

**Positive experiences of mothers of a child with Down Syndrome in the Western
Cape**

S. Mhlanga

23288256

Dissertation submitted in partial fulfilment of the requirements for the degree of Magister in
Social Work Child Protection at the Potchefstroom Campus of the North-West University

Supervisor: Dr C.C. Reynolds

September 2013

DECLARATION

1. I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is one's own.

2. I have used the **NWU Harvard** method for citation and referencing. Each contribution to, and quotation in, this research report from the work(s) of other people has been attributed, and has been cited and referenced.

3. This research report is my own work.

4. I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as his or her own work.

Student number: _____

Signature: _____

Date: _____

ACKNOWLEDGEMENTS

I would like to thank Susanne Jacobs and Dr Coen Reynolds for their time and for providing me with assistance and supervision throughout this research process. Their extensive knowledge in the field of disability-related social work has contributed greatly towards developing my understanding of research and ethics.

I am very grateful to Val Hoy for having warmly welcomed me as a Family Counsellor in the Toy Library Clinic. I have learned so much from her both as a mother of a child with Down Syndrome and as a tireless, enthusiastic volunteer. She has guided and supported in me my role at the clinic and always had the grace to allow me to grow and learn alongside her. It is through this experience that I have developed the passion I now have for working in the field of disabilities.

I would also like to thank the staff at the Western Cape Forum for Intellectual Disabilities for their support of me during this research process. I wish to thank them for the generous funding I received, and for understanding my need for time-off during the process.

I extend a huge thanks to my family and friends for their constant encouragement throughout this walk. Thank you also to my peers for their continuous encouragement and support while working together, to complete this research process.

Lastly, I would like to acknowledge God, who has helped me and encouraged me to see this project to completion.

DEDICATION

It has been a remarkable experience to walk closely alongside mothers of children with Down Syndrome at the Toy Library Clinic for the past three years. These mothers have opened up their hearts to me, sharing their pain, offering their strength, and portraying their unrelenting love and joy for their children. I have gained the greatest respect for these mothers. It has been an honour to be part of their journeys in learning to experience the positives of being a mother of a child with Down Syndrome. These mothers have shown such dedication to and concern for their children, despite the hardships imposed on them by the many challenges associated with the disability.

I dedicate this research report to these mothers. May they have the comfort of knowing that their experiences will be an invaluable contribution to new mothers of children with Down Syndrome, inspiring them to see the positive aspects of their situation right from the start.

ABSTRACT

There has been a significant increase in the number of Down Syndrome (DS) births over the past 3 decades in South Africa. This means there are increasingly more mothers, children with DS and family members experiencing the stressors associated with the condition. However, the increase in DS births has led to the advancement of related medical and educational interventions, resulting in more families with a child with DS overcoming these stressors and discovering the positive aspects of having a child with DS.

This study aimed to uncover these positive aspects by exploring the positive experiences of a sample of mothers of a child with DS, with the hope that the findings will help society to move away from its focus on the stressors of having a child with DS to instead concentrating on the many ways in which families can cope with these stressors.

As part of the research process, face-to-face interviews were conducted as a qualitative approach to gain an in-depth understanding of this research topic. The interviews were all recorded by means of a tape recorder. There is only one hospital in the Western Cape Metropole area that specialises in this condition, and that hospital was consequently selected as the location for this research, since all mothers of children with DS are referred to this hospital. A purposive sampling method and the criterion sampling strategy were used for the selection of these five mothers with whom interviews were conducted in the hospital's developmental clinic

The main findings of the research include both the difficult and positive experiences of being a mother of a child with DS. Two of the major themes that arose in terms of the difficult experiences were: (1) having to make many adjustments to one's life to accommodate unpredictable health implications, developmental delays, negative perceptions, and unprofessional conduct; and (2) the difficulty of dealing with emotions, emotions of: fear, aloneness, and grieving. The mothers' positive experiences generally developed out of their attempts to find coping mechanisms for the above challenges, and these positives centre on support, resources, faith in God, accepting the condition, a positive attitude and bonding with their child with DS.

The predominant finding in terms of participants' own recommendations for new mothers of a child with DS was for them to learn to accept the condition. Other findings addressing ways of coping with the condition were as follows: persevering, being hopeful, taking it one day at a time, having awareness and understanding of the diagnosis, being around positive people, attending regular appointments, seeking out guidance and support for your child's development, loving your child, enjoying your child, and being present in every moment.

The key terms for this study include: 'positive experiences', 'mothers' and 'child with Down Syndrome'.

