisomy 18, nine had trisomy 13, and 15 had trisomy 21. Other chromosomal abnormalities were identified in another 19 including marker chromosomes, isochromosomes and monosomy X and in 224 no structural / numerical chromosomal abnormalities were detected. There were environmental, genetic and multifactorial causes for these CAs although for some a cause was not identified. The prognosis for CAs varies and because as both ultrasound findings and the options for comprehensive testing and recurrence risk need to be presented to the women, there is a need for them to undergo genetic counselling.

Genetic counselling in a prenatal context

The moment parents find out that they have a child with a birth defect or are pregnant with a baby that has a congenital disorder, they immediately experience stress that can be associated with grief (Djurdjinovic, 1998). This is a crisis for the parents as they have been anticipating having a healthy child and the psychosocial effects may be a burden for them. The parents may grieve as they are “mourning” the loss of a normal healthy child (Brosig et al., 2007). This makes genetic counselling very important as it helps the parents deal with the situation, understand details of the such as the prognosis, inheritance pattern and what to expect when taking care of a child with a particular congenital abnormality. The genetic counsellor therefore needs to give accurate information to the patient about the counselling session itself, the diagnosis and its implications, the prognosis and its
implications and the options available. He/she also needs to provide psychosocial support for the patient.

Many women do not know what genetic counselling or what a genetic counselling session entails and may have limited genetic knowledge, (Morris et al., 2015). The counsellor will therefore need to establish the needs of the client and explain the purpose of the session.

Genetic counselling also provides information about available options that continuing with the pregnancy or TOP and allows the parents to make informed decisions about future pregnancies (Lampret & Christianson, 2007). Apart from the information provided, genetic counselling plays a role in the decision making process for a pregnancy affected with a serious congenital abnormality (Hawkins et al., 2013).

Genetic counselling in the context of serious congenital abnormalities is important as the clients are given information regarding the ultrasound findings and their implications. The information provided is essential because the counsellor will have to assess the client’s perception of the burden of disease. Burden of disease together with the benefit of having an affected child versus a healthy child is important for the clients (Weil, 2000). If the client considers the burden of the congenital abnormality to be minor e.g. cleft lip and palate or Down syndrome without cardiac complications, the clients may perceive the burden of the condition to be low and will consider having the child (Reed & Berrier, 2016; Weil, 2000). For conditions with a high recurrence risk and relatively high perceived burden such as cystic fibrosis and Down syndrome with cardiac complications the client may consider not having the child or give the child up for adoption (Reed & Berrier, 2016; Weil, 2000). For severe abnormalities, termination of pregnancy can be offered to the women. Decision making regarding a pregnancy is not easy, thus the genetic counsellors have to facilitate the decision making process, making sure that the decision is made from a well-informed and autonomous stance. Genetic counselling also provides psychosocial support for the clients to assist them in coping with the situation (Rauch et al. 2005). When informing the patients and assisting with decision making, the counsellor has to maintain non-directiveness while encouraging patient autonomy and efficacy. In doing so the counsellor needs to ensure that the decisions the patient makes are in line with the facts related to the pregnancy and the client’s personal beliefs and values (Weil, 2000).

The counsellor’s own personal views should not infringe upon the clients ethical, cultural, religious and personal views promoting client’s self-governance (Weil, 2000). South Africa is a diverse country with 11 official languages and a population made up of different ethnicities including black Africans (80%), Caucasians (9%), people of mixed ancestry
(9%) and Indian and Asian population (2%) (Statistics South Africa, 2011) so various cultural and religious views exist. About 63% of cases seen at the Genetic Clinic in Cape Town are people of mixed ancestry and 28% are black Africans (Kromberg, Wessels and Krause, 2013). Due to the diversity of clients seen in state settings, the counsellor needs to keep in mind that even when offering further testing for the pregnancy, the clients’ beliefs play a role.

During a session the counsellor outlines the different options available to the client, including prenatal testing and screening. Genetic disorders can be confirmed by diagnostic tests such as amniocentesis and chorionic villus sampling (Turnpenny & Ellard, 2011). These tests are usually offered when the pregnancy is considered to be at an increased risk for genetic and developmental abnormalities. Factors that increase the chances of the foetus having an abnormality include, but are not restricted to, maternal age, maternal medical history and a family history of hereditary conditions (National Health Service (NHS), 2014). Amniocentesis is a procedure whereby amniotic fluid is obtained (typically between 15 to 20 weeks gestation) to determine whether or not the foetus has a particular genetic abnormality (NHS, 2014). Amniotic fluid can also be used to aid the diagnosis of neural tube defects by α-fetoprotein assay (Turnpenny & Ellard, 2011:325). Chorionic villus sampling (CVS) allows for prenatal diagnosis to be made earlier as it is performed between the 11th and 14th week of gestation (NHS, 2015) CVS involves obtaining cells from the placenta (Turnpenny & Ellard, 2011:325) and, as with amniocentesis, the chromosomes and DNA are analysed using various techniques. However amniocentesis and CVS are not without their risks. Both amniocentesis and CVS pose a spontaneous abortion risk following the procedure is about 1% and 2% respectively. The risk of miscarriage is a significant factor when patients are deciding about invasive testing. The experience of the FMU PCC staff is that a large number of women who are offered prenatal testing for foetal abnormalities decline testing. Some of the reasons listed on the database for women declining invasive prenatal diagnostic testing were: would not terminate the pregnancy or accept the outcome child; fear of miscarriage; emotional factors that included denial and fear of the test. These might not be completely accurate as the database has predetermined categories and is based on the counsellor’s overall impression of the patient’s reasoning.

Another important factor to consider when offering invasive prenatal testing is the risk of mother-to-child HIV transmission (MTCT). SA has a high prevalence of HIV and AIDS, so it is important for pregnant women who are HIV positive to be informed about the risk of
MTCT when offering invasive. This may also affect the patient’s decision regarding invasive testing. Bee et al. (2013) found that there is a direct correlation between HIV status and the uptake for invasive testing. The risks of prenatal testing need to be kept in mind as they can impact on the decisions made about the pregnancy and possible TOP when counselling for foetal abnormalities. The gestation at which the diagnosis is made can limit the options the parents have for further management and may also affect the parents’ decisions about TOP.

**Termination of pregnancy**

Termination of pregnancy is frequently offered to women who have pregnancies affected by a serious condition. In South Africa, termination of pregnancy can be offered at any time during the pregnancy for a foetal condition that carries a poor prognosis. Women in South Africa may be offered TOP after the 13th week of gestation if there is a substantial risk that the foetus will suffer from a severe physical or mental abnormality. TOP after the 20th week of gestation is permitted provided the continuation of pregnancy will result in a severe malformation of the foetus or pose a risk of injury to the foetus (Termination of Pregnancy Act, No.92of 1996, 1996). As the act does not define the term severe, when offering TOP in hospital settings such as Groote Schuur Hospital (GSH), the internal consensus policy of the department needs to be considered.

At GSH, TOP after the 20th week gestation is permitted if there is significant evidence that the foetus will have a severe disability or has a life limiting condition. Cases that may fit that definition are discussed on an individual basis with a multidisciplinary team to decide on options that are available for the client (K Fieggen, Personal Communication 2017, 10 June). Therefore, before offering TOP after the 13th week of gestation, the gestation and the prognosis of the condition must be considered to determine if the abnormality allows for the option of TOP according to the Choice of Termination Act and the internal policy of the unit. In some cases late termination of pregnancy (LTOP), also known as fetocide may be offered to clients for a serious congenital abnormality. Even when this option is available to women, they take the gestation into account and often believe that if the abnormality had been diagnosed earlier, they may have considered the option of TOP differently. In a study by Benute et al. (2012), advanced gestational age was among the reasons why women decided not to request the judicial authorisation for termination of pregnancy required in their country. Even when women have this option and it is solely their decision (Termination of Pregnancy Act, No. 92 of 1996, 1996) although they may
choose to discuss their options with their families and consider CAs in the context of their family system.

**Decision-making**

Decision-making is difficult and women generally feel it is their responsibility to decide on terminating the pregnancy, but often that decision is influenced by their partners (Jaques et al., 2004). “Counselees bring values, beliefs, experience, previous decisions and information, both correct and incorrect, to the process of decision making” – Weil (2000:137). These values and beliefs affect the manner in which the information provided is perceived and interpreted to make a decision (Weil, 2000). The beliefs or meaning attached to parenthood may be affected following the diagnosis of a congenital abnormality. A child represents consummation of a relationship and also is a confirmation of fertility (Weil, 2000) making a child important for the family system. However decision making is influenced by various internal and external factors. These factors include the client decision making styles (Veach, LeRoy & Bartels, 2003) which determine the manner in which the client will make a decision. For example, a person with a fatalistic decision making style leaves the decision to fate whereas a planful decision making style involves rationalising the situation by considering the emotional and, cognitive circumstances of the situation. Other decision making styles include intuitive, agonizing, delaying, impulsive, compliant and paralytic (Dinklage, 1966). Other factors that affect decision making as described by Mealey (1984) are: medical constraints, financial constraints, legal and societal values, family values, client motivation and values, client personality and also counsellor constraints (i.e. financial, test availability etc.). The client decision making styles and the other factors that affect decision making can either facilitate or hinder the decision making process. It is therefore essential for the counsellor to assess the decision-making style and also the internal and external factors that may potentially affect the decision making process (Veach, LeRoy & Bartels, 2003). During the decision making process, clients undergo a search for meaning once a diagnosis is made (Weil, 2000).

**Factors affecting decision making**

**Information**

The Genetic counsellor should be able to assess the client’s information needs. Information regarding the condition, available options and extra support through referrals to support services can enhance the counselling session (Morris et al., 2015) and thus
empower the patient. However, language barriers, privacy and the timing of the session may hinder the experience for the client (Morris et al., 2015). In a Swedish study population, having the right amount of accurate information from the genetic counsellor was shown to influence the decisions made, especially by parents considering terminating the pregnancy (Asplin et al., 2012). In this study, 25.6% of women in the group felt that the information given was not adequate to make a well informed decision. Detailed information about the foetal anomaly is not always advantageous to the decision-making process and may depend on what women have decided about TOP. In the same study it was found that 71.4% of women opting to continue with their pregnancies did not find the information about foetal anomaly to be useful in their decision making process, whereas 88.4% of women who terminated their pregnancies found the information very useful (Asplin et al., 2012).

In our setting a significant number of the women are from low to middle income backgrounds and some have no formal education making it important for the counsellor to communicate the information at the level of understanding of the patient (Morris et al., 2015).

**Family and community**

Family and community play significant roles in the lives of women with children with a congenital abnormality as they can assist the women in coping with the situation. Some family members play the role of the major support structure and assist in relaying information to relatives about the condition (Morris et al., 2015). More commonly in black African families, as the grandmothers often serve as the care givers in the home, they are the decision makers in the family and are a source of wisdom in family related matters including healthcare (Penn et al., 2010; Kerr et al., 2008). In the past grandmothers were considered responsible for reproductive matters in the family too and could choose to end the life of a neonate born with a disability. However this cannot be practised any longer as most children are now born in hospitals and it is not a legal practice. (Morris et al., 2015). Even so, grandmothers are still seen as the gatekeepers (Kerr et al., 2008), making it essential that they understand the disability and the causes of it. They may, however, dismiss the information that the counsellor gives if it does not correlate with what they believe is the cause (Morris et al., 2015). Even in prenatal care, pregnant women do not always make decisions regarding their pregnancies alone, but rather with their partner (Benute et al., 2012) or other family members, such as the child’s grandmother (Morris et al., 2015).
Family and community views can influence an individual’s perception of disability and hence their decision to terminate an affected pregnancy (Weil, 2000). In some communities, disability is shunned and thus the parents have a fear of being discriminated against (Harries et al., 2007). Because of this some parents may choose not to disclose their child’s disability to anyone. Usually, in black African communities, the genetic causes of CAs are not understood making the concept of disability frightening. This sometimes leads to fathers ending their relationship with the mother and some of these mothers hide their children from the public (Morris et al., 2015). Although the community might not understand the genetic contribution, they usually have their own beliefs regarding probable causes of CAs. These include, but are not limited to, lifestyle-related causes (eating culturally forbidden food or wearing tight clothes), behaviour-related causes (promiscuity, laughing at others with disability), social causes, cultural causes (not performing cultural rituals) and consanguinity (Penn et al., 2010; Ingstad et al., 1997).

Even though disability is stigmatised, TOP and spontaneous abortions may be seen as something to be even more ashamed of, to the extent where women would rather have a child with a disability than have people know that they “lost” the child (Penn et al., 2010). An additional factor is the importance of bearing children. Women are expected to reproduce and have a lineage; TOP would result in one less child in the family. Inability to bear children is also stigmatised in some communities (Penn et al., 2010; Ingstad et al., 1997). There are however family members who would support TOP for certain CAs as caring for a child with special needs would be a great challenge (Penn et al., 2010).

**Ethnicity**

When considering family dynamics in counselling sessions regarding TOP for CAs, the ethnicity of the client should be considered as there has been a correlation between TOP uptake for serious conditions and the ethnicity of the clients (Hawkins et al., 2013; Todd et al., 2010).

In a United States of America (USA) study, Hispanic and Filipina women were least likely to terminate a pregnancy affected by a chromosomal abnormality when compared to women from Asian, Asian-Indian and Caucasian populations (Hawkins et al., 2013).

In a South African cohort, statistical significance was found between the ethnicity of clients who chose to continue with the pregnancy and those who terminated the pregnancy for a severe foetal abnormality (Todd et al., 2010). Factors found to contribute to this is this study included the fact that black women presented later for antenatal care when
compared with clients from other ethnic groups. In addition black women were more likely to believe that everything that happens is because of fate, and that the outcome is predetermined. TOP is viewed differently amongst different ethnic and cultural groups. In certain communities in South Africa, TOP is stigmatised. Although women are aware that they have a right to TOP, either by choice before 13 weeks or for medical reason later in the gestation, they may not consider it as a right due to their beliefs (Harries et al., 2007). Even after the law allowing for first trimester terminations was passed in part to address the high rate of illegal abortions, the stigma related to abortions is still substantial in South Africa. As a result, women would often prefer seeking TOP services in a different residential area than in their own community for fear of being recognised (Harries et al., 2007).

**Religion**

Besides ethnicity, religion also affects perspectives on TOP. In many religions TOP has been stigmatised even for CAs and this will influence religious women who may attempt to find reasons to have a child with a serious condition. TOP has been recognised to not be permissible in various religions as it is considered to be taking a life and therefore a sin or murder in the eyes of God / the Creator (Mookamedi et al., 2010; Harries et al., 2007). Some of the women who decided not to terminate their pregnancy believed that the baby was a gift from God and would be well after birth. Others believed that a pregnancy should not be interfered with preferring to allow nature to take its course rather than actively intervene. (Govender et al., 2015). Due to firm religious beliefs about TOP, clients may feel stigmatised by members of their religious community to the extent of a church threatening excommunication if it becomes known that an individual terminated a pregnancy (Mookamedi et al., 2010;). Therefore some women choose to keep the TOP as a private matter between them and God (Harries et al., 2007). In Christianity, it is believed by some that life begins at conception (Stuck, Faine & Boldt, 2001). However, church members may turn to church leaders for advice with regards to TOP for a serious CA. Some church leaders will support congregants if they choose to TOP depending on the abnormality, whilst others would not support TOP irrespective of the severity. Down syndrome is not considered to be as severe as trisomy 13, trisomy18 and anencephaly. Ministers are more likely to discourage TOP for less severe conditions and more likely to support TOP for severe life-threatening conditions (Stuck, Faine & Boldt, 2001). Individuals though may make their own decisions based on their personal views. Women may believe that having a child with a disability is a punishment or a gift from God (Penn et al., 2010). How they
view the circumstances of their pregnancy and the options available may be based on their religion and disclosing TOP within the church will depend on the position of their church.

Islam has different sects or schools that have different views on when TOP can be performed as abortion is not permissible from the time that ensoulment is believed to occur. Ensoulment is the stage of gestation where the embryo is believed to have a soul. There are five main schools and sects and each has a different time for which they believe ensoulment has occurred and when a woman may terminate a pregnancy. For all, TOP is not permissible for simple social reasons but may be considered if the reason is legitimate, taking into context the gestation. The Sunni Maliki and Sunni Hanbali schools believe that ensoulment occurs at 40 days and thus TOP for serious CAs may occur before that. The Sunni Hanafi and Sunni Shafie schools and Shi’ite sect believe that ensoulment occurs at 120 days gestation and thus TOP for a legitimate reason is permitted until then. In the Islamic community, medical reasons for which one may have a termination include a serious foetal abnormality causing profound intellectual disability and if the foetus poses a risk to the mother. Both the mother and the father usually need to give consent for the procedure in this culture (Al-Matary & Ali, 2014). However, unlike many Islamic countries, South African law allows the woman to decide on TOP alone and the partner or husband’s consent is not necessary.

Although these laws for TOP in the Islamic community may only be enforced in Islamic countries, they do impact on the decisions Muslims make in South Africa regarding TOP even for foetal abnormalities. Women may choose not to end a pregnancy because of their religious beliefs. Only 15.1% of the population in South Africa is not religious, suggesting that religion plays an important role for a large proportion of our population (Statistics South Africa, 2001) and moulds both day- to- day life and major decisions such as TOP. Religious groups consider the severity of the condition when permitting a woman to terminate a pregnancy indicating that the quality of life of the foetus and the family is an important consideration. Some of the reasons women give for to continuing with their pregnancy include religious values and beliefs. (Govender et al., 2015)

Quality of life

The perceived quality of life of the child plays an important role when making a decision to TOP. A study by Govender et al. (2015) in South Africa explored women’s experiences of late diagnosis of foetal anomaly and decision making about late TOP. Out of the 15 women in the study, 10 chose to continue with the pregnancy and five decided to
terminate the pregnancy. Common reasons for opting for TOP included perception of poor quality of life of the baby and inability to cope with a severely handicapped child (Govender et al., 2015). Pregnant women’s views and attitudes concerning late TOP were also explored in another study from Kwazulu-Natal. (Ndjapa-Ndamkou et al., 2013). Some of the responses in this study were similar to those in the study by Govender et al. (2015). The reasons for terminating the pregnancy in this study included healthcare costs and the quality of life of the child as well as the parents’ perception of their ability to cope with a severely handicapped child. These studies (Govender et al. (2015) and Ndjapa-Ndamkou et al. (2013)) also show that even though one may expect many women to terminate a pregnancy with a lethal prognosis, the majority of women in these studies opted to continue the pregnancy.