OPSOMMING

Daar was 'n beduidende toename in die getal van die Down-sindroom (DS) geboortes oor die afgelope 3 dekades in Suid-Afrika. Dit beteken daar is meer moeders met kinders met DS en die gesinslede ervaar die stressors wat gepaardgaan met die toestand. Hierdie toename in DS geboortes het gelei tot die bevordering van verwante mediese en opvoedkundige intervensies, wat daartoe aanleiding gegee het dat meer gesinne met 'n kind met DS hierdie stressors kan hanteer en ontdek daardeur die positiewe aspekte van 'n kind met DS.

Hierdie studie het die positiewe ervarings van moeders met 'n kind met DS verken met die hoop dat die bevindinge die samelewing sal help om weg te beweeg van sy fokus op die stressors van 'n kind met DS en eerder te konsentreer op die baie maniere waarop families hierdie stressors kan hanteer. As deel van die navorsingproses is aangesig tot aangesig onderhoude gevoer as 'n kwalitatiewe benadering ten einde 'n in-diepte begrip van hierdie navorsing onderwerp te kry. Die onderhoude is band opgeneem. Daar is net een hospitaal in die Wes-Kaap Metropool wat spesialiseer in hierdie toestand is, en gevolglik is hierdie hospital gekies as die plek vir hierdie navorsingprojek. 'n Doelbewuste steekproefneming is toegepas om die moeders te selekteer met wie onderhoude gevoer is. Die onderhoude het in die hospitaal se ontwikkelings-kliniek plaasgevind. Dataversadiging het die uiteindelijke steekproefgrootte bepaal. Die belangrikste bevindinge van die navorsing was dat moeders van 'n kind met DS beleef beide moeilike en positiewe ervarings. Twee van die belangrikste temas wat ontstaan het in terme van die moeilike ervarings was: (1) die feit dat baie aanpassings gemaak moes word. Aanpassings wat gemaak moes word was ten opsigte van onvoorspelbare gesondheidsgevolge, ontwikkelingsagterstande, negatiewe persepsies, en onprofessionele gedrag deur professionele persone en (2) probleme in die hantering van met emosies te wete vrees, eensaamheid, woede, hartseer en ontkenning.

Die moeders se positiewe ervarings spruit voort uit hulle pogings om hanteringsmeganismes vir die bogenoemde uitdagings te ontwikkel en hierdie positiewe ervaring steun op ondersteuning, hulpbronne, geloof in God, die aanvaarding van die toestand, 'n positiewe houding en binding met hulle kind.

Die oorheersende bevindinge in terme van die deelnemers se eie aanbevelings vir moeders met 'n kind met DS is dat hulle moet leer om die toestand te aanvaar. Ander bevindings met betrekking tot die positiewe aanspreek van die toestand van DS was soos volg: volhard, om hoopvol te wees, neem dit een dag op 'n tyd, meer bewustheid en begrip vir die diagnose, bly in kontak met mense wat positief is, kom afsprake na, soek leiding en ondersteuning vir jou kind se ontwikkeling, wees lief vir jou kind, geniet jou kind, en wees elke oomblik daar vir jou kind.

Die belangrikste terme wat vir hierdie studie sluit in: 'positiewe ervarings', 'ma' en 'kind met Down-sindroom'.

TABLE OF CONTENTS

DECLARATION	II
ACKNOWLEDGEMENTS	III
DEDICATION	IV
ABSTRACT	V
OPSOMMING	VII
CHAPTER 1	1
ORIENTATION AND STATEMENT OF PROBLEM AND RESEARCH METHODOLOGY	1
1.1 INTRODUCTION	1
1.2 BACKGROUND TO THE PROBLEM	1
1.3 OBJECTIVES	6
1.4 CENTRAL THEORETICAL STATEMENT	6
1.5 METHOD OF INVESTIGATION	7
1.5.1 Analysis of literature	7
1.5.2 Empirical investigation	7
1.5.2.1 Research Design	7
1.5.3 Research method	8
1.5.3.1 Sample of participants	8
1.5.4 Data collection method	9
1.5.5 Procedures	10
1.5.6 Ethical aspects	11
1.5.7 Data analysis	12
1.6 STRUCTURE OF RESEARCH REPORT	13
1.7 LIMITATIONS OF THIS STUDY	14
1.8 SUMMARY	14
CHAPTER 2	15
LITERATURE REVIEW:	15
MOTHERS OF A CHILD WITH DS AND POSITIVE PSYCHOLOGY	15
2.1 INTRODUCTION	15
2.2 THE HISTORY OF DS	15
2.3 IMPLICATIONS OF DS ON CHILDHOOD DEVELOPMENT	16
2.4 MOTHERS' EXPERIENCES OF HAVING A CHILD WITH DS	17
2.4.1 Support during pre- and postnatal screening of the diagnosis	17
2.4.2 Stress	20
2.5 ATTACHMENT BETWEEN MOTHER AND BABY WITH DS	22
2.5.1 Emotional Availability	22
2.5.2 Possible barriers to attachment between mother and baby with DS	24
2.6 POSITIVE EXPERIENCES OF MOTHERS OF CHILDREN WITH DS	25
2.6.1 Advancement and awareness	26
2.6.2 Temperament	27
2.6.3 Information	28
2.6.4 Inclusion	29
2.6.5 Belief system	30
2.6.6 Development	30
2.6.7 Family relationships and perceptions	32
2.7 AN OVERVIEW OF POSITIVE PSYCHOLOGY	33
2.7.1 What is Positive Psychology?	33
2.7.2 The background to Positive Psychology	34
2.7.3 The application of positive psychology	35
2.8 SUMMARY	36