The probable outcome of the pregnancy and severity of the condition is a consideration. Various studies have demonstrated that some pregnancies complicated by severe congenital abnormalities may not continue to full term irrespective of intervention and many of these infants that are live-born have a short lifespan. In a study by Houlinhan et al. (2013), 46 pregnancies with T18 and 24 with T13 were identified. Only 48% of infants with T18 and 46% of infants with T13 were born alive with a median survival of 1.5 days for T18 infants and 7 days for the T13 infants. Of all the infants in this study, only one infant with T13 survived past one year of age (Houlinhan et al., 2013). Having a child with a serious condition will typically mean a poorer quality of life for the family and the child than when abnormalities are less severe (Lemacks et al., 2013). These children often require medical intervention from birth with many doctors’ visits and sometimes specialised equipment which can have an impact on the family with implications for financial resources, psychosocial stress and relationships between family members may be strained (Lemacks et al., 2013)

Despite this, the decision to terminate a pregnancy may not always depend on the expected prognosis. In a study in the United Kingdom (UK), the uptake of termination of pregnancy for Down syndrome and nine other congenital anomalies associated with a poor prognosis (as defined by the UK Fetal anomaly screening Programme (FASP)) was compared (Budd et al., 2015). The nine conditions compared to Down syndrome are trisomies 13 and 18, spina bifida, serious cardiac conditions, renal agenesis, lethal skeletal dysplasia, exomphalos anencephaly and congenital diaphragmatic hernia. In this study, of the anomalies that were detected antenatally, there was a higher rate of TOP for pregnancies affected by Down syndrome (86%) when compared to disorders in the FASP9
group (70%) despite the mortality rate of Down syndrome livebirths being significantly lower (1%) than that of FASP9 group anomalies (10%). This study indicates that the decision to TOP for CA is also dependent on how familiar people are with the condition (Budd et al., 2015). Down syndrome is the most common chromosomal abnormality, so more people are aware of it than some other more serious conditions, and may base their decisions on their knowledge or lack thereof. However there are many other factors that play a role when making a decision about TOP and include parents’ perception of the effects the child would have on the family (Menahem & Grimwade, 2003).

**Finding meaning**

Following the diagnosis of a foetal abnormality, expectant parents attempt to find meaning in order to rationalise the diagnosis in line with their religious or spiritual framework and also to understand the condition on a deeper level than the scientific explanations of the aetiology (Weil, 2000). This may lead to compartmentalisation, where the cause of the condition is understood and is accepted on a scientific level but a different, more personal reason is invoked to explain the event (Weil, 2000). Victor E. Frankl stated that “I doubt whether a doctor can answer this question in general terms. For the meaning of life differs from man to man, from day to day and from hour to hour. What matters, therefore, is not the meaning of life in general but rather the specific meaning of a person’s life at a given moment” (Frankl, 2008:113). This reflects that the search for meaning is intensely personal but is also affected by circumstances at a certain point in time. This is the experience for women when they try to understand or give reason to why their child is affected with a CA. This also suggests that attaching meaning is necessary to assist the decision making process for these women. It is clear to that many different aspects of a woman’s life will have an impact on both her experience and her decision on terminating a pregnancy once a serious congenital abnormality has been diagnosed.

**Rationale for the Study**

There is limited information on the decision making process regarding termination of pregnancy for a serious condition in South Africa, particularly in the Western Cape. The studies by Govender et al. (2015) and Ndjapa-Ndamkou et al. (2013) found similar results, but these studies were conducted in similar settings and the study participants were those considering late TOP. In this proposed study, factors influencing the decision to terminate or continue with a pregnancy complicated by a serious foetal abnormality is investigated. The difference between this study and the two from KZN is that it hopes to explore how the
women came to their decisions for TOP or not, not just consider their attitudes, views and experience of the process. The study will include women at any period of gestation which may give different responses. The different setting may also have an effect, as the way of life of the participants may not be the same. The study by Govender et al. (2015) is a quantitative study. The advantage of a qualitative study over a quantitative study is that in-depth data can be obtained. The participants are able to tell their stories allowing for spontaneous disclosure which may give rise to new areas of research. Qualitative data also allows for a larger range of interpretation (MacFarlane, Veach & LeRoy, 2014).
Aims and Objectives

Aim
To explore women's decision making process of whether or not to terminate a pregnancy affected by a serious condition and the factors that contribute to the decision.

Objectives

- To explore the termination of pregnancy decision making process of women who have a pregnancy affected by a serious condition.
- To explore the role that genetic counselling, family and community play in decision making.
- To explore the different factors that affect decision making at different maternal and foetal gestational ages.
Chapter 2: Methodology

Introduction

In this chapter the methods used in the study will be described. This includes the study design and framework. The study population as well as the research setting, participant recruitment, data collection and data analysis will be included. The ethical considerations and how research trustworthiness was obtained will also be explained in this chapter.

Study Design

This study explores the decision-making process of women offered termination of pregnancy for a serious congenital abnormality. Since this requires rich descriptions of their experiences, a qualitative research approach was chosen. An exploratory study allows for the studying of a field or topic that is not well-researched to gain a better understanding about it and hopefully form a basis for future research, including quantitative research (MacFarlane, Veach & LeRoy, 2014; Singh, 2007). Qualitative research is subjective and allows for the participants to tell their stories about their experiences and understanding of their situation. This method also allows themes to be extracted from the data, and unlike quantitative research, it is usually not based on a hypothesis or pre-specified concepts but rather allows for a theory to be formulated.

Principles of phenomenology, which explores the lived experiences of people, were drawn on as an approach for this study (Creswell, 2013). The current study aims to explore women’s decision making process of whether or not to terminate a pregnancy affected by a serious condition and the factors that contribute to the decision. Their shared experience was, having to decide whether or not to terminate their pregnancy given that the probable prognosis for the pregnancy outcome was expected to be poor. This approach of phenomenology allows for a subjective-objective perspective to be observed, where the subjective perspective is the individuals own experience and the objective is what the participants all have in common in terms of the shared experiences.

Semi-structured interviews are commonly used in qualitative studies to acquire in-depth data from the participants. The participants are able to tell their story and how they view and understand the world. The data collection in the form of face-to-face individual interviews is ideal for sensitive issues such as termination of pregnancy (TOP) and to obtain rich descriptions of the women’s experiences (MacFarlane, McCarthy & Veach, 2014). In semi-structured interviews, a question guide is utilised with appropriate prompts
for further clarification and elaboration (MacFarlane, McCarthy & Veach, 2014). Semi-structured interviews make provision for the modification of questions, for example changing the wording and excluding questions in the question guide that are inappropriate for the participant. It allows for participants to respond in an open manner and in their own words. The questions are open-ended and in neutral, non-leading language to ensure that all the data reflects the true experiences of the participants (MacFarlane, McCarthy & Veach, 2014).

**Study Population**

The participants in the study are women who have had serious congenital abnormalities detected in their foetus on ultrasound examination. For this study serious congenital abnormalities are defined as conditions associated with a shortened lifespan or significant disability despite medical intervention.

**Inclusion Criteria**

Women with a pregnancy complicated by a serious congenital abnormality who have been offered termination of pregnancy at any stage in the pregnancy and have had genetic counselling were included in this study. The women were 18 years of age or older and were available to come for the interview and spoke a language familiar to the interviewer.

**Exclusion Criteria**

Women who had a pregnancy affected by Down syndrome and congenital abnormalities not considered serious according to the definition used were excluded from the study.

**Participant Recruitment**

The participants recruited for the study are patients that were seen at the Foetal Medicine Unit (FMU) at Groote Schuur Hospital (GSH), Cape Town, South Africa. The FMU at GSH is a referral centre for high risk pregnancies for patients from the Metro-west region of the Western Cape. Informed consent was obtained from all the participants (refer to section 10.2 on Informed consent, Appendix C)

**Participant Identification**

Participants were identified using the Division of Human Genetics Pregnancy Counselling Database (PCC, University of Cape Town (UCT), Cape Town, South Africa). Data for all patients seen for prenatal counselling at the GSH FMU by the genetic team are entered
into the database. The data were sorted and only those patients who had a pregnancy diagnosed with a serious abnormality who were offered termination of pregnancy were selected. Women were selected as potential study participants if they had a serious foetal abnormality diagnosed from January 2014 to October 2016. This was to ensure that the women would be more likely to remember the details of the experience and thus be able to give more in-depth information. Women could only be interviewed at least six weeks after the end of their pregnancy to allow for the initial acute grief stage of the death or birth of the infant to subside. This is typically the time of post-delivery counselling provided in the department. Using a Microsoft Excel spreadsheet the potential participants were sorted into four different categories:

- Women below 30 years of age and diagnosis made early in gestation (before 20 weeks gestation).
- Women below 30 years of age and diagnosis made late in gestation (after 20 weeks gestation).
- Women above 30 years of age and diagnosis made early gestation
- Women above 30 years of age and diagnosis made in late gestation.

A total of 129 women were identified and participants in each group were randomly selected using Microsoft Excel function. An additional five participants were identified during a post-delivery counselling session by the clinician / genetic counsellor. In total 134 women were identified as potentially suitable for inclusion in the study.

Recruitment

The women were recruited by the clinician / genetic counsellor who had initially counselled them on the pregnancy findings. This was to allow the women to be approached by someone other than the researcher who was familiar to them in order to feel free to decline participating in the study. This form of recruitment also allowed the counsellors to follow-up with their patients. The participants were informed about the aims and objectives of the study and once they agreed to take part, they gave permission to be contacted by the researcher. The researcher then contacted the participants later to further discuss the research, to answer any questions they had and to set up the date and time for the interview. This however had disadvantages as the researcher occasionally could not reach the participants, hindering the recruitment process. Based on this, the recruitment method changed to allow for the researcher to be present when the counsellor contacted the participant in order to speak to the woman at that time if she agreed to participate. The participants were informed that they would be able to be reimbursed for transport costs, which was a concern for some of them.
For the study, there was an over-recruitment anticipating that some women may agree to take part but not arrive on the day (MacFarlane, Veach & LeRoy, 2014). Forty women were invited to participate, however only 12 women were eventually interviewed. Reasons for not being interviewed were that some women declined participation, others were not contactable and some lived out of the study area.

The women who were recruited and had an appointment set for the interview were sent a reminder message or phone call a day or two prior to the interview to ensure that they did not forget about the interview and to confirm the time. The women were also called or sent a message on the morning of the interview asking them if they were still able to attend.

Reasons some of the women who had agreed to participate did not attend the interview:

- Partner did not agree
- Did not have time (busy at work)
- Just could not find a suitable time
- Death of a sibling at the time of the interview
- Misunderstanding about the day of interview
- Did not have transport

Most of the women who agreed to be a part of the study but did not come for the interview did not answer their phones on the day of the interview. The reason for this could be that the women did not really want to be a part of the study but felt obliged to agree to take part since their health care provider had contacted them.

There was heterogeneity in the final group of 12 participants who came from different backgrounds with different pregnancy outcomes. This allowed for theme extraction across people of different backgrounds (See tables 1 and 2).

**Description of participants**

The demographic data of the 12 participants are summarised in chapter 3 table 1.

**Research Setting**

When interviewing participants it is important to choose a place that is not only accessible to the participants, but also safe and private (MacFarlane, Veach & LeRoy, 2014). The participants were given the option of choosing the venue for the interview that they felt comfortable with. These options included the UCT Division of Human Genetics offices, the GSH Maternity Ultrasound unit or the Genetics Clinic at Red Cross War Memorial Children’s Hospital (RCWMCH). All three of the venues were convenient in terms of public transport and are a fair distance from where all the participants reside. There was no
geographical restriction for the participants who took part in the research referral pathways to GSH are based on residential location.

The rooms used for the interview were set up in a way which made the women feel comfortable and welcomed. These rooms were also private to ensure that the participants felt able to express themselves.

**Data Collection**

Data was collected in the form of face-to-face open-ended individual interviews. These were ideal for the study as the research topic is sensitive and very personal (MacFarlane, Veach & LeRoy, 2014). All but one interview were conducted in English. This interview was in English and isiXhosa as, although the participant understood English well and could speak the language, she felt that she could express herself better in her mother tongue. This did not hinder the data collection as the researcher understands isiXhosa, although she does not speak it fluently. The questions were asked in English and where necessary the participant responded in isiXhosa. The interview was later transcribed by a lay translator in the presence of the interviewer who has a background in genetics and whose home language is isiXhosa.

All the interviews were conducted by the researcher to ensure consistency (MacFarlane, Veach & LeRoy, 2014). Consistency in the interviewing process allows the data to be reliable and constant. The interviews ranged from 21 minutes to 1 hour and 10 minutes. The average interview time was 42 minutes. Only one interview was not completed (not all the questions on the question guide were answered) as the participant seemed to still be experiencing unresolved grief and was upset that there were no post-mortem results for the child she lost (She was referred for post-delivery counselling). A question guide (Appendix B) was used with the order being flexible to respond to what the participant was sharing. Demographic information was collected using closed ended-questions at the beginning of the interviews, which allowed for rapport to develop between the researcher and participant. The first open-ended question of the guide was a general question which allowed women to explain their experience with having to make a decision regarding TOP.

Before commencing with the research interviews the researcher had two mock test or practice interviews which were observed by her supervisor. The interviewees were two genetic counselling interns and both had experience with qualitative research. Both the supervisor and the interviewee gave feedback at the end of the interview regarding the questions asked, how they were asked including appropriate probing and reflecting. This
process allowed the researcher to modify questions and the manner in which the questions were asked. This included asking questions in a neutral manner, without leading the participant’s answers (MacFarlane, Veach & LeRoy, 2014)

Gaining rapport with the participants began during the recruitment process and was strengthened with the order in which the questions were asked (MacFarlane, Veach & LeRoy, 2014). The more sensitive questions were asked later in the interview, allowing participants to become more relaxed, to feel free to answer questions honestly and enabling them to disclose deeper feelings and thoughts. The first question was a broad open-ended question which allowed the women to discuss their overall experience. This gave rise to issues that the interviewer followed up on. The advantage of this question was that external ideas were not put into the women’s minds upfront and what they said was used to explore their experience further keeping in mind the aim of the study. Questions not answered by the first broad question were subsequently asked. The questions asked at the end of the interview were less emotionally charged to allow the participants to leave the interview without feeling saddened and to give them hope by thinking about the future.

The interviews were voice recorded and transcribed verbatim so that all the information shared during the interview could be captured. Notes were made during the interview regarding non-verbal cues, emotional reactions and issues the participants emphasised.

**Data Analysis**

The recordings were transcribed verbatim by the researcher and a research assistant. The data transcribed by the research assistant was verified by the interviewer who read through the transcript while listening to the interview.

The data was analysed using thematic data analysis. Thematic data analysis relies on extracting themes from the data. Using an inductive data analysis approach the themes extracted are based on what the participants said and not on any theories in the literature. An inductive approach allows the data to “speak” to the researcher without trying to make it fit into any pre-existing theories, codes or researcher biases (Braun & Clarke, 2006). It is not however possible for the data to be coded with complete absence of the researcher’s preconceptions so the researcher needs to be aware of her own biases and try to minimise these when coding the data. Clinical practice exposure assisted the researcher in separating her personal views and feelings from the research to ensure that the process was not hindered. The researcher reflected on the process by talking to peers and
supervisor. The researcher showed respect and empathy during the interviews, and used neutral language.

The thematic analysis was conducted as described by Braun & Clarke (2006). According to these authors, thematic analysis is comprised of six steps which the researcher used as a guide. These include 1) familiarising yourself with the data 2) generating initial codes 3) searching for themes 4) reviewing the themes 5) defining and naming the themes. The sixth step is producing the report.

1. Familiarising oneself with the data

Becoming familiar with the data began at the data collection stage. Since the researcher conducted all the interviews, it allowed the researcher to become familiar with the data from the beginning and develop initial thoughts. The data transcription of 11 interviews was conducted by the researcher herself. This is advantageous as it is a good way for one to become familiar with the data (Riessman, 1993). In a way, the transcription stage is an early stage of the thematic analysis as a deeper understanding of the data is attained. The transcriptions were read, while also listening to the interview. Reading the transcript concurrently with listening allowed the researcher to take note of tone of voice and mood of the participant. Notes about patterns or ideas were made in the margins as the transcripts were being read. Only one interview was transcribed by the research assistant. The researcher first became familiar with the data when proof reading the transcript while listening to the recording.

2. Generating the initial codes

This stage involves extracting the first set of codes from the data. The researcher began by open-coding, which is the writing of the headings, thoughts or anything that was thought to be interesting about the content in the margins of the text (Elo & Kyngäs, 2007). True to the phenomenological inductive approach, the coding aimed to represent the entire data set, and not just focus on one particular feature of the data. The data set was coded manually by first highlighting and writing notes in the text and later “post-it” notes were used on a poster. With each code, supporting data in the form of extracts from the interviews were placed with each code. As many codes as possible were analysed for potential themes. The similar codes were then grouped together.

3. Searching for Themes

Searching for themes involves dividing or grouping the codes into higher order categories. This step involves analysing the codes and sorting them appropriately under broader headings which are to become the themes (Elo & Kyngäs, 2007; Braun & Clarke, 2006).
The codes were sorted into categories by using a mind map. This was useful in that it allowed for relationships between different codes to be recognised and also identified the codes that do not belong together. The codes that were found to be similar were categorised together under a theme. This process involved shuffling and reshuffling the codes into categories that fit together well. Some of the codes with their extracts became subthemes with other codes falling under these subthemes.

4. Reviewing the Themes
Refining of the themes occurs at this stage by reviewing each theme. Themes identified by the researcher that were seen not to have enough data to support them were collapsed into others that and themes that were found to be similar to each other were combined to form a single theme. Fifteen themes in total were identified and discussed with a peer who has experience with qualitative research. This discussion assisted in further collapsing and combining of themes that seemed to have a relationship. This resulted in six broad themes, allowing some of the codes to become subthemes (domains) and others become the categories (which fall within the domains). These themes were further discussed with the supervisor assisting in ensuring both internal homogeneity of the content in each theme and external heterogeneity where all themes are clearly distinguishable from each other. Although the themes had to have heterogeneity, they still had to represent the data set and have some adherence with each other. Therefore data reviewing occurred at two levels: the first was to review the data extracts in each theme to make sure they form a clear pattern and that they are all congruent. The extracts that did not “fit” the theme were re-evaluated to find a theme they fell under or, if needed, a new theme could be created. The second level involved reviewing and reading the entire data set to determine if the themes represented all the data. This also allowed for additional data, thought to be significant but not yet coded, to be coded into the themes. A theme map was devised after this review.

5. Defining and naming the themes
The themes needed to be refined and named appropriately. The names had to be “concise, punchy and immediately give the reader a sense of what the theme is about” (Braun & Clarke, 2006:93). At this stage each theme was analysed to determine what aspect of the data it is communicating and how it fits with the research question i.e. the essence of the theme. This step is important as this is what the reader will interact with and required to understand the data. Each theme was described in a couple of sentences
and the themes that could not be explained in short paragraphs were further refined. The themes were analysed so that overlapping ones could be collapsed and collated together.

During the process of data analysis there was peer-debriefing in which the data was discussed. This was done to challenge the codes and themes obtained and to also assist in enhancing the structure of the data. The codes and themes were further discussed with and challenged by the supervisors to make sure the themes represent the dataset.

Due to her clinical experience, the researcher reflected on her own personal biases and preconceived ideas before and during the research process regarding the topic. These biases and preconceptions included the following:

- The researcher assumed that the majority of the decisions made regarding the termination of the pregnancy were based on religious beliefs and prognosis.
- The researcher assumed women would choose a TOP based on poor quality of life of the child taking into account that a significant number of the women attending the clinic are from low socioeconomic backgrounds and therefore would consider the impact of the child’s outcome on the family.
- All the participants were expected to still be deeply saddened by the experience.
- Based on the religious beliefs and personal views regarding TOP of the researcher, she expected that some of the women would share feelings of regret regarding their decision to TOP.

**Research Trustworthiness**

The research trustworthiness refers to the quality of the research. The quality of the research is dependent on research rigour, which includes a systematic approach and high standard as well as the relevance of the study (Baillie, 2015). The trustworthiness of the research can be assessed using four principles; credibility (how well the themes cover the data set), dependability (how reliably the research is conducted), transferability (ability to repeat the study and obtain similar findings) and confirmability (the researcher’s ability to recognise their position and any biases or preconceptions) (Baillie, 2015; Lincoln and Guba, 1985). To uphold these four principles, each participant was represented in the results with peer debriefing and discussion with the supervisor occurring throughout the data analysis. The data collection and analysis were described in detail and the link between the data and the results demonstrated through data extracts. The characteristics of the participants (tables 1 & 2) and the research setting were described in detail to enable the reader to make a judgement about the potential for transferability (Baillie, 2015; Elo & Kyngäs, 2007). A heterogeneous participant sample was used to allow for variability.
within the data. Throughout the study, the researcher reflected on personal beliefs and biases regarding the research topic thus enhancing academic rigour.

**Ethical Considerations**

**Ethical Approval**

The research project received ethical approval from the University of Cape Town Human Research Ethics Committee (HREC) (Appendix D).

**Informed Consent**

In the study there were two phases of consent. The first phase involved consent to contact being obtained by the clinician/ genetic counsellor recruiting the participant. The reason for the clinician contacting the researcher was to ensure that the participants would be able to be honest regarding taking part in the study, to allow them to feel able to decline participation. The genetic counsellor explained the research aim and objectives and how the data would be collected. They also explained the reason for conducting the study and emphasised that participation is voluntary. Agreement to take part included the women giving permission to be contacted by the researcher. The researcher then contacted the participants regarding the study and gave them the opportunity to ask questions. The participants were also informed that they are welcome to ask questions anytime and they were given the researcher’s contact details. The second phase of consent took place on the day of the interview. The researcher together with the participant went through the information sheet and consent form (Appendix C) ensuring that the participant understood the study and what it entailed. Once the participant agreed to take part, the consent form was signed and the participant was given a copy which also contained the contact details of the researcher, supervisors and HREC chairperson. All the participants who took part in the study were adults and had the capacity to give informed consent. The participants understood that they were able to withdraw from the study at any time and that the obtained data would be used for scientific purposes.

The participants were not offered any incentive to take part in the study but they were offered R50.00 reimbursement for transport. One woman received R70.00 as she resided further than all the other participants. Considering that most of the participants are unemployed, having to pay for transport would have limited their ability to participate if they would not be able to afford travel costs.
Privacy and Confidentiality

The privacy and confidentiality of the participant were upheld by storing all confidential and identifying documents separate from the data. The interviews were recorded verbatim and removed from the audio recorder once uploaded onto the computer. The raw data and transcripts were saved on a password protected computer which only the researcher had access to. The participants were given pseudonyms. The data from the research were backed-up on an external hard drive that was stored in a locked cabinet and will be deleted after conclusion of the study.

Risks/harm and benefits

The potential harm of the study was that the research was of a sensitive nature and could evoke strong feelings that could upset the participants. The participants may have felt uncomfortable discussing intimate details of their experience with a complicated pregnancy. The women were made aware of this during the informed consent process and had the freedom not to answer any questions they felt uncomfortable with. The researcher has had clinical and theoretical training in the Principles and Practices of Genetic Counselling courses and has also attended a Loss, Grief and Bereavement workshop. She therefore has the skills to be able to recognise unresolved grief and emotional distress. A qualified genetic counsellor was available at all times to assist if there was a need. There was a potential risk that the women might experience some sadness or psychological distress after the interview, and as a result they were given the contact details of the clinic, counselling services and a support group that assists bereaved parents and family members in dealing with their loss.

The benefit to the participants in this study is that they had another opportunity to talk about their experiences. Being able to talk about their experience might have a therapeutic effect. For those who had not been counselled after delivery or who had additional questions, a genetic counselling session and social work referrals could also be arranged if needed.
Chapter 3: Results

Introduction

In this chapter the main findings of the study will be discussed. The results that will be discussed include the themes that emerged from the data. The participant demographic information as well as pregnancy outcomes will be included. Pseudonyms will be used for all participants, family members and the healthcare practitioners whose names were mentioned. All the interview excerpts included are verbatim extracts from the transcripts. The excerpts in some instances include the researcher’s additional notes and/or explanations in parenthesis. Punctuation marks were inserted to aid reading and understanding of the excerpts.

Participant Demographics and Pregnancy Information

The demographic details of the 12 participants are summarised in table 1. These women were assigned pseudonyms to de-identify the data. Pseudonyms were assigned rather than numbers as it was felt that referring to the women as numbers is too impersonal. Six of the women were black (African ancestry) and six were mixed ancestry and 11 of the 12 interviews were in English. One interview was in isiXhosa and English.

The information regarding the affected pregnancy as well as the number of previous pregnancies and children the women had was included as might have impacted on how the participants experienced the pregnancy complicated by a serious abnormality. This information is summarized in table 2. The pregnancy outcomes were termination of pregnancy (TOP), intrauterine death (IUD), early neonatal death (NND) and surviving live-born children (LB).

For three surviving live births, the parents did not believe their children are severely affected and they have not required extensive medical intervention and are doing better than expected. The fourth child has severe spina bifida and requires a lot of medical care.
Table 1: Demographic Information

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Marital Status</th>
<th>Ethnicity</th>
<th>Educational Background</th>
<th>Religion</th>
<th>Residence</th>
<th>Gestation at diagnosis</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>38</td>
<td>Married</td>
<td>Black</td>
<td>Higher certificate/Diploma</td>
<td>Christian</td>
<td>Township</td>
<td>3 Months</td>
<td>Full-time</td>
</tr>
<tr>
<td>Nomvula</td>
<td>24</td>
<td>Stable Union</td>
<td>Black</td>
<td>Secondary Education (Grade 12)</td>
<td>Christian</td>
<td>Suburban</td>
<td>5 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Sindy</td>
<td>28</td>
<td>Single</td>
<td>Mixed ancestry</td>
<td>Primary School</td>
<td>Christian</td>
<td>Township</td>
<td>5 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Lucy</td>
<td>28</td>
<td>Married</td>
<td>Black (Congo)</td>
<td>Higher Certificate</td>
<td>Christian</td>
<td>Township</td>
<td>5 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Suzie</td>
<td>39</td>
<td>Married</td>
<td>Black</td>
<td>Higher Certificate</td>
<td>Christian</td>
<td>Township</td>
<td>5 Months</td>
<td>Full-time</td>
</tr>
<tr>
<td>Linda</td>
<td>38</td>
<td>Married</td>
<td>Mixed ancestry</td>
<td>Higher certificate/diploma</td>
<td>Islam</td>
<td>Township</td>
<td>8 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Faith</td>
<td>42</td>
<td>Married</td>
<td>Black</td>
<td>Primary School</td>
<td>Christian</td>
<td>Township</td>
<td>4 Months</td>
<td>Self-Employed</td>
</tr>
<tr>
<td>Sthembiso</td>
<td>24</td>
<td>Single</td>
<td>Black</td>
<td>Higher Certificate/Diploma</td>
<td>Christian</td>
<td>Township</td>
<td>4 Months</td>
<td>Full-time</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Marital Status</td>
<td>Ancestry</td>
<td>Education</td>
<td>Religion</td>
<td>Location</td>
<td>Duration</td>
<td>Employment</td>
</tr>
<tr>
<td>---------</td>
<td>-----</td>
<td>----------------</td>
<td>--------------</td>
<td>----------------</td>
<td>----------</td>
<td>------------</td>
<td>----------</td>
<td>--------------</td>
</tr>
<tr>
<td>Lerato</td>
<td>43</td>
<td>Married</td>
<td>Mixed ancestry</td>
<td>Secondary (Grade 12)</td>
<td>Islam</td>
<td>Township</td>
<td>5 Months</td>
<td>Full-time</td>
</tr>
<tr>
<td>Tumi</td>
<td>32</td>
<td>Married</td>
<td>Mixed ancestry</td>
<td>Secondary (Grade 8)</td>
<td>Christian</td>
<td>Rural</td>
<td>5 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Reneilwe</td>
<td>29</td>
<td>Single</td>
<td>Mixed ancestry</td>
<td>Secondary (Grade 11)</td>
<td>Christian</td>
<td>Township</td>
<td>5 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Refiloe</td>
<td>31</td>
<td>Married (Recently)</td>
<td>Mixed ancestry</td>
<td>Secondary (Grade 12)</td>
<td>Islam</td>
<td>Township</td>
<td>5 Months</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Participant</td>
<td>Maternal age at diagnosis</td>
<td>Gestation at diagnosis</td>
<td>Diagnosis/ Abnormality</td>
<td>Pregnancy Outcome</td>
<td>Planned or Unplanned Pregnancy</td>
<td>No. of miscarriages/stillbirths excluding affected pregnancy</td>
<td>No. of children excluding affected</td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>--------------------------</td>
<td>------------------------</td>
<td>------------------------</td>
<td>------------------</td>
<td>-------------------------------</td>
<td>-------------------------------------------------</td>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Mary</td>
<td>37</td>
<td>15 Weeks</td>
<td>Trisomy 18</td>
<td>TOP</td>
<td>Unplanned</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Nomvula</td>
<td>25</td>
<td>23 Weeks</td>
<td>Strawberry sign, holoprosencephaly, large multicystic dysplastic kidney</td>
<td>NND</td>
<td>Planned</td>
<td>0</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Sindy</td>
<td>24</td>
<td>14 Weeks</td>
<td>Complex cardiac defect: dextrocardia, bradycardia, atrioventricular septal defects</td>
<td>TOP</td>
<td>Planned</td>
<td>0</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>27</td>
<td>18 Weeks</td>
<td>Twins: Anencephaly</td>
<td>TOP</td>
<td>Unplanned</td>
<td>0</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Suzie</td>
<td>38</td>
<td>19 Weeks</td>
<td>Cleft lip and palate, macrocephaly and severe brain abnormalities</td>
<td>TOP</td>
<td>Unplanned</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Linda</td>
<td>38</td>
<td>32 Weeks</td>
<td>Spina bifida (Large meningomyelocele)</td>
<td>LB</td>
<td>Unplanned</td>
<td>2</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>GW</td>
<td>Diagnosis</td>
<td>Outcome</td>
<td>Status</td>
<td>NND</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-----</td>
<td>------</td>
<td>----------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td>-----</td>
<td>------------------------</td>
<td></td>
</tr>
<tr>
<td>Faith</td>
<td>41</td>
<td>12 Weeks</td>
<td>Holoprosencephaly</td>
<td>LB</td>
<td>Unplanned</td>
<td>0</td>
<td>3 (2 passed away)</td>
<td></td>
</tr>
<tr>
<td>Sthembiso</td>
<td>22</td>
<td>22 Weeks</td>
<td>Inferior Vermian Hypoplasia, nuchal oedema</td>
<td>LB</td>
<td>Unplanned</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Lerato</td>
<td>42</td>
<td>13 Weeks</td>
<td>Cystic Hygroma</td>
<td>IUD</td>
<td>Planned</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Tumi</td>
<td>30</td>
<td>24 Weeks</td>
<td>Lumbosacral Spina bifida: at least 6 segments involved</td>
<td>LB</td>
<td>Unplanned</td>
<td>0</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Reneilwe</td>
<td>27</td>
<td>22 Weeks</td>
<td>Limb body wall defect with ectopia cordis</td>
<td>TOP</td>
<td>Unplanned</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Refiloe</td>
<td>27</td>
<td>21 Week</td>
<td>Congenital Diaphragmatic Hernia</td>
<td>IUD</td>
<td>Planned</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

**Notes:**
- TOP: Termination of Pregnancy
- NND: Neonatal Death
- IUD: Intrauterine Death
- LB: Surviving Live-born
When the women were contemplating the option of termination of pregnancy for a serious congenital abnormality, the factors that influenced their decision were multifaceted. Five main themes emerged from the data that shed some light on their decision making process. With some of the themes and domains it was clear that amongst the women there were contradicting views on certain aspects indicating that the decision making process was multi-layered and unique to each woman.

The decision making took place over a period of time. It was a process and began in the hospital when they were offered TOP and they continued to contemplate their options when they went home. The decision making process took place in two main settings, in the hospital during the time of their prenatal visit and at home following the appointment or between hospital visits. The hospital setting included their experience with health care services which encompassed the health care received and the support or lack of it at the time of diagnosis. The home setting refers to interaction with family members, the community and their partners who impacted on the decision they made.

Further aspects of their lives had an impact on the decision the women made and how they made it and included in particular their roles and obligations as a woman with emphasis on child-bearing (theme 3). Having a child with a disability threatened this aspect of their lives and they tried to make sense of the entire situation and find the reasons why this had happened to them (theme 4). These pregnancies were precious to them, although some were not planned, all the women truly wanted to have their child. As a result they went through phases of losing and gaining hope for their child during the decision making process. The process did not only affect them while coming to a decision, but also affected them following the birth or death of the child, (theme 5). Although the women consulted with their families, partners and community members, ultimately they all made the final decision themselves.

**Themes**

The diagram below contains the summary of the themes and domains (subthemes).
Theme 1: Health Care Services

- Information
- Freedom of Choice
- Genetic Counselling
- Testing

Theme 2: Home

- Family
- Partner Support and Relationship Dynamics
- Community and Stigma

Theme 3: Being a Woman

- Precious Pregnancy
- I must decide

Theme 4: Finding Meaning

- Why did it Happen
- Religion
- Hope

Theme 5: The Aftermath

- Seeing the Baby Off
- Moving on
- The Unexpected

Figure 1: Summary of the themes and domains

Theme 1: Health care service

Health care services were an integral part of how the women experienced being informed of the diagnosis of foetal abnormality found on ultrasound. This theme incorporates the participants’ experiences at the Foetal Medicine Unit which was made up of genetic counsellors, medical geneticists, obstetricians and gynaecologists, foetal medicine experts and nurses as well as the birthing experience at the GSH Labour ward. The genetic counsellors and medical geneticists in this case will be referred to as the genetic specialists. The health care they received played a major role in their overall experience and for some, how and what they felt about their decision.
Domain 1: Genetic Counselling

Genetic counselling in this setting is provided for all women with a foetal abnormality detected on ultrasound for explanation about the findings and may include offering invasive testing and TOP if appropriate. It became apparent during the interviews that none of the women knew about genetic counselling and what it entails prior to being referred to GSH. As a result they did not know what to expect during the session. Due to the lack of knowledge regarding genetic counselling, some of the women expected to be informed of solutions for the pregnancy such as repairing the defect and the others expected that they would be told that there is nothing wrong with their foetus.

“I didn’t know what to expect there because it was my first time to be in that kind of situation. I didn’t know what to expect”- Nomvula, Multiple Abnormalities, Declined TOP (DTOP), NND

“I just expected the doctor to say no the baby is fine there’s nothing wrong *laughs* I was just waiting for the doctor to say only that” - Lucy, Anecephaly, TOP

The majority of the women felt that it was beneficial for them to attend genetic counselling as it had provided them with all the information they needed in a manner they could understand. It helped them comprehend the information, assisted them in their decision making and provided them with the necessary support. More importantly it made some of the women feel that they were supported regardless of the decision they make. Having this support as part of their health care service made a significant impact on them. It also assisted the women in normalising their feelings and understanding that it was not their fault.

“It was a good thing for me for Thato*(the counsellor) to give time, the questions and counselling talk to me and the guy and there was a guy also…he was also talking with me so I feel like there's a lot of people around me who cares about what I am doing and it's right and the if it's not right then I must do that, then I take all those words then I went home. thinking about you saying this you saying this but this is what it was right this wasn't right for me, this is gonna suit me this is not gonna suit me…”- Suzie, Multiple Abnormalities, TOP
“…all I ask him was it was it my fault it that that happened so he said no it's like one in a million females that it happened so I said oh I thought it was my fault that that happened to the baby, he said no…” - Reneilwe, Limb Body Wall Defect, TOP

Domain 2: Information

Amongst the women it was evident that the majority understood the information provided to them by the genetic specialists and therefore were able to recall the information. Although they all mentioned that initially they were shocked and in disbelief about the ultrasound findings, the information they received from the genetic specialists and the manner in which it was communicated allowed the women to interpret and comprehend the foetal abnormalities in their own way.