CHAPTER 3	37
DATA ANALYSIS AND FINDINGS	37
3.1 INTRODUCTION	37
3.2 PROFILE OF PARTICIPANTS	37
3.3 DATA COLLECTION.....	38
3.4 DIFFICULT EXPERIENCES OF BEING A MOTHER OF A CHILD WITH DS	40
3.4.1 <i>Adjustments to having a child with DS</i>	40
3.4.1.1 Unpredictable health implications	40
3.4.1.2 Developmental delay	42
3.4.1.3 Perceptions	43
3.4.1.4 Perceived unprofessional conduct	45
3.4.2 THE EMOTIONAL EXPERIENCES OF BEING A MOTHER OF A CHILD WITH DS	47
3.4.2.1 Fear	47
3.4.2.2 Aloneness	49
3.4.2.3 Grieving	49
3.5 POSITIVE EXPERIENCES OF MOTHERS OF A CHILD WITH DS	51
3.5.1 <i>Coping mechanisms</i>	51
3.5.1.1 Support	52
3.5.1.2 Resources	54
3.5.1.3 Faith in God	55
3.5.1.4 Acceptance of the condition	56
3.5.1.5 Positive attitude	57
3.5.1.6 Bonding	58
3.5.2 <i>Changes in perception through experience</i>	61
3.5.2.1 Knowledge	62
3.5.2.2 Development of child	64
3.5.2.3 Positive approaches of others	65
3.6 SUMMARY	66
CHAPTER 4	67
CONCLUSIONS AND RECOMMENDATIONS.....	67
4.1 INTRODUCTION	67
4.2 CONCLUSIONS WITH REGARD TO THE OBJECTIVES OF THE STUDY	67
4.3 CONCLUSIONS WITH REGARD TO DIFFICULT EXPERIENCES.....	67
4.3.1 <i>Adjusting to having a child with DS</i>	68
4.3.2 <i>Difficult emotional experiences</i>	69
4.4 CONCLUSIONS WITH REGARD TO POSITIVE EXPERIENCES	70
4.4.1 <i>Conclusions with regard to coping mechanisms</i>	70
4.4.2 <i>Conclusions with regard to changes in perceptions through experience</i>	71
5.4 RECOMMENDATIONS.....	72
5.4.1 <i>Participants' recommendations to mothers of a child with DS</i>	72
5.4.2 <i>Researcher's recommendations</i>	73
BIBLIOGRAPHY.....	76
ADDENDUM A: ETHICAL CONSENT FORM	88
ANNEXURE B: HOSPITAL RESEARCH APPROVAL	90

LIST OF TABLES

Table 3.1	Participant's particulars	p.48
Table 3.2	Table of findings	p.50

CHAPTER 1

ORIENTATION AND STATEMENT OF PROBLEM AND RESEARCH METHODOLOGY

1.1 INTRODUCTION

The following chapter contains a discussion on the background to the research problem. The rationale behind this choice of topic is also given, together with relevant statistics. The research topic is stated, the main research questions are given, followed by the main research objectives and the methodology adopted. Ethical considerations with regards to this research are discussed. Finally, the structure of the report is laid out.

1.2 BACKGROUND TO THE PROBLEM

Down Syndrome (hereafter referred to as DS) is the most common chromosomal cause of intellectual disability worldwide (Bittles *et al.*, 2007:221; Dixon, 2008:8; Van Cleeve & Cohen, 2006b:47). Due to the widespread association of DS with intellectual disability (hereafter referred to as ID), the term ID is sometimes used in reference to DS in this study.

DS is a condition that occurs during the fertilisation period of pregnancy, when an extra chromosome is passed on from either the mother or the father (Moeller, 2005). The extra chromosome has an impact on the facial features of a person and furthermore on the orderly development of that individual's body and brain (NICHCY, 2010:1). In addition to developmental delays, children with DS are vulnerable to a variety of congenital conditions, such as chronic heart defects and ears, nose and throat problems (Lampret & Christianson, 2007; Van Cleve & Cohen, 2006a). Such children therefore require regular medical assessments.

Internationally there have been significant improvements over the past 100 years in terms of medical research in understanding the condition and resources for the treatment of DS (Dixon, 2008:4; Leonard *et al.*, 2000:163). These improvements have impacted positively on the lifespan of people with DS ("Down Syndrome", 2008; Morris & Alberman, 2009; Steward *et al.*, 2010:2526). Statistics reveal that the lifespan of a person with DS has doubled

from 25 to 50 years (Moeller, 2005; Sharp & Frey, 2006). Yet despite these advancements, the prevalence of DS births is on the increase (Steward *et al.*, 2010:2526). This increase is attributed to the fact that globally more couples are starting families later on in life, which increases their chances of having a DS baby by 50% (Christianson, 1996:89; Molteno *et al.*, 1997:428; Morris & Alberman, 2009; Sharp & Frey, 2006). The statistics in South Africa (hereafter referred to as SA) reveal an increase from 1.8 DS births out of 1,000 (Christianson, 1996:89; Molteno *et al.*, 1997:438) to 1 out of 600 (Naidoo *et al.*, 2011:27). Ultimately, the DS population in SA has to date been steadily growing.

According to the literature, research on the lived experiences and needs of mothers who have children with DS in SA is scarce (Christianson & Kromberg, 1996; Christianson & Modell, 2004; Freedman & Boyer, 2000; Lampret & Christianson, 2007). Christianson (1996:89) reports that between 1980 and 1996, 2,000 related studies were conducted internationally, compared with only 25 in sub-Saharan Africa. International phenomenological studies (Gupta & Singhal, 2004; Hassall & Rose, 2005:71; Hastings & Taunt, 2002; Hastings *et al.*, 2002:273) also conclude that publications offering support for these parents are rare and that research into parental cognitive processes of children with an ID is increasingly needed.

The researcher has had regular contact for the past three years with parents of children with DS at an early childhood development clinic where she occupied the role of a family counsellor. The counselling service is offered at the developmental clinic of the same hospital where professionals (which includes pediatricians, genetic counsellors, and neuro-paediatricians) are the referral sources for children who are diagnosed with an ID. At present 150 children – the majority of whom have been diagnosed with DS – attend the clinic with their parents or caregivers for continuous support in terms of the developmental, medical and emotional challenges associated with an ID. Families are offered supportive counselling at the clinic after receipt of the baby's diagnosis, and further counselling is available to them any time thereafter.

The counsellor noted that patients with DS in the clinic are more often accompanied by mothers than by fathers, siblings or caregivers. On the very rare occasions when both the parents attend the counselling session together, it is usually the mother who voluntarily requests counselling after the baby has been diagnosed with DS. A study by Pelchat, Lefebvre and Perreaults (2003) on the differences between mothers' and fathers' responses to

children with an ID reveals that mothers tend to engage in more interpersonal and group communications than do fathers. In light of the above-mentioned dynamics, mothers were chosen to form the focus group of the study.

The many stressors that mothers of babies with DS who visit this clinic experience correlate with international literature on the topic (Gupta & Singhal, 2004:22; Lam & Mackenzie, 2002:225; Saloviito *et al.*, 2003:300; Sari *et al.*, 2006:29; Van Riper, 2007:116). These stressors include the common fear that their child with DS will not be accepted by the family or by society due to the negative 'definition' or the negative perception that is associated with having DS (Dixon, 2008:4; Saloviito *et al.*, 2003:300). An international phenomenological study by Skotko (2005:64), which asked mothers of babies with DS to reflect on their experiences of postnatal support, found that physicians generally speak very little about the positive aspects of DS.

The mother of a DS baby also tends to experience anxiety about her baby's health due to the many medical complications of the DS diagnosis, including the heart operation that is commonly needed for the child's weak heart (Firth *et al.*, 2007). Another stressor includes concern for her child's development due to developmental delays that impact on future plans, specifically inclusion into society and education (Hassall & Rose, 2005:71; Lam & Mackenzie, 2002; Moeller, 2005; Ulrich *et al.*, 2001). Financial strain has been communicated by parents as another major stressor due to the many needs (medical check-ups, specific diets, special schools and intervention) involved in caring for a child with an ID (Gupta & Singhal, 2004:27).

All these stressors have an impact on the family as a whole (i.e. individual members as well as the child with DS). Many mothers in the clinic have made known to the researcher their grievance of having the father abandon the family because he could not accept a child with an ID. Mothers further reported that the stressors negatively affect the siblings of a child with DS. The siblings struggle to cope with the greater attention given by the mother to their sibling with DS owing to the latter's more demanding needs. Children who have DS also experience many stressors. These include various physical challenges (such as developmental delays) and emotional problems (due to a lack of social acceptance by society and even sometimes by family members). Yet despite these diverse experiences, all of which are

worthy of further investigation, for the purpose of this study the researcher will expand solely on the experiences of mothers of a child with DS.