Some women did not reflect the foetal abnormality correctly by either minimising the severity or believing incorrectly that the child had Down syndrome. This might have been because Down syndrome is often discussed as part of the differential diagnosis for foetal abnormalities and is a condition familiar to most women.

“For me it was ‘whatever is going on, if Jessica* is okay, if she is not okay, Down syndrome, not Down syndrome; we will deal with it’” - Haley, Cystic Hygroma, DTOP, IUD

For others even though they had an incorrect diagnosis, they had understood the implications of the abnormalities. Faith, also recalled Down syndrome being discusses but pictures she was shown allowed her to understand the probable outcome and she used the word “bad” to describe severe disability. This indicated that she was prepared for the outcome because of the information that was provided.

“And then they told- they give me counselling they tell me about it, they show me a book of a child with a small head, what could happen. Could have Down syndromes, could not walk could- could have fever all the time, could be very bad child who can do nothing for himself” - Faith, Holoprosencephaly and Abnormal Stomach Bubble, DTOP, LB

However the majority of the women were well aware of the diagnosis and/or ultrasound findings and the probable prognosis. Even during the interviews they were able to clearly explain the information that they had received. This indicated
that understanding of this information was essential and allowed for them to make a well informed decision regarding TOP. It was more evident in the group that accepted TOP that the information was essential as the decision was in part based on the expected prognosis.

“The time that they referred me, I was feeling fine, I was feeling fine, yes because the way she explained everything to me, I understand it, I understand the whole process”- Nomvula, Multiple Abnormalities, DTOP, NND

“I was expecting because of some people that I know who had babies at an old age, like things like Down syndrome and all that, but nothing this severe, this was the first time ever”- Mary, Trisomy 18, TOP

It was apparent that although it is important to provide all the necessary information for them to make a well-informed decision, large amounts of information given at the same time may have overwhelmed the expectant parents. Two of the women felt that the information should have been provided in a sequential manner not to overwhelm them, and also limit the amount of information given on the first appointment as they were still in shock and were unable to process all or most of it. These women also mentioned that they were only able to understand the information on the follow-up session.

“When someone has just found out that they have a baby inside of them that has a defect you know bombarding that person with all this information, it’s too much, it’s just too much”- Linda, Declined TOP, LB

Linda felt that more creative approaches, such as meeting other families raising a child with a similar serious congenital abnormality (in her case a child with spina bifida) would have been more beneficial to her and have allowed her to gain first-hand insight into the condition. None of the women felt that the information provided was unnecessary; it was just the manner in which it is conveyed that could have been improved.

Domain 3: Freedom of Choice

Making the right decision is important for women deciding on TOP to ensure that they do not regret the decision they made. In a genetic counselling session,
facilitating decision making is a major component and, women need to weigh up their options and think of the impact of having the child in their lives. The pressure of making the right decision is usually an internal conflict but some of the women in this study explained that they felt pressured by health practitioners at the hospital to make the “right” decision which they understood to be to terminate the pregnancy. In contrast to other participants who felt that their decision was supported; these women felt that their decisions were not. They felt that the manner in which their options were communicated led to them to feel that they should terminate. This feeling was more common amongst the women who declined TOP. Sthembiso mentioned having a bad experience for the remainder of the period that she was receiving antenatal care at GSH. She felt that she was not treated appropriately because she made the “wrong” decision. She perceived being asked about how she would cope with a child with a serious condition, given her age and marital status, as being pressurised to terminate her pregnancy.

“You only 22 years and you are still young, what are you gonna do with a baby who is not gonna see, walk, do nothing?”- Sthembiso, DTOP, LB

Faith felt that being asked if she was sure that she was able to take care of a child with disability and the staff mentioning a disability grant made it seem as if she should terminate the pregnancy. She felt that staff was saying to her that she would be a burden to the government by possibly using a disability grant.

“And the government always (always mentioning the government), it’s like government, it’s like me, they saying - there's lots of children the government is looking after. It's like I'm making more, I'm doing more response- uh making more problem for government to support the children…it was very painful and then I feel like the more they talk to me about this thing, I feel they pushing me to decide (decide to terminate their pregnancy)”- Faith, DTOP, LB

**Domain 4: Testing**

The testing and follow-up scans played a significant role in the women’s overall experience at the hospital. The utility of the genetic test was questioned when the women were deciding about testing and having the follow-up scans as they believed the outcome would not change. Some of them felt that testing was of no use as the
results could be normal and yet the child would still have the abnormalities and disability.

Having the option of further testing was something other women considered of value. They sometimes accepted further testing as it could influence future reproductive options. For example, Mary had an amniocentesis and her foetus was diagnosed with trisomy 18. Those results allowed her more comfort in her decision to TOP as there was a recurrence risk of less than one percent. Therefore the invasive testing was useful for her. One participant opted for a post-mortem to gain further information but did not receive any results. She was upset as she does not know the cause of her child’s death. She lost trust and questioned whether the post-mortem was even performed. It had an impact on her future reproductive choices as she has delayed having further children until she knew what the cause was of the abnormalities in the pregnancy she lost.

The women had their first scans at their maternity outpatient clinics, and were then referred to GSH for further investigation. The first ultrasound at GSH was difficult for the women as the majority were able to see the foetal abnormalities. Some of them expected the scan at GSH to confirm a healthy foetus and to show that the maternity outpatient clinic was wrong.

“At that moment they told me, I didn’t take it seriously; I was just telling myself that the scans are wrong” - Nomvula, Multiple Abnormalities, DTOP, IUD

Follow-up ultra-sound scans were provided for all the women to monitor the progress of the foetus. However, these scans were not pleasant for the women as they would have hope that the condition would improve only to have the scan confirm the abnormalities. The scans served as a reminder of the child’s abnormalities. This reality made the follow-up scanning process an unpleasant and disheartening one for the women. For example, Sthembiso expected to be informed that the abnormality has resolved however, on follow-up scans it had not resolved. As a result she stated that she requested the counsellor to cancel further follow-up scans as it was too emotional for her to experience disappointment on each follow-up scan.

“Because I thought maybe they’d say no, we longer seeing what we saw, but everytime I went for the scan they’d tell me that they baby is growing well but what they said the child has hasn’t changed. I told Thato (the counsellor) I’ve
decided to not go to the scan anymore… Always! If I go for the scan, I come back not alright. I go to the scan thinking maybe he doesn't have the thing anymore, they don't see anything, but all the time when I am there they say the child is growing well, in the right position but still has that one thing”

Sthembiso, Dandy-Walker Malformation, DTOP, LB

**Theme 2: Home**

The participants’ interactions with people other than the clinicians and counsellors at the hospital played a significant role in the decision they made and their perception of TOP and having a child with disabilities. The home setting refers to their interactions with partners, families, friends and their communities in which they live and work. It is here where they received most of their support. Partners and family members played an important role in how they made sense of the diagnosis.

**Domain 1: Family**

The support from family served as a pillar of strength for the women. This support not only came as strength but also as guidance where the family advised and assisted them in making a decision regarding terminating the pregnancy. Family refers to immediate family, the women’s parents, her siblings and her children (for the women with children). However, even though the family as a whole played a significant role, it was the mothers of these women who were their main support system and care-givers. They were the ones who informed other immediate and extended family members, people in the community and their religious groups as a way to gain more support for their daughters.

“They (immediate family) usually used to call me bathi Sthembiso please, don’t do that, what if ngumntwana ozoba yinto yonke ebominibacko, ngumntwana ozo barithi, zoba yint ebominibacko, suyenza. I mean be bezama ukundibonisa.”

(They usually used to call me saying Sthembiso please, don’t do that, what if the child is the most important thing/ be everything in your life, the child will be alright he will be the most important, don’t do it. I mean they were trying to show me the way/they were guiding me) - Sthembiso, Dandy-Walker Malformation, DTOP, LB
The family assisted in normalising the feelings and accepting the decision the women made regarding the pregnancy. This allowed the women to feel content with the decision they made knowing that they have the support of their family. The women valued family support irrespective of whether they had come to a decision themselves or whether they needed guidance to make their decision.

Their families also assisted them in rationalising the situation and weighing up the two options in terms of what would be good for her, her family and how it would affect her children. Sindy for example explained the diagnosis to her family and the probable outcome. She also informed them that she would like to continue with the pregnancy. Her family made her reassess the situation and how it would affect her children and in this way they guided her in her decision making process.

“So I asked now, what was the cause, so they said they can't exactly tell me what it is, your baby he won’t be able to talk or or do anything so I had to do termination, okay, speak to the family. It was quite difficult for them also. I couldn't do a decision on my own because for me it was I wanted to keep because I had that bond with her (the baby). So I said okay, I have to go(to terminate the pregnancy) because on the end of the day I'm gonna struggle with a disabled child and I still got two kids still at home then I'm gonna get-neglect them and more attention to this one. So I just told myself okay, just go through with it” - Sindy, Complex Cardiac Defect, TOP

Even though the women felt that it was important to make a decision as the adults in the family, they did not exclude their children in the decision making process. They had to consider how the decision they made would impact their relationship with their children in terms of the amount of care and attention they gave them. One of the women was also experiencing other health complications due to the pregnancy and had to consider her live children when contemplating whether to terminate or to continue with the pregnancy. She felt that continuing with her pregnancy would be a risk to her life and therefore this supplemented her decision to terminate the pregnancy as she had to consider her quality of life and that of her children.

“What if I get problem on the way and I can die what about these two, especially my big neh, my big one never see the father, the father run away when he was six months…but I can see he have that anger, I don't have a
father why me…so if that one I am not here I am dead that one who is gonna stand for that one because this one at least he have father he have family that one he never go see the family for the father he have only my family and his a very difficult boy demanding, so my sister won't take it so if I keep that pregnancy, get problem because of my stubbornness what that gonna do, especially the for big one?” – Suzie, Multiple Abnormalities, TOP

Some of the women found it helpful to also discuss the pregnancy complications with their children. Their children expressing acceptance and love for their unborn sibling assisted them in making a decision. This was especially important for the women who continued with their pregnancies. For Tumi, her daughter was the main reason she continued with the pregnancy and declined TOP.

“…What actually really made me keep her was for the fact that my kids knew I was pregnant with her and they knew what I was carrying and they were excited for her especially my eldest daughter who was very excited because she was gonna have a sister and because I actually told her she was actually the reason she told me no, you keep our baby, our baby is gonna walk and our baby is gonna come out fine you just gonna see and she's gonna have nicer hair than mine. She's- my daughter is 12 years old and she told me all of these things and she's my main reason for keeping my daughter. She's actually the person that pushed me through…”– Tumi, Spina Bifida, DTOP, Surviving Live-born, LB

These discussions also allowed for the women to prepare their children for what was to come and that the amount of attention received from their mother would reduce. This also allowed the children to know what would be expected from them in terms of chores and extra responsibilities once their new sibling was born. Preparing their children was helpful and a necessary stage for the women to attain validation from their children for their decision.

“Some of them are still small so it was difficult to explain to them but I had to tell them that listen mommy is going to have a baby and they were all excited…So I had to explain to them that she's not going to be like the rest of us, and she is going to require a lot of attention and a lot of love and extra love and extra special care and so forth and uh I said to them that mommy
won't be able to do all the things I am doing with you now and that I would like to do with you even more I won't be because I will have to give her a little bit more attention and they were in agreement with that. So it made also things even easier” - Linda, Spina Bifida, DTOP, LB

While this was a difficult time for the women and their families, this experience assisted in building relationships within the family. It mended broken relationships and facilitated better communication. The women said that the situation they were in allowed their families to be more open with each other and able to discuss unpleasant situations which were not discussed prior to this experience.

“We closer now because of the experience even more closer and more open because now we talk about things and being sick and medical things and not to shy away from izintozenzekayo (things that happen)” - Mary, Trisomy 18, TOP

“She (Sindy’s mother) is very close now because what happened she wouldn't have- and what I went through she doesn’t want me to go through it again. Yah that's why when she found out I am pregnant then she told me “you mad I don't know why you would go for another child, now you going into hospital in and out again.”- Sindy, Complex Cardiac Defect, TOP

“…I didn’t actually expect that my parents will support me because we constantly fighting and it's constant drama in the house and there's judgement in the house but there was never show any support in the house up until Lethabo (her daughter). Lethabo is actually a blessing in the house, she is actually the reason most of things change at home, where we can speak openly there.”- Tumi, Spina Bifida, DTOP, LB

Domain 2: Partner Support and Relationship Dynamics

The diagnosis of the foetus also had an impact on the participants’ partner and their relationship. Some of the women’s relationship dynamics with their partners were altered by the diagnosis of the foetus and in some of the cases this exacerbated problems the couple were having. The dynamics of the relationship impacted on the support the partners provided for the women. Ultimately most of the partners supported the women’s decision as long as there was no danger posed to the woman.
Some of their partners went through their own grief process and the support they provided to the women was dependent on the stage of grief. For most of the women, the support from their partners was integral to their experience especially since some of the women only had their husbands for support as no other family members were available. Their partners were the first people that they informed making their reaction to the news crucial. The partners initially went through a stage of withdrawal and disconnection. They did not talk with the women for days to weeks while trying to accept the situation. This suggested that they too go through the initial shock and then process the news by withdrawing and not discussing the circumstances of the pregnancy until they have accepted the situation.

“But before my partner when he hear about this, we didn’t talk like, for a week I didn’t know what he was thinking so firstly, I don’t know because I wanted- I was trying to talk to him but he was not responding, he was just quiet the whole week, so I didn’t know what was going on through his mind because he was just quiet, he was not talking to anyone and I didn’t know if he blames me or what? Yes because even the following week when he was trying to talk to me, but he never op- he never talk what is happening with this issue. Even if I try to talk to him about the baby issue, his not gonna talk about it. So until like a month (a month after the diagnosis) yah”- Nomvula, Multiple Abnormalities DTOP, NND

Following the withdrawal stage, the partners attempted to rationalise the situation and in doing so, for a short period of time they blamed their partners for the child’s disability. This was for them to try to find a cause because it was difficult to understand how a child went from “healthy” to sick. Like the withdrawal and disconnection, blaming the women infringed on the amount of support given to the woman. Nomvula explained that her partner initially blamed her for the pregnancy but once he had processed the situation, he no longer blamed her and began to discuss the pregnancy complications and provided her with support.

“Because before I went to the scan I think about a month, I went to, to the Northern Cape to see my mother so when I come back and then I went to the scan and then there was this issue. So maybe he was thinking by, by me going out there by my mother’s, far from him maybe there was something I did wrong that is why now they say the baby is not fine. So I don’t know what was
happening to him it was like he was blaming me for all these things yah, because after some time he was gonna be saying from the first month the baby was fine why now after you went home?”- Nomvula, Multiple Abnormalities, DTOP, NND

Even so, the blame was not one-sided, some of the women also blamed their partners for what had occurred, attributing it to neglect or the partner’s infidelity. Having a child with a disability in a relationship where the partner was not faithful was perceived as a punishment for the wrong that the husband did.

“I’ve had seven healthy pregnancies this it’s impossible, why is this happening to me, what did I do wrong or uh it’s you, it’s because you had an affair and you did this”-Linda, Spina Bifida, DTOP, LB.

Sindy blamed her partner because she was feeling ill during the pregnancy and she felt he neglected her. She explained that he preferred socialising with his friends instead of taking care of her. As a result she felt he was the reason for the foetus’ abnormalities.

“Because I felt that it was his fault. There was a time I was so sick in my pregnancy he was always partying, never there when I was, you know, so it was just that… yah if he maybe took things too serious it wouldn’t have happened like that, you know what I mean”- Sindy, Complex Cardiac Defect, TOP

In the end, the experience brought couples back together; it mended some broken relationships and assisted in making others closer than before. Most of the women expressed that their relationship has developed and is going well.

“…But he is more supportive now as before so I think things are alright”- Sindy, Complex Cardiac Defect, TOP

The woman is however still a part of a larger community, in which she lives, works, makes friends and follows her religion. This broader community impacted on the women’s overall experience.

**Domain 3: Community and Stigma**

Interactions with people other than their family members meant something different for each woman. While some felt that it was necessary for them to share their
unpleasant news with friends, colleagues and neighbours to gain a better understanding, others felt as if they would be the outcast of the community for either choosing to terminate the pregnancy or having a child with a disability and therefore did not share their experience. This demonstrated that their community plays a role in the decision making process. The support from others was important to the participants, but not as important as how they themselves made sense of the entire situation and what it meant to them and their womanhood or their search for answers.

The community, in which the women belonged, affected which decision most of them would make. Some of the women were able to disclose the details of their pregnancies to colleagues, friends and neighbours who then gave them advice and assisted them to make their decision. One of the participants said that sometimes it is better to discuss things with a person that is not a part of the family as they can give you a more objective view on the situation. She found it helpful to talk to her neighbour.

“...it's always good to have that somebody else's advice or somebody else not knowing you but knowing you for who you (Someone who is not a family member) are just in and out by road everyday that's not that person something is wrong with her and she actually encouraged me…” - Tumi, Spina Bifida, DTOP, LB

However stigma was a recurrent theme amongst the women. This included the stigma of having a child with disabilities, of having a TOP, of being a foreigner and also the stigma attached to women considered to be barren. The stigma attached to TOP and disability played a significant role in the decision making process, especially for those who terminated their pregnancies. They felt that either terminating a pregnancy or having a child with a disability would lead them to being shunned. One of the participants expressed that she and her partner did not disclose to their church that they terminated the pregnancy; they just informed them that their children (twin pregnancy) were not well and that they had a miscarriage. This was for fear of being judged. The stigma of disability was significant enough to also consider TOP due to fear of being shunned by the community. Mary’s family was thought of as a family to be respected in the community due to their socio-economic status. Her family is considered to be of a higher social standing due to all the accomplishments
she and her siblings achieved. As a result, she felt that their neighbours would shun them as a family and point her out as the sibling that has failed.

“But we know mos in our cultures, especially black people, you have a disabled child and you are shunned upon...because which means you're sick. People don't understand whether it's you who was sick or it's actually the baby. How can a baby get such diseases...I wasn't expecting people to judge me (not looking forward to being judged) and tell me "Ooh ha ah (disapproval) you have given birth to a cripple and she is Miss hoity-toity get in the car and just drive around what does she have to say for herself?"”-Mary, Trisomy 18, TOP.

Some of the women felt that going to full-term only to lose their child in the neonatal period raised the expectations of the people around them. One of the women expressed that her neighbour advised her to terminate the pregnancy while people did not know that she was pregnant to limit the community’s expectation of a child. Another woman felt that it would be upsetting for her to have others excited about a baby, while she knows that her child has complications and that she would also have to deal with their disappointment.

“…we realised the trauma of having to carry a child, people being happy and excited knowing the fact that I know the child is not going to make it or whatever. The expectation uyabo? (you see)”-Mary, Trisomy 18, TOP

**Theme 3: Being a Woman**

In this theme the personal journey of the participants with regard to their womanhood and in particular their roles and responsibilities as a mother will be discussed. These women went through their own internal conflict with regard to making a decision on whether or not to terminate the pregnancy. All the women consulted with their partner or family regarding the diagnosis; however in the end the decision was the woman’s own. All the women had unique experiences and for some of the participants, upon hearing the news, they took on a physical response to their child’s diagnosis. One of the participants felt physically sick because of the sad news she had just received. The sickness of the child was internalised as the children felt like an extension of these women.
The physical internalisation reflected the close bond the women felt to their unborn child and is illustrated below in the domain “precious pregnancy”.

**Domain 1: Precious Pregnancy**

All the women wanted their babies irrespective of whether or not the pregnancy was planned making it difficult for them to make a decision regarding TOP. These babies were precious and to each of the women, having the child meant something different. For some, it was their first pregnancy and thus it was important to have a healthy baby. Sthembiso, like other women confirmed more than once in the interview, how precious this first pregnancy was.

“I believed that God wouldn’t do that, God wouldn’t give me a child that isn’t right, in my first pregnancy, hmm mm (disagrees)”- Sthembiso, Dandy-Walker Malformation, DTOP, LB

The affected pregnancy was particularly important to some of the women because this was the first child with their current partner even if they or their partners had children from previous relationships. Therefore it was vital for these women to have a healthy child.

“oh-kay, because I wanted this baby so much now, so this other three babies are from my past relationship, so I met this person recently, I think its four years now we are- we dating so we planned this baby since I don’t know (planning for a long time).”- Nomvula, Multiple Abnormalities, DTOP, NND

Mary felt this pregnancy was precious to her, not just for her new partner, but because it allowed her to be a mother. She explained that she was always known as the aunt who took care of her nieces and nephews. She did not have children of her own and this pregnancy allowed her to move from being an aunt to being a mother, therefore fulfilling her maternal role. This pregnancy was especially precious to her as it confirmed that she is not infertile and it removed the “stigma”, as she described it, of being unable to reproduce.

“…Has given me and idea of “Okay I could maybe also do this, be a mother to my kids, you understand? And not be the always available aunty…”- Mary, Trisomy 18, TOP
The expectant mothers started bonding with their children prior to the diagnosis. Reneilwe mentioned that she spoke to her foetus throughout the pregnancy and also apologised to the foetus for her decision. This bond with their foetus was strengthened by the women experiencing foetal movements allowing them, to feel a connection with their unborn children.

After receiving the bad news, some of the participants held onto that bond and for some of them feeling foetal movements made them feel that they could not terminate the pregnancy due to a shared connection.

“..but I just told myself that "No because I was feeling the baby moving, kicking, I was just hoping that the baby is well because I didn’t feel anything funny because everything was going the way it should be there were no signs that maybe there is a serious problem with me because everything was just going normally.”- Nomvula, DTOP, NND

Mary however had a different experience. She lost the connection she had with her foetus following the prenatal diagnosis of Trisomy 18. In her interview she said that she did not always “feel pregnant” as she was anticipating that something like Down syndrome could be wrong. Convincing herself that she “did not feel pregnant” may have been a coping mechanism as she had also expressed initially being excited to be pregnant. Her experience of feeling pregnant and in that way the bond to her baby changed when a serious abnormality was diagnosed.

“I was expecting because of some people that I know who had babies at an old age, like things like Down syndrome and all that, but nothing this severe, this was the first time ever… Because la (here) when I was pregnant last year, I was pregnant, I should have been excited because it was my first time but because I knew uba (that) something was wrong(I was no longer excited)” - Mary, Trisomy 18, TOP

Domain 2: I Must Decide

The role of a mother extends to caring for her children and also making the best decisions for the family. The women in this study ultimately felt that it was their role to make a decision as they were the ones who were pregnant. The women did consult their partners, family members and members of the community and also considered the information provided by the genetic specialists when they were
considering TOP. However, the majority of the women felt confident to make the final decision regarding TOP even though they sought guidance from the people around them. Linda did discuss the pregnancy findings with her husband and he suggested TOP however Linda declined TOP as she considered her own personal feelings and beliefs. She stated that she made the final decision irrespective of her husband’s views.

“But for me it was more of a holistic approach where I said well no, this was given to me, it was placed on my path and I'm going to embrace it and then uhm so no I'm not having a termination and that was what was solely what my decision”- Linda, Spina Bifida, DTOP, LB

The women did consider multiple factors including the quality of life of the foetus and how the presence of a child affected by a serious abnormality would affect the quality of life of the family. While Suzie was processing the news, she considered the possible quality of life for her and the child. She made the decision she felt was right for her which was TOP. She was aware that she would not be able to cope physically and psychologically with a child with a serious congenital abnormality.

“What am I going to do with that for the whole life, it's not gonna work for me it's gonna be a stress for me and it's gonna hurt me because this one the time he grow up he is sitting in this bed I must feed him I must do everything and he is not growing, no process (progress) how I'm going to stay with a baby like that? It's not for me. If, God, I do something wrong just forgive me but this I think it's right for me, it's the right time for me to do this”- Suzie, Multiple Abnormalities, TOP

It was important for the majority women to make the final decision regarding their pregnancy. Even though they did discuss this with others, they made themselves suggesting that they gained confidence in their ability to make the decision.

**Theme 4: Finding Meaning**

The women were trying to rationalise or find a reason why they had a foetus with a serious congenital abnormality. Following the initial acute shock, they went through a phase of wanting to make sense of why this had occurred. Understanding their reasoning was important as the manner in which they rationalised the situation
affected the decision they made in the end regarding TOP. Finding meaning for the women was intertwined with their religious beliefs and hope. In this theme how the women found meaning and how religion and hope played a role in decision making will be discussed.

Domain 1: Why did it happen?

The women questioned why this had happened to them. They were emotional when they were describing their journey in finding meaning in having a pregnancy affected with a serious congenital abnormality. Finding an answer to “why” this had happened and sometime why it was not detected earlier was difficult for some of the women.

When Sindy was asked during her interview how she felt when she was first informed about the diagnosis. She described a feeling of “brokenness”. She attributed this feeling to asking herself why this had occurred and why it was not detected earlier. She also experienced feelings of shock related to the possibility of not being able to continue with her pregnancy to full-term.

“I just asked myself why? Why did it happen? Why wouldn't they see it earlier? Or isn't there a way where they can fix it or save the baby or anything…It was, it was shocking to me because why couldn't I carry on until the last, why five months, you know what I mean?” - Sindy, Complex Cardiac Defect, TOP

Some of the women attributed the reason for having a pregnancy with a condition associated with poor prognosis due to their lifestyle habits such as smoking (Lerato) and recreational drugs (Tumi). Attributing abnormalities to their lifestyle choices contributed to these women to finding a meaning for why this had occurred but also induced guilt and contributed to declining TOP. Lerato was a smoker and smoking was the physical thing that she could attribute to causing the foetal abnormalities.

“…so at the time I was still smoking but to a lesser extent. I was, instead smoking full cigarettes; I was just doing half cigarettes…That sort of thing – giving myself a tap on the back, I’m not doing it all the time and so on. Yeah, it is something that still haunts me…” - Lerato, Cystic Hygroma, DTOP, IUD

Tumi attributed having a baby with spina bifida to the fact that she did not engage with sufficient prenatal care in the beginning of the pregnancy. She was aware that
she did not take the daily recommended dose of folic acid due to the social circumstances surrounding the pregnancy. Prior to the diagnosis, she had attempted a social TOP using home remedies in order to punish her partner’s parents as they would not accept the pregnancy as Tumi and her partner are unemployed and have four other children. In the lengthy discussion regarding the influence of her partner’s parents on the pregnancy, she described feeling pressurised to TOP. These factors contributed to Tumi taking responsibility for why this had occurred and declining TOP.

“I owe her for what I have done and I don’t-the causes that I did for wanting to punish her for family (partner’s parents) I went to go drink and I went to go do drugs and I went to go take this medication this *Als-Water. took, I took those just for her to come down…and even if it had to be that she just live so I will still take her will still look after her because that is my fault it is my doing that she is like that it’s because of me for wanting to punish them. Instead of punishing them God punished me, so I must work God’s work through” - Tumi, Spina Bifida, DTOP, Surviving Live-born

*Als-Water: African wormwood plant prepared by boiling the plant in water. Usually consumed for gynaecological issues, digestive issues, intestinal parasites and also believed to have anti-malaria properties and may be prepared differently depending on cultural believes. (Abad et al., 2012; Van Wyk & Gericke, 2000).

In attempting to find a reason, feelings of blame for some partners emerged. Although relationship dynamics were discussed in theme 2, here blame came through as a way of finding a reason to why this had happened to them. The blame was associated with punishment. For Linda, it was punishment from their Creator for her partner’s neglect or infidelity. Linda’s husband was unfaithful at the time the foetal abnormalities were diagnosed and she felt that it was punishment for his infidelity through their child. She was also not content with his initial decision to TOP as she felt that his decision was based on convenience and therefore this was partially the reason why she declined TOP.

“I was sort of blaming him and uhm because of what he was doing and where we were at... in our marriage at the time so I was blaming him that this is sort
of God's way of punishing the child you know, punishing him but the child but because of what he was doing...but because of where we were at... in our marriage I thought it was more his decision was more based on convenience because if the child is not there it's one less thing for him to hold him back you know”- Linda, Spina Bifida, DTOP, LB

Some of the women took a more positive stance in trying to find meaning. As explained in the previous theme, Mary struggled to conceive and thought that she was infertile; so she saw this as a sign that she is able to fall pregnant and could do so again so she might have children in the future.

“The deciding factor was that I finally saw that I could actually have kids…And that's an opportunity of a lifetime for anybody...Oh okay someone (God) didn't forget about you somewhere”- Mary, Trisomy 18, TOP

Faith, like Mary, believed having a child, irrespective of the abnormalities was a blessing. A couple of months prior to her pregnancy, her eldest son was shot dead. The death of her son greatly affected her and therefore she was excited about this pregnancy as she saw it as her Creator replacing her dead son. She viewed the pregnancy as a consolation. In the interview she stated that she saw this pregnancy as her Creator’s attempt to comfort her for her loss. She even named her son Junior, after her son who passed away.

“I told myself that I can't just sit, I was just crying yesterday of my son who was there, who was being shot, now today I am pregnant, I will terminate the baby, I'm gonna try and say what to God? (If she terminates she cannot cry to God about her son who passed away) ”- Faith, Holoprosencephaly and Abnormal Stomach Bubble, DTOP, LB

Attaching a meaning to the diagnosis assisted these women in accepting the situation better. However not all of the women were able to attach meaning and hence experienced greater emotion in their search for answers. Some of them just accepted the situation without meaning and attempted to find closure and move on. Some of them attributed it to fate or religion and also moved on without answers. Nomvula explained that she was questioning the situation which affected her emotionally as she was looking forward to having the child. She attempted to find a reason for what happened but failed and eventually came to believe that her Creator
knows the reason. In her journey of finding meaning, she used religion as a means of closure.

“It affected me very badly, very bad so I was even asking, like why is it happening now? I was just having those mixed feelings, that why is it happening to me at this moment when I want a baby. So I couldn't find the answers…I just let it go, yes I just let it go now. I'm just thinking that maybe God knows why, there is a reason why because I'm a very religious person so I'm just telling myself that maybe He knows the reason why…”- Nomvula, Multiple Abnormalities, DTOP, NND

The women, who were able to attach meaning, even if it was fate or religion, were able to find peace with the diagnosis and get closure. Eventually the majority of the women managed to accept the situation. Only Refiloe could not accept what had happened or find peace because this was happening to her for the second time. The interview with her was also particularly emotional because she was still experiencing complicated grief. In between her moments of crying she explained that at that moment she could not understand or find a reason why this has occurred to her for the second time. It has been difficult for her to accept the situation but her family (mother and husband) assisted her on a spiritual level. They attempted to explain to her why it had happened from a religious perspective. This assisted her to understand the situation better but she does not have closure yet.

“I was confused because I didn't know why I never knew why because it was the second time… It (the support of her husband and mother) made me understand things much better…Like spiritually…”- Refiloe, Congenital Diaphragmatic Hernia, Declined TOP, IUD

Religion played a big role in finding meaning and was an important component in allowing them to accepting the situation and to be able to move on. Most of them had to reconcile their own beliefs with what is permitted in terms of termination of pregnancy in their religion.

Domain 2: “In God’s hands, not ours.”

Religion was important and served different functions. Some of the women used their religion as a determinant for their choice on TOP. They shared that in their religion (Christian and Muslim) it is not permitted to terminate a pregnancy and
therefore for them, termination was not even a choice. There was no choice but to continue with the pregnancy and leave it in the hands of their Creator. As stated in the previous domain, Linda’s husband had initially decided on TOP but following discussions with Linda, he supported her decision and since he is also of the same religious faith, he understood her wanting to continue with the pregnancy.

“The first thing that crossed my mind was No! That wasn’t even an option because holistically speaking you know we cannot do that. In our religion it is not allowed so I’m not even going to entertain that and then so my decision or our decision, myself and my husband our decision was based on that”- Linda, Spina Bifida, DTOP, Surviving Live-born.

Others used religion as a form of support and found comfort in their belief that God is in control of the situation and that He is the giver and the taker of life. Some were also able to make peace with the decision they made because they had faith that God will provide and maybe that it was not the right time for them to have a child. One of the participants mentioned that she could not question God because he is the one in charge of all their lives.

“…and I was thinking look nature man you can’t question God you see? You can’t have grudges against natural things (Referring to God’s creations) that were meant to happen or never meant to happen.”- Mary, Trisomy 18, TOP

Prayer is an essential part of both Christian and Muslim faith. Prayer is a route of communication between a person and their Creator and was something most of the women had in common. They prayed either by themselves, with family or with members of their religious groups for a good outcome for their foetus and also for the strength to continue. Prayer was a manner in which the women gained support from the people around them and from their Creator. Tumi had a prayer group created for her and for the outcome of her pregnancy on social media. Her mother’s friends and other members of her church held regular prayer sessions at her home in the hope of a better outcome. This gave Tumi strength to make her decision and also provided her with the support that she needed.

“…My mom’s friend came to me to pray, pray on my tummy put the ointment on there, prayed again and that made me stronger and put me back and I came and I made my decision without anybody but just the support of the
Suzie like some of the other participants had prayed for the health of her foetus. However when she realised that nothing had changed on the ultrasound scan, she rationalised it by thinking that if it was the right time to have a baby, everything would have improved while still questioning why this happened to her. Suzie left it to fate, saying that any outcome would be alright and if it was meant to be then the baby would have been healthy.

“Then I just have a prayer in my heart. I say I wish something change then I can keep my baby because I told myself because I told myself this is a loved one but when it come, I said also if it's nothing change which is, this is not is not the time this is not the right time to get the baby because if it's the right time everything it will go well then I sit there; but I was crying first when they talk feeling why me why now and you know…”- Suzie, Multiple abnormalities, TOP.

However not all of the women continued to pray following the news of the ultrasound findings. Linda stopped praying from the time of diagnosis as she experienced anger towards her Creator. This was her initial reaction to the news although she later accepted the situation. During her discussion on this matter she expressed that she could not understand why her foetus had a serious abnormality whereas she does what is right when compared to other people around her who are involved in immoral behaviour or acts. She explained that she had felt angry towards God from the time of diagnosis because she could not understand why this had happened. Her religion played a major role in her life so, although she stopped praying, she declined TOP based on the rules in her religion.

“This was put on my path and I couldn’t understand why and uhm you know so a lot of my anger was directed at the Creator as well therefore for a while that I actually stopped actually from the time that I found out that uhm you know she there was this problem you know uhm I just stopped praying and I just refused to pray”- Linda, Spina Bifida, DTOP, IUD

For all the women religion played an important role in the decision making process but it played different roles. Some women used it as the deciding factor for or against

family that I had and the people on Facebook and church…”- Tumi, Spina Bifida, DTOP, LB
TOP (table 3), others as support and for yet others it provided consolation. Religion also contributed to hope, hope for the future and hope for the pregnancy.

**Domain 3: Hope**

Throughout the interviews all the women expressed an aspect of hope be it loss or gain of hope. Gain of hope came in the form of hope for the outcome of the pregnancy, hope for the future and hope for having more children. All of the women were aware of the reality of the findings in the pregnancy but had hope for a different outcome. This hope first seemed to be denial but it was clear they understood the condition and outcome. It was also clear that hope and religion do not occur as two independent entities. The women’s religious beliefs gave them hope and therefore they had faith that their Creator would change the outcome. Due to this, the women sought different signs of hope such as a baby kicking. Faith, who viewed this pregnancy as consolation from her Creator for her son who passed away, saw the foetal movements as a sign of hope and an indication that she should continue with the pregnancy.

“…then the baby was kicking, one thing that was making me sure the baby was right- is gonna be right is the way he was kicking…so I decide to keep my baby”- Faith, Holoproscephaly and Abnormal Stomach Bubble, DTOP, LB

Sthembiso relied on her religion and her faith in her Creator that her foetus would improve and have a good outcome. Her follow-up ultrasound scans revealed that the foetal growth was good and also the foetal position was as it should be. The only abnormality seen was the Dandy-Walker malformation. This too gave her hope that the outcome of the pregnancy would be good allowing her to view the abnormality as minor.