The mother's emotions toward the many above-mentioned stressors may pose a problem in terms of her forming a healthy attachment to the baby with DS, including her emotions of grievance after hearing the diagnosis. Kidder and Skotko (2001) explain that grieving is a normal reaction toward the loss of having a healthy, normally developing baby. Gupta and Singhal (2004:24) concur in the view that negative environmental attitudes, for example the judgemental attitudes portrayed from people staring at the child and family while in public, adversely affects the parents' attitude toward their child with DS, who in turn is affected. A positive and accepting attitude on the part of the mother is essential in that first year of nurturing if she is to form a healthy or secure attachment to her baby (Aucamp, 2010:13; Schore, 2001:8). Attachment theorists, whose ideas greatly inform psychology today, conclude that an insecure attachment style, including anxious or ambivalent attachment, developed between mother and baby, poses significant future challenges regarding the emotional regulation and relational capacity of the individual with DS (Bowlby, 1988; Klein, 1959; Mahler, 1972; Winnicot, 1965). If there is an insecure attachment, the child with DS may well struggle throughout his/her life to build relationships and integrate into society.

Despite the many negative associations of having a baby with DS, many mothers who have attended the clinic regularly from their child's birth up till the child was placed in a school have articulated certain positive aspects of having to raise a child with DS. Positive reports have been made with regard to overcoming certain challenges, such as having a successful cardiac operation, seeing improvements in developmental delays or milestones, and successfully integrating the child into a school. In addition to these positive reports, many mothers have displayed positive attitudes in relating to children with DS, who in return have shown them much affection. In some cases, mothers disclosed that having a baby with DS, has led to the strengthening of relationships within their family.

Gupta and Singhal (2004:30), in concurrence with the findings on coping strategies made by Hastings and Taunt (2002), argue that parents of children with disabilities do experience many stressors, and they suggest that there becomes a shift from only describing these stressors and their adverse effects to "exploring the ways that such families cope with varying degrees of success". The benefits of having positive perceptions of DS according to Gupta

and Singhal (2004:30) extend to benefiting the family unit as a whole. This perspective seems to be rooted in positive psychology, with the aim as Seligman and Csikszentmihalyi (2000:5) describe as a shift from focusing on restoring the negative “to also building positive qualities”.

Positive psychology is premised on the idea that although one is faced with adverse circumstances which may never change, one can choose to identify qualities in that situation or in oneself that can serve as strengths with which to deal with the adversity or view the adversity positively. This view correlates with that of the National Dissemination Centre for Children with Disabilities (hereafter referred to as NICHCY), which suggests that although children with DS differ from non-disabled children in their abilities, families and healthcare professionals should place fewer limitations on the capabilities and achievements of children with DS and instead seek to recognise the capabilities of the latter and reinforce them (NICHCY, 2010:1). In addition, the NICHCY (2010:2) views children with DS as being very much the same as other children and it highlights that one should strive to provide them with the same opportunities enjoyed by other children.

Gupta and Singhal’s (2004) research has led to the view that the development of positive perceptions is a process that occurs through coping, and that these positive perceptions continue to act as a coping strategy in the face of the stressors involved in parenting a child with an ID. They emphasise that although there are no reports on the positive perceptions held by families of children with IDs, an awareness of these positive perceptions could serve to reframe the situation in a more positive light, creating a coping strategy in the face of the stressors associated with parenting a child with an ID. Seligman *et al.* (2005), in accordance with other positive psychology theorists, shares evidence that positive strategies and beliefs can serve as a resource in the face of adversity as they fuel psychological resilience and also decrease depressive symptoms.

It is clear from the above information that the problem arising out of the increase in DS births in the South African context is that there are increasingly more mothers, more children with DS and more family members experiencing the stressors associated with the condition. Unawareness, due to limited research on the coping strategies and positive beliefs in parenting a child with DS, may have an effect on the bond between mother and baby, and between those family members. The focus of the proposed study will be solely on the

mothers of children with DS so as to provide future mothers of babies with DS with knowledge that will help them cope with the many stressors of their situation.