“I believe that God wouldn't do that, God wouldn't give me a child that isn't right…I was like yoh no man sometimes, sometimes I usually used to think maybe it’s a little thing because the baby is growing well so it is just a problem which is small, so I thought no man…”- Sthembiso, Dandy-Walker Malformation, DTOP, LB.

In contrast some of the women lost hope during the decision making process, especially when they realised that there was no improvement in the foetal abnormalities on ultrasound indicating that the prognosis was still poor. One of the
participants perceived on being informed on a follow-up scan that there was no improvement in the foetus’ condition to mean there was no hope. Therefore as a result she lost hope for the pregnancy and decided to terminate the pregnancy.

“Okay I didn't want to give her up. I always believe in hope, but when they told me there is no hope, so everything just- I just gave up and I told myself, okay and I also fell a part of giving up hopes and things like that.” - Suzie, Multiple Abnormalities, TOP

**Theme 5: After the birth**

“After the birth” is the experiences of the women following the birth or loss of their child. It describes the initial emotions, coping strategies, letting go of the child and moving on. It also describes the adjustment of the women who had surviving live-born children.

**Domain 1: Seeing the baby off**

Seven of the women opted to continue with their pregnancies of whom three lost the baby following and IUD or NND. Four of the women had surviving live-born children. Five women decided to terminate their pregnancies. Of the women who lost their children (TOP, IUD, NND) none of them expressed regret for the decision they had made. Despite this, the experience was difficult for them with different aspects of the decision making process and losing the child being identified as the most difficult for individual woman (Summarised in table 4).

Losing a child is difficult and it was important for some of the women to be able to bond with or to see their demised children before they were taken away. This moment was to allow them to bid farewell and for some it allowed them to find closure. One of the women was distressed because she does not remember the face of her child. She had a Caesarean section and was under general anaesthesia, so following the birth of her child she was drowsy and unable to remember her child. Not being able to recall her child’s face was the most difficult aspect of the entire experience for her.

“Okay, the most difficult thing was when the baby now, uhm, when I, the time I went to the Caesar and I went- the baby come out alive and just (die) after maybe two three hours now, after a very short a very short time I didn’t even
have much time to bond with the baby, the baby just passed away so that was a very very very very bad thing (bad refers to that this situation to be in and bad refers to that it affected her whole being [N Tyam, Personal Communication 2017, 22 March])…So, I don't know his picture because the time that they show me I was still, I don't know I did not even see his face clearly, So I didn't even have the chance to see him and that is the most difficult thing 'cause I still like, I'm still trying to figure out how the baby look like, the baby- how did the baby look like. I didn’t (sigh) I didn't see the I didn't have the chance”- Nomvula, Multiple Abnormalities DTOP, NND

Lerato had the opportunity to bond with her child before saying goodbye. She expressed disappointment in herself during the interview because she spent the time looking for the abnormalities and any “imperfections” and not focussing on the time she had with her daughter.

“When she passed away, it was very – I was told by whoever was present, the nurse, that there was something on her neck. But I just saw this perfect baby. I didn’t see any imperfections and I felt about disgruntled afterwards because I had been looking for whatever imperfections and not just rejoicing at the fact that I was holding this baby, whether she was passed away or not, I was able to feel her presence, her essence”- Lerato, Cystic Hygroma, DTOP, IUD

In contrast to Lerato not seeing any abnormalities in her daughter, Suzie found peace with her decision to TOP when she saw her baby. She saw the abnormalities that were diagnosed prenatally. For her the postnatal time was not just to bond with her child but also to confirm that the decision she had made was the right one. She found closure in what she saw.

“but after that I was having that feeling but when see the baby out it's all that they what they tell me you see, then sooner I get peace because I see everything what they are saying to me it's be gonna be like this no even the nurses they were making taking out the baby they saying it wasn’t going to be right it's the best decision you made.”- Suzie, Multiple Abnormalities, TOP

Although it was important for some of the mothers to see and bond with their children, others did not want to see them. They did not want the image of the children they lost in their minds as it cannot be erased. Lucy was one of the women
who did not want to see her children; her husband was the one who saw them and described them to her. She, like Suzie, found comfort in her decision to terminate the pregnancy when the abnormalities were described to her by her husband.

“but the problems was in the heads yah but my husband say when he saw the kids was normal everything but there's something here (pointing to head) they think that side and the arms were small for one and for the other one here but the kid was very big”- Lucy, Twin Pregnancy, Both affected with anencephaly, TOP

The remaining four women with live-born and surviving children had to adjust their lives to accommodate a child with congenital abnormalities and extra medical needs. They were also satisfied with the decision they had made to continue with the pregnancy.

Faith, Sthembiso and Tumi found the adjustment easier than Linda. They expressed that the outcome was much better than what they had expected and their children have less health complications than they anticipated. Sthembiso’s son was walking, and according to her, was doing all that children of his age were doing. Faith’s son was sitting with no other health complications but was at an increased risk for seizures and was being monitored. Tumi was also happy with the progress of her daughter despite some complications and was especially happy because of all the joy that she has brought into her family by bringing Tumi and her parents closer.

“Everything so far so good choice is still the right choice I made in life and I don't regret it I'm actually glad for what I do, and if I had to do it again I would do it all over again and not for the fact that I had to, anybody I'm still talking about her even with friends family anybody I still talk to them about it”- Tumi, Spina Bifida, LB

Linda’s child was more severely affected and suffered from frequent seizures and other spina bifida related complications. She has had to adjust her life drastically and also sacrifice activities she would usually partake in with her other children. She struggled to accept her daughter’s situation up until she was 3 weeks old. However she was grateful for her daughter because she too mended her family relationships and allowed her to be more spiritual. She did admit though that it was not an easy
task and there were very difficult days and those were the days when she did question whether or not she had made the right decision.

“But it hasn't been an easy journey there are still days when I feel you know uhm what I had, you know done the termination uhm things could have been so much easier for me now because my life is difficult as whole times when I feel*sighs* uhm you know if I had the termination uhm you know things wouldn't have been so difficult right now and then I just have to take a step back and I just have to remind myself that you know she was placed here for a reason uhm she brought this positive change, it's a pity that uhm it had to take this for those positive things to happen…”- Linda, Spina Bifida, DTOP, LB

Domain 2: Moving on

The women who lost their children had to find a way to cope and let go. Each woman found their own coping mechanism to deal with the loss of their children. Each coping mechanism was different because the experience was unique to each woman. One of the participants found it helpful to “block out” the entire experience and only recalled it again during the interview. Another found comfort in her pet cats. She said they are like “children” to her and the presence of these cats assisted her to cope. Other mechanisms of coping amongst the women included both becoming open about the experience by sharing it with others and becoming antisocial to avoid coming into contact with children as it would be a reminder for them of their loss. No matter what the coping mechanisms are, they assisted each woman to adjust to a new environment without the deceased baby.

Moving on required the women to complete tasks that they felt were necessary to help them let go. Some of these tasks were burying the child and giving away the baby clothes. Burying their children was important to some of the women as it allowed them to send them off and to say goodbye. Those who were unable to bury their children were emotional, like Refiloe who found the most difficult aspect of her experience to not be there to bury her child as she had to stay in the hospital for observations. In Islamic practice, burial is on the day of the death so she was not able to attend the funeral.

"I think it was the funeral (Most difficult thing) because I had to stay at the hospital for 3 days because they were buried on the same day I spent the
time, so for me it was the hardest part just to send them off “- Refiloe, Diaphragmatic Hernia, DTOP, IUD

Reneilwe only found a way to move on a couple of months after the death of her child when she visited her baby’s grave with his father. She realised that if she did not let go of him she would continue experiencing complicated grief. Therefore talking to her son at his grave allowed her to regain strength and move on.

“I just told myself if I was gonna be sad for the rest of my life nothing will be going alright so I said okay well to make peace with it I went to his grave, I said stuff there and I said well it’s easy to go down downhill but to come up again it will take years for me to recover from something so I said well, that’s not who I am just because I did something it doesn’t mean it must affect me for my whole life through so I said well, it’s not gonna, I’m still the same person I was losing him”- Reneilwe, Limb Body Wall Defect, TOP

Giving away the baby clothes was also a difficult aspect for some of the participants. Refiloe was unable to giveaway the clothes herself and asked her husband to do it. However she did not give all of the clothes away, she kept those that she had purchased. Mary too found it difficult to give away her child’s clothes, but she gave them away gradually over a period of time. But, like Refiloe she retained some of the clothes as she too felt a connection to them.

In contrast to these women, the women of Xhosa ancestry and one of mixed ancestry did not purchase many clothes for the baby because it is not permitted in their culture. The reason for this is because they believe that one cannot be certain that a child will be born prior to the actual birth and hence clothes are to be purchased only after the birth of a child. In their culture, family and friends purchase clothing for the baby and bring it to the hospital when they visit. This was helpful for these women as they did not have to experience the process of giving away the clothes of their children which could potentially have worsened the grieving process for them.

“It was almost like I’m told to wait until eight months and then we go buy stuff for him but nogals for that six months I did buy something from here, just a small pants and vest just one, one outfit, nothing more than that and I still have it…but I’m glad I didn't have a lot of baby stuff actually because giving it
away would have been much harder also” – Reneilwe, Limb Body Wall Defect, TOP

Domain 3: The Unexpected

As mentioned in domain 1 of this theme some of the surviving live-born children were thriving and this was unexpected for the parents. They did have hope and believed that their Creator would improve the condition of their children (Theme 4) but they were prepared for a worse outcome. Linda and Faith had expected their children to live only for a few hours but with each medical intervention life expectancy increased. In Linda’s interview she stated that when making a decision about TOP, one should not just base the decision on the scientific information but rather take other factors into account as the outcome of the pregnancy cannot be guaranteed. She did however discuss that it was difficult raising a child with a serious abnormality as she had to neglect some of her other children due to the needs of her daughter.

“Because initially were we told because all because of her condition she's not going to, she's only going to live for a few minutes {mm} and then she was born, she lived for a few minutes and then we were told okay fine her spinal defect was repaired and she's going to live maybe up till 3 months. She's 18 months old and she's still alive and she's doing very well” – Linda, Spina Bifida, DTOP, LB

Sthembiso had prepared herself for her son to be severely developmentally delayed but he was babbling and standing and was learning to walk at the time of the interview. This assured her that the decision to continue with the pregnancy was the right one and she even wanted to prove that to the clinicians and counsellors who had provided her with prenatal care. In the interview she stated that she wishes to show them pictures to prove that the decision she made was right. Interestingly, following the interview for the current study she asked to see the genetic counsellor who had counselled her. During their interaction she showed the counsellor the pictures. This satisfied Sthembiso’s need to prove that the decision she had made was the right one. This was particularly important for her to do because she had perceived the manner in which she was provided with information as being pressurised to terminate the pregnancy.
“The doctor had said that my child will not be alright, but my child is alright… I always said I can take all the pictures and send to all the doctors and see how he is doing. Some of the doctors I see them in Mowbray. They see him, they meet him and they also, they all surprised”- Sthembiso, Dandy-Walker Maloformation, DTOP, LB

The women who received information regarding the probable poor prognosis were relieved when they realised that their children are thriving because it was reassurance that they made the right decision. This was also important for Tumi as she was worried about the decision she had made (table 4) but when she saw her daughter she realised that the defect was not as severe as she had anticipated.

“Because I actually expected the way they told me that but when I saw myself it's like no man it's not that worse, not that bad as they told me…”- Tumi, Spina Bifida, DTOP, LB

The four women were relieved with the outcome but from the interviews feelings of distrust in the healthcare system came up. These feelings related to being informed prenatally about a poor prognosis whereas their children are not as severely affected as they had anticipated. However they tried to look past that and embrace their children and also expressed feelings of joy and gratitude for a less severely affected child. The women had to adjust their lives and those of their family to accommodate the needs of the new child, but these children have integrated well into their families. However all the women felt that the decision that they made was the right decision.

**Reasons for Decision**

Each woman had the freedom to decide whether or not to terminate their pregnancy. Out of 12 women, five decided to terminate and the remainder continued with the pregnancy. Their decisions were based on various factors (Table 3).

Table 3-Decision to the offer of TOP and the deciding factors

<table>
<thead>
<tr>
<th>Participant</th>
<th>Decision</th>
<th>Deciding Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>TOP</td>
<td>Poor Prognosis</td>
</tr>
<tr>
<td>Nomvula</td>
<td>Declined TOP</td>
<td>Hope and Religion</td>
</tr>
<tr>
<td>Participant</td>
<td>Factors</td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Sindy</td>
<td>TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor Prognosis</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor Prognosis</td>
<td></td>
</tr>
<tr>
<td>Suzie</td>
<td>TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor Prognosis</td>
<td></td>
</tr>
<tr>
<td>Linda</td>
<td>Declined TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Faith</td>
<td>Declined TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Religion (God's Gift)</td>
<td></td>
</tr>
<tr>
<td>Sthembiso</td>
<td>Declined TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hope and Religion</td>
<td></td>
</tr>
<tr>
<td>Lerato</td>
<td>Declined TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Tumi</td>
<td>Declined TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Guilt</td>
<td></td>
</tr>
<tr>
<td>Reneilwe</td>
<td>TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Poor Prognosis</td>
<td></td>
</tr>
<tr>
<td>Refiloe</td>
<td>Declined TOP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Previous Miscarriage</td>
<td></td>
</tr>
</tbody>
</table>

During the interviews each woman was asked about the most difficult aspect during their experience as it is assumed that deciding to terminate or continue with a pregnancy affected by a serious abnormality is likely to be the most difficult. The entire process of deciding whether to undergo a TOP or not was unpleasant, however each of the women expressed a different aspect that was the hardest for them. These have been summarised in table 4 below.

Table 4-Most difficult aspects for each participant

<table>
<thead>
<tr>
<th>Participant</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>Mary expressed two aspects that she found the most difficult for her. The first was the fact that her partner has healthy children from a previous relationship and now she felt guilty for carrying a foetus with abnormalities: “My current partner, we’ve been together for quite some - quite a few years now and he has children…. So my concern was, &quot;iyo this guy has already got normal kids” The second aspect was her fear of disappointing her immediate family as</td>
</tr>
</tbody>
</table>
they were not expecting complications:  
“For people, for the next person out there, my family…The disappointment”

| Nomvula            | Nomvula had a caesarean section and expressed sadness that she was not able to remember how her child looked:  
|                   | “I didn’t even see the baby face, I just saw (Saw the baby briefly) because I was still traumatised,” |

| Sindy              | For Sindy it was simply losing her baby through TOP, as she said that this child was “a loved one”.  
|                   | “..It was losing my baby” |

| Lucy               | Lucy had complications following her TOP and was admitted for two weeks and could not take care of her sons and therefore they were staying with her sister, which she was not comfortable with:  
|                   | “…Was when the time to take the baby out, no one could take the children (her older sons) I stay two weeks…” |

| Suzie              | Suzie was experiencing other complications and pain during her pregnancy which required to her to be at the hospital often.  
|                   | “The pains I was having…In and out the hospital and I don’t like hospital” |

| Linda              | Linda found it difficult to accept the diagnosis of her foetus. She explained that prior to delivery she found it difficult to accept the diagnosis because she felt that she did not deserve to have a child with severe abnormalities.  
|                   | “I think the acceptance part (Acceptance of the prenatal diagnosis), uhm like I said you know I accepted that this was but it wasn’t a sincere acceptance” |

| Faith              | It was difficult for Faith to attend follow-up prenatal appointments as it was a reminder for of her son’s condition and also being reminded that she still has an option to terminate:  
|                   | “To me it’s like, when I come to the clinic it was, it was the fear of getting hurt again” |
| **Sthembiso** | Sthembiso found going for the follow-up scans difficult because it was a constant reminder that the diagnosis of her foetus had not improved.  

“The most difficult thing is i-scan and then I told Thato (the counsellor) I don't want to go to the scan anymore” |
|---|---|
| **Lerato** | During an ultrasound, Lerato was informed by the clinician that the heartbeat could not be detected and that her foetus demised. Finding out about the death of her child was the most difficult for her:  

“…Is when the doctor said “I don’t see a heartbeat”. The first time that they actually find that Oratiloe’s (her daughter) passed on” |
| **Tumi** | Tumi decided to continue with the pregnancy and she was concerned whether she had made the right decision and would be able to cope with a severely handicapped child.  

“For me was actually if I made the right decision, when I decide I’m gonna keep the baby” |
| **Reneilwe** | Reneilwe found having to take the tablet to induce labour in preparation for TOP as the most difficult.  

“When they gave me this white tablet, that was difficult thing because I knew that is how the baby is gonna be- (demise) was now so I took it” |
| **Refiloe** | Following the birth of her child, Refiloe had to remain in the ward for three days for observations and therefore could not attend her child’s funeral as in her religion; the deceased are buried on the day of death.  

“I think it was the funeral because I had to stay at the hospital for three days” |
Chapter 4: Discussion and Conclusion

The current study explored the decision making process of women offered termination of pregnancy (TOP) for a serious congenital abnormality to gain insight which will have implications for clinical practice when counselling women with similarly affected pregnancies.

Twelve women were interviewed to elucidate how they decided whether or not to terminate their pregnancy and what factors played a role in their decision making process. Thematic data analysis was used to analyse the data.

In this chapter, the demographic information and the pregnancy outcomes will be discussed to provide context. The major findings (themes) of the research that influenced the decision and experience of these women and what the participants found to be the most difficult part of the entire process are also discussed. The conclusion, study limitations, implications for practice and future research also form part of this chapter.

Participant Demographics and Patient Information

The study included black (African ancestry) and mixed ancestry participants. This is representative because the majority of the patients seen at genetic clinics in South Africa are of mixed ancestry (63%) and African ancestry (28%) (Kromberg, Wessels & Krause, 2013). In a previous study by Todd et al. (2013), ethnicity was found to play a role in decision making regarding TOP as the majority of South African black participants in their study declined TOP leaving the outcome of their pregnancy to fate. In contrast to that, in the current study most of the women who terminated their pregnancies were black while the majority of the participants who declined TOP were of mixed ancestry. This could be due to the religious affiliation of the women. The majority of the mixed ancestry women are of Muslim faith while and the majority of the black women are Christian which is in keeping with the national statistics provided by Statistics South Africa (Statistics South Africa, 2001).

Most women who accepted TOP had had the abnormalities in their pregnancies diagnosed prior to 20 weeks gestation which was also seen to be a contributing factor in a study by Todd et al. (2010). The women with a pregnancy diagnosed prior to 20 weeks were more likely to terminate the pregnancy. In another population,
gestation has been shown to play a role in TOP decision making in other studies too where advanced gestation was a reason for women declining TOP (Benute et al., 2012). Although not explicitly stated by the women in this study, the literature would suggest that gestation may have played a role in the decision making regarding TOP. Marital status and educational background did not seem to play a significant role in the decision making in this study.

**Deciding Factors**

When making a decision regarding TOP for a pregnancy affected by a serious abnormality, expectant parents, particularly the women, took a number of factors into account as was found in the study by Govender et al, (2015) but there may be one factor that is the main contributor to the decision making. In this study seven of the participants decided to continue with their pregnancies. The reasons for continuing with the pregnancy included hope that the child would be healthy, religious beliefs that prohibit termination of pregnancy as it is considered a sin and only God can take away life. Another religious belief that was a common contributor to a TOP decision was viewing the pregnancy as a gift from God. Accepting that the outcome would be determined by fate and the experience of a previous miscarriage also influenced their decision. One woman felt that her 12 year old daughter’s advice and acceptance led to her declining TOP. The deciding factor for all the women who terminated their pregnancy was the poor prognosis and expectation of a poor quality of life. This finding is in line with that of Govender et al. (2015), Benute et al., (2011) and Fonda Allen & Mulhauser (1995) where the primary reasons for TOP were similarly focused on the prognosis and influenced by religion.

The decision making process regarding TOP was difficult for all the women. However the one aspect of the entire process that made it the most difficult for each woman that was different for each of the participants. This indicates that the decision making process is not the same for any two women, but rather that each woman’s experience is unique. These findings are in agreement with those of Reed & Berrier (2016) who likewise found that each woman had their own different experience.

Both the decision and the overall experience of the women was influenced by the health care services as well as the family, partner and community. It was clear that each woman went through their own personal process in an attempted to rationalise
the diagnosis. Following the delivery, all the women had to adjust their lives to the decision they had made in an attempt to move on.

**Health Care Services**

Foetal abnormalities were initially detected at the maternity outpatient clinics during a routine ultrasound and then the patient was referred to GSH Foetal Medicine Unit (FMU) for further investigation which involves another ultrasound and invasive testing when indicated. This gave the women hope that the more specialised scans would show a healthy foetus. Invasive testing is typically an attempt to identify or exclude a chromosomal abnormality. This is useful for the management of the pregnancy, prognostication, recurrence risk counselling and may also determine if medical intervention is appropriate. At Groote Schuur Hospital (GSH) Pregnancy Counselling Clinic (PCC), when women have a pregnancy diagnosed with a foetal abnormality, they are referred for genetic counselling. It was evident that the women did not know what to expect from a genetic counselling session. It was similarly found in another South Africa centre that the majority of patients attending state genetic clinics initially do not know what genetic counselling is (Morris et al., 2015). As a result of this, the genetic specialists had to explain what the session entailed as some of the participants had expected to be given solutions or to be informed that the foetal abnormality had resolved. Genetic counselling is important for various reasons, one of which is providing the psychosocial support needed by the women to cope with the diagnosis in their foetus (Rauch et al., 2005). Most women appreciated the genetic counselling session as it provided them with the necessary support they needed, minimised guilt and also assisted them with decision making regarding TOP. Satisfaction with genetic counselling was reported by Morris et al (2015) in a different setting in South Africa. This suggests that although further education is required about genetic counselling in South African communities, genetic counselling is valued.

During the genetic counselling session patients receive information regarding the condition, probable causes and are offered further invasive testing and TOP where appropriate (McCarthy, Bonnie & LeRoy, 2006). In the current study, the amount of information and the manner in which it was conveyed mattered to some of the women. The information was overwhelming for some of them and the women
suggested ways to improve sharing information which included speaking to families with an affected child and providing the information in smaller sections so that it is less overwhelming. It has been shown to be common practice for patients to be provided with large amounts of information at a fast pace and so attempts should be made to provide the information in a manner the client can comprehend (McCarthy, Bonnie & LeRoy, 2006). One of the women mentioned that the use of visual aids provided information in a way that she could comprehend and was helpful for her in understanding the condition and preparing for the probable outcome. These findings, like those of Fonda-Allen & Mulhauser, (1995) indicate that the women were not prepared for the scope of information and it thus became overwhelming for them.

The majority of the women understood the information which also influenced the decision they made especially the women who accepted TOP. The women who decided to TOP based their decision on the associated poor prognosis and poor expected quality of life. The women who declined TOP did not base their decisions on the information given although they understood the probable pregnancy outcome but rather on other factors such as religion. A novel finding in this study was that one woman considered her young daughter’s approval to be the major factor in deciding to continue with the pregnancy.

Govender et al. (2015) and Asplin et al. (2012), in different settings also found that information influences decisions made regarding TOP although factors other than information are also considered during the decision making process. The participants in this study felt that all the information given was necessary but their views on the manner in which it was provided differed. This suggests that assessing the different information needs of each patients, especially those considering TOP, is essential as it could potentially affect their comprehension of the information shared. Following information giving, these women were confronted with making a decision on whether or not terminate the pregnancy. It is known that genetic specialists assist e patients in making decisions that are in line with their views and beliefs (Fonda Allen & Mulhauser, 1995).

All the women in this study were offered invasive testing but some questioned the utility of the test because even if the results were normal, the foetus would still have the abnormality and have a poor prognosis. Regardless of acceptance of invasive testing, the women who declined TOP were offered follow-up ultrasounds to monitor
the foetus. These follow-up scans caused further stress for the women as they were a constant reminder of the foetal abnormality particularly because they could see the abnormality. Health care professionals therefore need to treat patients with sensitivity when they return for the follow-up ultrasounds. Where possible they should give them the option of seeing the ultrasound monitor or not and discuss what information to share with them prior to the scan. It would also be helpful if the women are provided with information on the “healthier” aspects of the foetus as found by Asplin et al., (2012).

From the study it was apparent that some of the women felt pressurised by health care providers to make a “right” decision. These healthcare providers included the nurses and clinicians at the antenatal clinic and those in the labour ward. It is important that they are educated about the sensitivity of such decisions and treat the patients with respect and care irrespective of the decision they made regarding TOP. Making the right decision is a worry for women considering TOP for a foetal abnormality. These women feel pressurised as women are expected to be the protectors of the unborn child (Lupton et al., 2011), emphasising the need for health care workers to provide the women with support and respect regardless of the decision they make. This need to show care and respect for the woman irrespective of the decision made was also highlighted by Asplin et al. (2012). It is important that geneticists facilitating decision making use sensitive language so as not to cause emotional harm to the women.

**Home**

Following the first genetic counselling session, the women in the current study were given an opportunity to discuss the diagnosis with their partners, families and community members before making a decision regarding TOP. This home setting served as the main support system for the women as it is the environment in which they spent most of their time. As a result, the views of the family and community influenced their views on TOP. Previous literature has demonstrated that views of family and sometimes community are important because, as in the South African context, the patient is not a woman alone, but rather subject to the views of the entire family (Penn & Watermeyer, 2012).
The women in the study found it important to discuss the diagnosis with their families as a means of receiving support and guidance. This guidance allowed the women to consider both options and how it could impact on their lives and that of the family. These results support previous literature where family discussions have been deemed essential when making a decision regarding a congenital abnormality as the family provides advice that is in line with the family belief system (Morris et al., 2015; Weil, 2000). Although the women discussed the matter with various members of their families, it was apparent that their mothers played a greater role. Their mother's role extended from being the main caregiver and support for the women to informing extended family members and members of the community as a means of gaining support for their daughters. These results are consistent with the data obtained by Penn et al. (2010) and Morris et al. (2015) where the roles of grandmothers includes being the care-givers as well as being the family informants.

Surprisingly, in the current study, some of the women discussed the matter with their children to gain insight and assistance with making a decision. This was more common amongst the women who continued with their pregnancy who found it helpful as it gave them insight as to whether or not their children would accept a sibling with a congenital abnormality. The acceptance of the foetus allowed the women to continue the pregnancy with the support of their children. This finding however has not been described in the literature and is novel to this study. Another important finding was that the women found it necessary to inform their children about the affected pregnancy, in particular that priorities and expectations in terms of chores would change once the child was born. This step was necessary for the families to ensure that they (the children) understood and did not feel neglected. These results seem to be consistent with those of Reed & Berrier (2016) and Zierhut & Bartels (2012) where parents were concerned with how the new child would integrate with the siblings and attempted to include them in the day-to-day caring of their new sibling. The findings in the study suggest that parents considering continuing with a pregnancy affected with a congenital abnormality consider how the presence of a sibling with a disability will affect their other children. It was also important for them to gain approval to continue with the pregnancy because of the probable impact it will have on the family.
The diagnosis also affected the relationship dynamics between the women and their partners. The partners’ initial reaction to the news was to become withdrawn and not communicate with the women particularly about the ultrasound findings for a period of time. They therefore did not provide the women with adequate support over this period. This led the women to feel that they were to blame. This finding suggests that men also go through their own grief process while attempting to rationalise the diagnosis and reach acceptance. Following the acute grief period, they were then able to provide the support needed. These results support the idea that the diagnosis of a foetal abnormality affects the partner as well as the relationship between the couple (Fonda Allen & Mulhauser, 1995). A possible explanation for the effect on the relationship may partially be due to the differences in coping mechanisms between men and women (Weil, 2000; Fonda Allen & Mulhauser, 1995). This was demonstrated in the current study where the women’s partners became disconnected and initially did not want to discuss the foetal abnormalities whereas the women yearned to discuss the matter with their partners. Weil (2000) stated that men tend to internalise their feelings whereas women want to discuss their feelings and that limits the amount of support that can be provided. It was evident in the current study that men go through their own phases of grief before they are able to support the women adequately. This is consistent with the findings of Benute et al., (2012). These findings give insight into the grief process of men following the diagnosis of a foetal abnormality and will be useful in the clinical setting.

The women’s partners initially blamed them for the abnormalities in an attempt to comprehend the cause of the foetal abnormality during their acute grief. However the women also sometimes blamed their partners for the abnormalities. They attributed this to lifestyle causes and cultural beliefs. Blame is not uncommon during the grief process and these findings suggest that the women and their partners may have been feeling anger which presented as partner blame. Blame was an attempt to find a reason for the foetal abnormality but also was linked to their beliefs about the cause of genetic conditions (Penn et al., 2010) and could function as a means of coping with the diagnosis. However, ultimately the couples were able to reconnect and support each other and in most cases the relationship improved. This mending of a relationship further supports literature that suggests that supporting each other adequately during the diagnosis of a genetic condition can bring a couple closer
These findings on partner dynamics illustrated that both the men and the women go through an acute grief stage where communication and support is limited but once they have overcome the acute grief, they are able to support each other efficiently.

Support and care from the community was also appreciated as some of the women were able to share their experiences with an objective person. However, there was some ambivalence amongst the women regarding the support received from their communities. Some of the women found it helpful to talk to members of their community whereas the other women feared being discriminated against. The contradictory views on sharing the diagnosis of the foetal abnormalities with the community are in line with the results obtained by Morris et al. (2015) where the perception of whether or not their child will be accepted by the community determined whether not women introduced and explained their child’s condition. The women who felt that they would be stigmatised did not disclose their child’s genetic condition. Literature also suggests that this discrimination is in part due to the lack of knowledge of genetic conditions and to attributing the cause to cultural and religious transgressions (Penn et al., 2010). TOP has also been stigmatised by various communities over the years (Todd et al., 2015) and so some of the women in the current study did not disclose to members of the community the option of TOP for fear of being discriminated against. This is illustrated in the current study where women who feared being stigmatised informed neighbours and religious group members that they had a miscarriage because they felt that TOP, even for a serious congenital abnormality would not be permitted.

Some South African cultures would permit TOP for a serious abnormality as disability is not readily accepted in the community and would consider the quality of life of the child and impact on the quality of life of the family (Penn & Watermeyer, 2012). In the past, in some circumstances, the elder women who were the community’s “midwives” would evaluate a neonate for any serious abnormalities and if any were present, would terminate the neonates’ life and also provide a reason for the death (Penn et al., 2010). Miscarriages are also sometimes seen as something to be ashamed of, in communities where having children is thought to be a necessity as it confirms inability to reproduce successfully. This is one of the reasons women would prefer to terminate a pregnancy before members of the community became
aware that she was pregnant and also influenced the decision to rather have a child with a disability as it is important for the family name to be carried through (Penn et al., 2010). The views of women in the study suggest that there is still not enough knowledge regarding congenital abnormalities and their causes in the various communities in which they reside.

**Being a Woman**

The pregnancies were precious to all the women, in part because they felt a need or responsibility to reproduce. They also felt that society expects a woman to reproduce. Having a child is a confirmation of the couple’s fertility (Weil, 2000). Therefore the first child between a couple is particularly precious because it is a way of consummating the relationship (Weil, 2000). This may be reason that women from the current study found it particularly stressful to adapt to the diagnosis if this was their first child or if it was the first child with their new partner.

It was difficult for the women to hear that their foetus had been diagnosed with a potentially life-limiting abnormality. They had to adjust from being excited about the pregnancy to dealing with the news and having to make a decision regarding TOP. However each woman reacted differently – their reactions included physical illness as a result of the shock of the news. This has been described to continue even until after the birth of the child as a way of adjusting to the loss (Pitt, McClaren & Hodgson, 2016) however in this current study this illness only continued through the prenatal period. This highlights that the foetus is perceived as an extension of the mother (Weil, 2000) and may explain why a foetus is so precious to them. Personification of the foetus gives women hope and strengthens the bond between the foetus and the woman. In a study by Aune & Möller (2012) the repeated visualisation of the foetus on ultrasound strengthened this bond and led to the women in their study declining TOP. As with this study, the personification of the foetus occurred through feeling foetal movement which led some of the women to decline TOP in the hope that their child would be healthy. Repeated visualisation of the foetus was not pleasant for all of the women: for some it was a reminder of the abnormality that was present and therefore threatened the mother-foetus bond. Mothers disconnecting from their unborn babies in anticipation of the outcome as was found in the study conducted by Pitt, McClaren & Hodgson (2016). This is well
illustrated in this study by Mary who disconnected from her pregnancy following confirmation of the diagnosis in her unborn baby of Trisomy 18 and deciding on TOP.

The decision to continue or to terminate a pregnancy affected by a serious abnormality is found to usually be a collective decision made by the patient and her partner or family (Morris et al., 2015 Benute et al., 2012). Contrary to these studies, the women in the current study felt that they should ultimately make the final decision regarding the pregnancy themselves. The women did discuss the decision with their partners and families many of whom guided them to make the “right” decision in line with their moral values, belief systems and how it would affect their quality of lives. The women valued the support but they needed to be the ones to make the final decision suggesting that they wanted to regain control over the situation. The literature suggests that having a foetal abnormality diagnosed poses a risk of narcissistic injury and the loss of self-worth and can lead to women feeling as though they have lost control of the self and the situation (Weil, 2000). Making the final decision was a positive step for these women to regain control over the pregnancy and has been found to be beneficial in coping post-delivery (Fonda Allen & Mulhauser, 1995).

Finding Meaning

In the current the study, the women looked for meaning to explain why their pregnancies were affected with a serious congenital abnormality. The women were aware of the scientific explanations of the disease aetiology but their personal beliefs or meanings had a greater impact on their decision. This search for meaning assisted them in making a decision based on their beliefs regarding the cause of the abnormality. These results are in line of that of Fisher (2008) & Weil (2000) who found that parents attempt to find meaning following the diagnosis of a genetic condition. Through their journey to find meaning, each woman found a different reason for the event such as lifestyle choices, punishment, a sign of fertility, consolation for a previously child lost and fate. For one woman who saw this pregnancy as a “sign” from the Creator confirming her ability to conceive, decided to TOP. In contrast to this, previous studies indicated that women with a history of infertility were more likely to continue with their pregnancies (Hurford et al., 2013;
Hawkins et al., 2013). Attaching meaning was a unique experience for each woman and is consistent with the findings of Reed & Berrier, (2016). It can therefore be assumed that attempting to find a non-scientific explanation for this event was important as it affected the decision making process in allowing the women to reflect on their beliefs.

For the majority of the women, religion played a prominent role in their search for meaning as they attempted to fit this event into their religious framework as stated in literature (Weil, 2000). Religion also played a significant role in the decision making process of the women in this study, although the role it played was unique to each woman. It was evident that religion was a part of the women’s daily lives and hence the impact that religious beliefs had on them was significant. These results are in line with those of previous studies where it was found that religious factors had a greater impact on the decision making regarding a foetal abnormality than other factors (Hurford et al., 2013; Balkan et al., 2010). As stated, the role of the religion was unique to each woman and hence some continued with their pregnancies because TOP is prohibited amongst various religious groups. For other women, their religion gave them faith that their foetus would be born healthy. These results were consistent with those of many other studies including Hurford et al., 2013; Ndjapa-Ndamkou, Govender & Moodley; 2013; Mookamedi et al., 2010; Penn et al., 2010 and Harries et al., 2007. It was important for some of the women to have open communication with their Creator through regular prayer. They prayed for the health of the foetus. In this study one of the women expressed her anger at her Creator until she accepted her child’s condition because she felt she did not deserve having a child with a disability. It is possible that other women may have similarly felt anger towards their God but did not express it during the interviews. This could be one area to be explored further during genetic counselling sessions and in research to elucidate the role of religion in decision-making.

Religion was closely linked to the women having hope and some sought signs as confirmation that they should continue with the pregnancy. Interpreting foetal movement as a sign of health was consistent with the study by Hurford et al., (2013). This gave the women hope that their foetuses were healthy and contributed to their decision to continue with the pregnancy. In contrast some women lost hope as the pregnancy progressed without improvement in the foetal abnormalities on ultrasound
or prognosis leading to a decision to terminate the pregnancy. Losing hope served a purpose in confirming the reality of the condition.