The researcher hoped to achieve this goal by answering the following question: *What are the positive experiences of mothers of a child with DS?*

1.3 OBJECTIVES

The specific objectives of the proposed research study, aimed to *explore and describe the positive experiences of mothers of a child with DS*, through the following:

- To explore mothers' experiences of having children with DS
- To ascertain how these mothers relate to their babies with DS
- To highlight and share the positive experiences of mothers of a child with DS
- To describe the experiences of and make suggestions for future mothers of babies with DS

1.4 CENTRAL THEORETICAL STATEMENT

The awareness of positive perceptions and coping strategies as provided by mothers who have already experienced parenting a baby with DS may help counter the negative perceptions related to the many stressors faced in having a baby with DS. Such knowledge could reduce the anxiety and fear of future parents of babies with DS. Furthermore, an awareness of these positive perceptions could help future parents of babies with DS to have a positive attitude toward their situation, which would in turn increase their acceptance of the child and enhance the mother-baby attachment, both of which are essential to the child's relational ability, emotional regulation and capacity for achievement

1.5 METHOD OF INVESTIGATION

1.5.1 Analysis of literature

According to Botma *et al.* (2010: 64), “A thorough literature review lays the foundation for good research.” Thus, for the purpose of the proposed study, the researcher conducted a literature review on the experiences of mothers of a child with DS throughout the research process. Various sources and literature was consulted (including books, professional journals, research reports, and internet and newspapers articles) on themes such as DS and parenting, children with DS, DS and support, positive psychology, and DS and attachment. Databases such as Ebsco Host, PubMed, SAePublications, NexusLexus, ProQuest, Sabinet, ScienceDirect and Google Scholar was utilised.

1.5.2 Empirical investigation

1.5.2.1 Research Design

A qualitative design was used to explain the phenomenon under study, as the qualitative method is more holistic in approach and more emergent of variables than is quantitative research (Leedy & Omrad, 2005:94). Fouché (2011:116) states that qualitative research methods are used to discover important questions, processes and relationships, not to test them. According to Creswell (2007:57) and Botma *et al.* (2010:190), phenomenology is a type of study that describes the meaning of experiences of a phenomenon. In the case of this study, the phenomenon is the positive experiences of mothers of a child with DS. Phenomenology was therefore selected as the research strategy best able to accomplish the descriptive purpose of this study. An applied research approach was chosen to address problems in this field by practically applying the research gained in this study (Botma *et al.*, 2010:75). This will be achieved by firstly exploring the experiences of the mothers and secondly describing their positive experiences. These experiences will assist future mothers of babies with DS and furthermore assist with informing further research on this topic.

Due to the qualitative nature of the proposed study (Fouché, 2011:267) as well as the central theoretical statement that serves as its guideline, an inductive process (Botma *et al.*, 2010:189) was carried out during the research. Observations and data collected from the

sample of mothers of a child with DS was lead to a conclusion for a general theoretical explanation of the population of mothers of a child with DS in SA (De Vos & Delpont, 2011:49).

1.5.3 Research method

1.5.3.1 Sample of participants

The population of mothers of a child with DS was represented by mothers of children with DS who were referred to the early childhood developmental clinic at a hospital in the Western Cape. This hospital is the only specialised children's hospital in the southern hemisphere of Africa and therefore the central referral source by professionals from hospitals around the Western Cape, for a diagnosis and specialised medical or therapeutic intervention. The researcher gathered participants according to the purposive sampling method (Creswell, 2008:214) as the interest was in selecting only those with particular properties (Botma *et al.*, 2010:52) useful for the purpose of this study. The researcher made use of a criterion sample strategy (Maree, 2007:80) to assist in selecting participants who possess adequate knowledge and experience of the topic. Five participants were utilised. Additional participants would have been recruited if this number was insufficient for data saturation.

The criteria for participant selection included the following:

- The mothers must have a child with DS who are within a toddler (between 1 year to 6 year) age group to ensure they have adequate experience of raising a child with DS. This clinic offers a service to patients until they are placed in a school
- The mothers must have children who were diagnosed with DS, more than a year ago, in order to allow mothers a respective period to respond to their child's diagnosis and avoid the possibility of their being negatively affected by the sensitive nature of this study topic
- The mothers must have children who were only recently (as of 2012) referred to the clinic (this limit has been set so as to avoid data contamination in light of the researcher's long-term relationships with those mothers who received counselling during the period of 2009 to 2011)

- This criterion is viable as not all mothers of babies with DS attend the clinic after their baby is diagnosed. Some mothers only approach a helping professional within the hospital when their baby enters toddler-hood at which period mothers become concerned that their baby is not reaching their milestones appropriately. This referral could be from a speech therapist, a physiotherapist or an Occupational Therapist
- The researcher was aware that in the case where there is a limited number of suitability for this study, a participant who has been in relationship with the researcher previously may be used. In this case, the support of a research assistant will be present to ensure objectivity is achieved in the data collection process

1.5.4 Data collection method

Face-to-face, in-depth interviews were used as the chosen qualitative data collection method. In-depth interviews, by probing into the meaning that the participant gave in responses, ensured the generation of first-hand, rich, quality data of the phenomenon under study. The interviews were carried out in an office in the hospital's developmental department. The use of interviews to achieve the aim of this study corresponds with the definition of qualitative interviewing as a repetitive process that allows one to gain a closer and clearer picture of the phenomenon being studied (Rubin & Rubin, 1995:46). According to Seidman (1998:1), interviews are utilised in research to convey an interest in people's stories. In support of the aim of this study, De Vos (2011:342) adds that stories are a way of knowing and that they are essentially a meaning-making process.