**After the birth**

Each person grieves differently and no significant differences in grief have been found following IUD or TOP (Keefe-Cooperman, 2005). Following the loss of a child, it was important for some of the women to find closure by seeing their children and being given a moment to bond with the baby and to say goodbye. One of the women who did not remember the face of her child due to anaesthesia, felt disheartened as she cannot picture the child she was carrying. For those who terminated the pregnancy, being able to see the abnormalities confirmed that they had made the right choice and they thus found peace. However not all of the women wanted to see or bond with their children because they did not want to have the “picture” of the deceased child in their mind for fear that they would not be able to move on. There was no difference in the grief process between women who lost their pregnancy as a result of either IUD or TOP in this study. This is in keeping with the finding of Keefe-Cooperman (2005) who found that although each person grieves differently, the mechanism of loss did not cause a significant difference in the grieving process.

Letting go and moving on involved certain tasks that had to be completed. The first one was the burial. Burying a family member is a way of saying goodbye and this was important to some of the women so they could formally bid farewell to their children. As a result it was difficult for one of the women who was not able to bury her child in person as she could not have a formal send off to assist her in moving on. Grieving is a process and Worden’s fourth task of grief is: “To find an enduring connection with the deceased in the midst of embarking on a new life” (Worden, 2008:50). For one of the women this fourth task was completed when she went to her child’s grave to speak to him and bid him farewell. Allowing parents to bond with their deceased child and having a burial ceremony for the child is found to often be important for the grieving process but may also exacerbate the grief symptoms (Sommerseth & Sundby, 2010). However in the current study, it is the woman who was not able to remember the face of her child who seemed to have experienced more grief when compared to those who chose to see their children. This suggests that she might still be going through complicated grief.
Making the right decision seemed to be of greater importance to the women who continued with their pregnancies. As mentioned above, some of the women felt pressurised to terminate their pregnancies and hence the women with live-born surviving children felt relieved that their children were mostly thriving. This affirmed that they had made the right decision and created a need to prove the health care practitioners who were involved in their prenatal care that they made the right decision. This finding of wanting to prove their decision was the right one is has not been described before. The outcome of serious abnormalities detected prenatally cannot be guaranteed and therefore the variability of the outcome including the worst probable outcomes are communicated during medical consultations. Therefore it is essential that the diagnosis, chances of survival (neonatal and long-term), possible impairment and illness, the required treatment and the possible effect the child will have on the family should be discussed with the women (Wilkinson, Crespigny & Xafis, 2014). The discussion about the aspects listed is important as in some circumstances the prospective parents consider personal and family stability and also the possible quality of life of the foetus (Gaille, 2016). For that reason, it explains why although the women decided to continue the pregnancy, they did not expect a good quality of life.

Beyond what the women expected, the unexpected outcome has brought the women joy and they are content with their decisions as they all feel that the child has brought a positive change in their lives. This finding is similar with that of Hurford et al. (2013), where many women offered TOP for prenatally diagnosed Down Syndrome were content to continue with their pregnancy and felt that their children brought joy to the family irrespective of the multiple hospital appointments. The women in the current study focussed more on the positive attributes that their children brought into the family rather than the health complications. This suggests that they searched for a deeper meaning of which they attached to the presence child in their family system. This meaning seems to have also assisted the women with overcoming grief and coping with the child postnatally, which is seen especially with Linda. The meaning she has attached allows for her to be able to carry-on despite the multiple medical complications her daughter has. Victor Frankl describes tragic optimism, which means a person is able to stay optimistic despite tragic circumstances (Frankl, 2008:139). It seems that the women in this present study displayed this tragic
optimism as they turned something negative into something positive and made the best of their situation

**Conclusion**

The current study demonstrated that the decision making process is multifaceted where women consider a multiple of factors before making a decision. These women then filter through the factors to determine the one factor that is the most important to them, which is the decision-determining factor. The decision making process is unique to each women.

Five main themes emerged from the data. The first two themes were related to external influences on the decision making process which took place in two settings: healthcare services and home. The other three themes are related to internal factors affecting decision making and how the women aimed to adapt following the birth of their children.

The healthcare services theme encompassed information they had received, freedom of choice on termination of pregnancy, genetic counselling and testing. It was clear that further education on what genetic counselling is needed and findings also emphasised the need for greater respect by health care workers for the autonomy of women’s choice on TOP. Women were not convinced of the utility of invasive genetic testing in the setting a diagnosed serious fetal abnormality and often unexpectedly found follow up ultrasound a negative experience.

The home setting was focused on support (or lack of it) provided by the family, partner and community. The women discussed the pregnancy circumstances with their families and members of the community and even their children seeking support and guidance whether to TOP or not and how the affected child might be integrated into their lives.

Insight into how the diagnosis influenced relationship dynamics illustrated the partners’ grief process with initial withdrawal from the woman but subsequent support for her eventually resulted in a strengthening of the relationship despite feelings of blame for both the woman and her partner.

Stigma of TOP, disability and fertility was of concern to some of the women preventing them from disclosing the circumstances of their pregnancies to members
of their communities. This also had an impact on the decision making process and how the women felt about their pregnancies.

The third theme (Being a Woman) and the fourth theme (Finding Meaning) were internal factors that affected the women’s decision making. The pregnancies were all precious to the women in the study but even more to those women who were pregnant for the first time or for the first time with a new partner. Childbearing emerged as an important factor in how the women perceived their roles and responsibilities. They also believed that while others could guide and support, the final decision about TOP was theirs to make. The women all sought meaning and reasons for this happening to them. This allowed them to fit the scientific information and diagnosis into their own cognitive framework and interpret it in a manner that was in line with their feelings and beliefs. Finding meaning was intertwined with their religious beliefs and gain and loss of hope throughout the remainder of the pregnancy and influenced their decision. Finding meaning continued until after the birth of the child was demonstrated in the importance of seeing the baby after the birth and attempts to move on and cope with their loss by completing various tasks. The women who had live-born surviving children found meaning in the way in which their children are thriving and are less severely affected than expected. This, for them, was affirmation that they had made the right decision.

This process was difficult for all the women but none of the women regretted their decision. They were content that they had made their decision in line with their beliefs and the meaning they attached to the pregnancy.

The aim of the study was to determine the decision making process for women offered TOP for a serious congenital abnormality. The decision making process was determined which in turn allowed for the research question to be answered. The decision making process (figure 2) for the women in the current study can be illustrated as follows:

- Once the foetal abnormalities were detected, the women experienced acute grief emotions.
- The women then went through a process of searching for meaning and an attempt to accept the diagnosis.
• The women were then faced with having to make a decision regarding TOP and therefore they considered a multiplicity of factors both external and internal that impacted on their thought process.

• The women have filtered through all these factors to determine the one factor that is the most important to them which then determines the decision the woman makes.

• The decision making process was not linear however and the search for meaning and acceptance often continued until after the birth or death of a child.

From the study objectives, the roles of the family, the community and genetic counselling were determined and there was no correlation found with the decision taken and maternal age or the gestational age at diagnosis.

**Study Strengths and Limitations**

Qualitative methodology, using open-ended questions to obtain the data was beneficial as it allowed for in-depth information to acquire understanding on the decision making process of the women. The women were all given an opportunity to express themselves in a language they felt comfortable with, which was valuable as all the women were able to communicate their feelings and their experiences. The researcher had clinical exposure prior to the interviews, which gave insight into the genetic counselling session and the procedures of the hospital. This insight allowed the researcher to understand fully the references the women made regarding the services. As the researcher was also the interviewer, this allowed for appropriate prompts to be made during the interview. The women who came for the interview benefitted therapeutically from sharing their experiences. The women who needed post-delivery counselling appointments were able to have them arranged.
The study limitations included time constraints and the inability to recruit a large number of participants this resulted in the data not to be saturated. The recruitment process was complex and majority of the women recruited did not come for interviews. It is possible that they had not wanted to take part, but had agreed to participate so as not to disappoint the clinician that initially contacted them. Due to this it is recommended that a study with a larger sample size is conducted.

**Study implications**

The results of this study provided insight into the decision making process of women offered TOP for a serious congenital abnormality which will impact on clinical practice in this and possibly other similar settings. These are the recommendations for practice:

- The individual information and support needs of women in this situation should be assessed and provided.
- Education of other healthcare workers including nurses and foetal medicine specialists on the sensitivity and complexity of the TOP decision making process for women is needed. This will allow them to treat the women with greater respect and care regardless of the decision made.
- Taking a picture as a manner in which parents can remember their children should be offered to all women who lose their children by the birthing staff.
This was important to some of the women, especially for those who had a Caesarean section.

- Further community education about genetic counselling is needed, so that the public may be aware of the availability of the service and also be able to prepare adequately for the session.

**Research Recommendations**

The current study has given rise to new topics to explore such as:

- Exploring the grief process of the women’s partners during the decision making process.
- The concept of a decision determining factor.
- To explore in detail the process of finding meaning for a foetal abnormality and how that continues after the birth of the child.
- A longitudinal study on the outcomes and health complications of surviving live-born children who were prenatally diagnosed with a serious congenital abnormality.

This research project was conducted to gain more knowledge about the decision-making process of women offered termination of pregnancy for a serious congenital abnormality since there was a gap in the knowledge, especially in the South African setting. Through this study a better understanding of the decision making process was gained. The main themes that emerged to have influenced decision-making in these women included the healthcare services, the home setting, what is meant to be a woman, finding meaning and negotiating the aftermath. These findings will be valuable for genetic counsellors, particularly in our setting, to meet the needs of women faced with this decision. These findings also provide foetal medicine specialists and other healthcare workers with a better understanding of the women’s thought process and the care that they require once they have made a decision. Since this was a qualitative study, it has created the platform for further studies to be conducted on this topic.
References


Dinklage, L. B. (1966). "adolescent choice and decision-making--a review of decision-making models and issues in relation to some developmental stage tasks of adolescence."


National Health Service Choices 2015, 08/06-last update, *Chorionic Villus sampling* [Homepage of National Health Service], [Online]. Available: http://www.nhs.uk/conditions/Chorionic-Villus-sampling/Pages/Introduction.aspx [2016, 04/06].


## Appendices

### Appendix A

**Research Project Socio-Demographic Information Sheet**

1) **Age Range (in years)**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td></td>
</tr>
<tr>
<td>26-30</td>
<td></td>
</tr>
<tr>
<td>31-35</td>
<td></td>
</tr>
<tr>
<td>36 and above</td>
<td></td>
</tr>
</tbody>
</table>

2) **Marital Status**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td></td>
</tr>
<tr>
<td>Married / Stable Union</td>
<td></td>
</tr>
</tbody>
</table>

3) **Ethnicity**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
</tr>
<tr>
<td>Coloured</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td></td>
</tr>
<tr>
<td>Other (please specify):</td>
<td></td>
</tr>
</tbody>
</table>

4) **Educational Background (please tick one)**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No Formal Education</td>
<td></td>
</tr>
<tr>
<td>Primary Education</td>
<td></td>
</tr>
<tr>
<td>Secondary Education but no Grade 12 (Matric)</td>
<td></td>
</tr>
<tr>
<td>Grade 12 (Matric)</td>
<td></td>
</tr>
<tr>
<td>Higher certificate/ Diploma</td>
<td></td>
</tr>
<tr>
<td>University Degree</td>
<td></td>
</tr>
</tbody>
</table>

5) **Religion**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Christian</td>
<td></td>
</tr>
<tr>
<td>Islam</td>
<td></td>
</tr>
<tr>
<td>Judaism</td>
<td></td>
</tr>
<tr>
<td>Traditional/ Cultural</td>
<td></td>
</tr>
<tr>
<td>Other (Please specify):</td>
<td></td>
</tr>
</tbody>
</table>

6) **Residence**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban (Metropolitan/city)</td>
<td></td>
</tr>
<tr>
<td>Suburban (developed area)</td>
<td></td>
</tr>
</tbody>
</table>
7) Gestation Period when diagnosis was made:

<table>
<thead>
<tr>
<th>Trimester</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Trimester (1 to 3 months)</td>
<td></td>
</tr>
<tr>
<td>2nd Trimester (4-6 months)</td>
<td></td>
</tr>
<tr>
<td>3rd Trimester (7 months and later)</td>
<td></td>
</tr>
</tbody>
</table>

8) Employment Status

- Unemployed
- Part-time
- Full-time

9) Planned or unplanned pregnancy: ___________________

10) Number of Children excluding the affected pregnancy: ____

11) Number of miscarriages/stillbirths excluding the affected pregnancy: ____
Appendix B

Interview guide

1. Can you tell me about your experience of having a pregnancy affected by a serious condition?
2. What were your feelings when you were first told about the diagnosis of your pregnancy? (Tell me more about how you felt when you were first told about the diagnosis about your pregnancy)
3. What were your thoughts when you were referred to genetic counselling?
   - What were you expecting?
   - What were you told when the referral was discussed?
4. What information were you given by the counsellor and/doctor?
   - What were you told about the condition?
   - What were you told about the prognosis?
5. What options were presented to you regarding your pregnancy?
6. When the option of termination of pregnancy was presented to you, what were your thoughts?
7. How did this information help you in decision making?
8. How did you make your decisions? (considerations)
   - How did the amount of time you were given affect your decision?
   - How have your beliefs impacted on your decision?
   - How did information given influence your decision?
   - What were your thoughts on termination of pregnancy when considering your age and ability to have more children?
   - How did having a support system/or not help you come to the decision you made?
9. What would you say was the most important factor for you when you were making the decision a regarding the pregnancy?
10. How has your experience of the whole process impacted on your life?
11. What was most helpful during this process?
12. What was the most difficult?
13. Who supported you during the whole process and how did their support help you make your decision?
   - Partner?
   - Family members?
   - Friends?
   - Professionals (Counsellor, Doctor etc.)?
14. How are have things been going with the baby?
15. How are you feeling now? What are your future plans?
16. How has this interview been for you?
Appendix C

University of Cape Town, Department of Pathology, Division of Human Genetics
Research Project Information Sheet and Consent Form

For any questions about the survey contact:
Malebo Malope: 021 406 6304/ 076 921 6095/ email: MLPMAL005@myuct.ac.za
Dr. Tina-Marié Wessels: 021 406 6373 / email: tina.wessels@uct.ac.za
Dr. Karen Fieggen: 021 406 629/ email: karen.fieggen@uct.ac.za
Ethics Chairperson: Prof. Marc Blockman, Division of Pharmacology, Department of Medicine, K Floor, Old Main Building, Groote Schuur Hospital , 021 406 6492

Research Project Information Sheet and Consent Form

Title: Exploring the decision making process of women offered termination of pregnancy for a serious congenital abnormality.

The research project aims to explore your experiences when you were making the decision about your pregnancy and the things that affected your decision. The study will be in the form of face-to-face interviews and will take place at the Groote Schuur Hospital pregnancy counselling clinic or at the Genetic Counselling offices at the University of Cape Town, Division of Human Genetics, 4th Floor Falmouth Building, depending on what you are most comfortable with. A translator will be present during the interview if you speak a language the researcher is not fluent in. The interview should run for about 45 minutes to an hour and will be voice recorded.

Your privacy will be protected by keeping the documents with your personal details separate from your responses given in the interview, and a false name (pseudonym) will be used. No personal information will be shared with anyone.

The interview questions are personal and may cause you to feel strong emotions and if you feel that you may need more counselling, it will be arranged for you by the counsellor. If you feel that you cannot or do not want to answer a particular question you may tell the interviewer that you want to skip the question and keep in mind that you do not need to give a reason for not answering the question.

Any health care that you are receiving from our clinics or anywhere else will not be affected by your decision to take part in this study or not.

Participation in this study is completely voluntary and taking part/not taking part in this study will not affect any health care you are receiving. If at any point in this study you feel that you no longer want to take part, you are free to pull out from the study and you do not need to give any reasons for pulling out. Contact details are given.
above and you may contact the researcher or supervisors, Dr. Tina-Marié Wessels and Dr. Karen Fieggen, if you have any questions during office hours (08H00-16H00) weekdays.

Statement of participation:

1) I am aware that taking part in this research project is voluntary and that I can withdraw from the study (without giving reason) at any time I feel a need to.
2) I know that I may answer questions that I am comfortable with and am free to not answer any question I am not comfortable with during the interview.
3) I am aware that personal questions will be asked in the study that may bring about strong emotions.
4) I have been provided with information about the study; the aims and objectives have been explained to me and I was given enough time to decide about taking part in the study.
5) I was given the opportunity to ask questions about the research project, I understand the aims and objectives of the study and I understand that I may ask questions at any time during the research.
6) I am taking part in this study at free will and was not pressurised by anyone who is a part of this study.
7) Provided my personal information is kept private and confidential, I agree to the results of this project to be used for scientific purposes and may be published.
8) I am aware that all my personal details will be kept private and confidential as long as there is no conflict with the legal or ethical obligations of the researcher.
9) I am aware that I will not be given any money or any other form of incentive for participating in the project.
10) I am aware that if the researcher notices that I am experiencing unresolved grieve a lot or is concerned about my mental health, the researcher will refer me for counselling and it is my choice to attend the counselling or not.
11) I am aware that any health care I am receiving will not be affected by my participation in the study.
12) I understand that the interview will be voice recorded.

I give my consent to participate in this project and agree that I am participating at my own free will.

_________________________________  _____________  ____________
Name and Surname of Participant    Signature              Date
13 July 2016

HREC REF: 378/2016

Dr TM Wessels
Division of Human Genetics
Suite 4.23-Level -4
Falmouth Building-FHS

Dear Dr Wessels

PROJECT TITLE: EXPLORING THE DECISION MAKING PROCESS OF WOMEN OFFERED TERMINATION OF PREGNANCY FOR A SERIOUS CONGENITAL ABNORMALITY (MSc candidate- Malebo Malope)

Thank you for your response letter dated 29 June 2016, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has formally approved the above-mentioned study.

Approval is granted for one year until the 30 July 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Malebo Malope will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator must obtain appropriate institutional approval before the research may occur.

Yours sincerely

[Signature]

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

HREC 378/2016
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC 378/2016