The interviews followed a semi-structured schedule in order to allow participants to do almost all the talking. The researcher merely guided the conversation according to a general plan and according to information raised by the participant that was felt to be further pursued (Babbie & Mouton, 2001:289). It is estimated that interviews of 60 minutes each will allow each participant to reflect on her experiences and respond to the question in adequate depth and detail. In order to gain a clear picture of what was being described during the interviews, it was essential for the researcher to bracket (Babbie & Mouton, 2001:291; Botma *et al.*, 2010:182) personal experiences and knowledge of the topic and instead ask the interviewees to explain what they said, albeit that the researcher's questions was born out of an informed viewpoint.

A video recorder was used as a data capturing apparatus with the use of the voice recording only and not the picture to ensure anonymity of the participants' identity. The recorder was faced away from the participants' direction to offer more privacy and respect while sharing personal information with the researcher. The several communication techniques suggested by De Vos *et al.* (2011:345) was taken into consideration to enhance the quality of each interview. The first interview was used as a pilot to test the use of the interview schedule as well as the tools used in capturing the data. Data from the pilot was included in the study's results.

1.5.5 Procedures

The following steps were taken as part of this study:

- Obtained permission from the North-West University's Human Research Ethics Committee to conduct the study
- Obtained permission from the superintendent of the hospital to conduct the study
- Identified mothers of a child who are new to the clinic, which involved identifying the date of their child's diagnosis (all this was done with the help of a management staff member at the clinic in order to protect confidential patient information)
- Participants were approached telephonically, or in person while waiting for their child's appointment at the clinic, to inform them about the study and enquire of their willingness to participate in it
- Consent forms were issued to the participants
- Appointments were made for the interviews (including the initial pilot study)
- Participants were informed about the interview procedure and the necessary ethical considerations such as confidentiality
- In the absence of field workers for this study, the role of the researcher was to conduct the interviews with the participants
- A debriefing was offered to each participant by the researcher as well as a referral was offered to a counselling professional from the researcher's list of practitioners in the Western Cape
- Participants were consulted regarding the validity of the data captured
- The researcher then analysed the captured data and recorded the results

1.5.6 Ethical aspects

In order to show due consideration and respect for the study's participants (Botma *et al.*, 2010:3), the researcher complied with the following ethical considerations as agreed upon by professionals in researcher practice (Babbie & Mouton, 2001:520):

ETHICAL ACTION	HOW IT WILL BE APPLIED TO THIS STUDY
Avoid inflicting physical harm	The method of investigation was through a face-to-face interview, where the participant and researcher were seated across from one another. The conversation did not involve physical contact
Avoid harm from emotions that may be evoked	The researcher had intentionally selected mothers whose children are of an older age, which had allowed mothers more time to process the diagnosis and to ensure that sensitivity toward their emotional process of the diagnosis was respected. Even still, due to the nature of the topic, negative experiences of having a child with DS may possibly be recalled. The researcher intended to avoid any harm that the situation may impose on the patient, by preparing the participant during the contracting (beginning phase) of the interview. They were informed that this may occur and in that case, they could at any time request not to continue with the topic if it was too difficult. If they would have liked to continue, a debriefing session would be available to them after the interview in which they could speak to a professional to support their emotional process
Avoid deception	During the selection process, mothers were given an opportunity for informed consent to participate in this study, with the provision of the topics details and specifically what the interview process entailed
Ensure participant is protected and respected	Participants were informed that their name will remain anonymous in order to protect them from feeling that they would be exposed in what they shared. To respect what they shared, the researcher contracted that their information will

	remain confidential and furthermore that they have the option of predetermining any matters they would prefer not to discuss at any point during the interview.
Ensure competence when handling data	The data was handled with care to respect the participants' anonymity by using the voice recording only and not the video recording (which will not be aimed in the participants' direction). Recordings will be stored by the researcher and the institute in Wellington for a period of 2 years (in the case of future reference), after which it will be discarded. In addition, the researcher remained accountable to professionals in the field to ensure the most competent measure of the research process was achieved

1.5.7 Data analysis

The data collected from the video recorder was transcribed and analysed according to the twelve-step process outlined by Tesch (1990:343), which is as follows:

1. Read and understand the transcripts carefully, to gain the true meaning of respondents' words.
2. Re-read and start making notes in the margins about underlying meanings.
3. Do this with entire document.
4. Group together similar thoughts and assign labels.
5. Rethink labelling and collapse similar labels.
6. Colour code labels for easy identification.
7. Group together different labels and form themes.
8. Re-think themes and ensure that they are linked to your objectives. Ensure themes are "Mutually Exclusive".
9. Develop a framework with themes/categories/subcategories set out.
10. Avoid too many subcategories.
11. This framework provides the structure for discussing and analysing findings.
12. When writing up findings, follow this structure, using actual quotes to highlight certain points and link these to authors in the literature review.

This twelve-step process helped the researcher to manage the data in a structured manner that limited necessary themes and topics useful to this study. It also helped to guarantee the validity of the collected data.

Data is stored in such a way as to ensure it is kept safe and the confidentiality of the participants is in no way compromised.

For the purpose of achieving a valid and trustworthy study, the researcher incorporated into this research process a pilot study as described above. To ensure the credibility of the study, triangulation was achieved through ‘member checks’ during which participants were approached to confirm that their responses were recorded accurately. In addition, the process of crystallisation – which involved remaining accountable to professionals within the research field (including supervisors, editors and the Board of Ethics) – provided an objective lens throughout the study (Maree & Van der Westhuizen, 2007:40).

To safeguard against any possible subjectivity on the researcher’s part toward the data collected – especially when comparing the findings to information that was disclosed by mothers in the clinic to the researcher during the role of counselling work – a literature control process was carried out (Botma *et al.*, 2010:196). The researcher incorporated this process at the end of the study to compare the findings with existing literature so as to confirm the findings, identify findings in studies other than the literature review, and/or discover that the findings are unique and not to be found in the literature (Botma *et al.*, 2010:197).

1.6 STRUCTURE OF RESEARCH REPORT

This research report is structured as a dissertation with its content presented in four chapters. The dissertation will thereafter be structured into an article format with the hope of being published in a social work journal.

1.7 LIMITATIONS OF THIS STUDY

- A limitation of this study is that literature on this topic in the South African context is scarce and outdated, hence limiting the contextual reference of this phenomenon in this study.
- A second limitation of this study is that the data from this study will represent experiences of mothers of children from a young age group. This limits the application of these experiences to mothers of children from an older age group who may disclose different findings in their experience of their child at a different age.

1.8 SUMMARY

This chapter introduced the background to the research topic which discussed an overview of the major problems and the aim, goal and research question for this study. An overview of relevant literature studies and practical experience of the author was used to highlight the significant context of the problem. The method of investigation and research methodology was expanded on in this chapter and the structure of the report has been explained. Limitations of this study has been thought through and highlighted in this chapter.

The next chapter discusses the topic through a more in-depth literature study review on mothers of a child with DS. The various aspects of this topic to be studied will be unpacked in chapter two.

CHAPTER 2

LITERATURE REVIEW:

MOTHERS OF A CHILD WITH DS AND POSITIVE PSYCHOLOGY

2.1 INTRODUCTION

The purpose of this chapter is to give a brief history of DS in order to contextualise the experiences of mothers, the implications of DS on the development of a child, mothers' experiences of having a child with DS, our understanding of the attachment between mother and baby with DS, and the positive experiences of mothers of a child with DS. Literature on the subject over the past three to four years is reviewed so as to gain a greater understanding of the topic as well as consider scholars' suggestions and the gaps in the research to date. At times outdated resources are referred to in the literature review because the history of this diagnosis dates back to the early 1800s; at that time people with DS were referred to as Mongols and so this term is used on occasion, but only in reference to the findings of these earlier sources. Lastly, this chapter provides more understanding on the grounded theory of this research specifically what positive psychology theory is, the background and application of this theory.

2.2 THE HISTORY OF DS

Down Syndrome is the most common chromosomal cause of intellectual disability (Bittles, *et al.*, 2007:221; Dixon, 2008:8; Van Cleeve & Cohen, 2006a:47). The genetic make-up of DS is referred to as Trisomy 21, and it occurs when an extra chromosome is passed down from either the mother or father, causing atypical facial features (Fidler, 2005:86). In the past Westerners with DS were called Mongols, due to their common facial features that were thought to resemble those of the central Asian population of Mongols ("Down Syndrome", 2008; Gordon *et al.*, 1961:426). Professionals in those days involved in the treatment of these children did not understand this particular diagnosis. Effective treatment did not exist for many of the medical conditions related with this condition, such as heart and respiratory problems, and treatment was not offered to children and adults with DS, who were simply viewed as a burden on society (Bauer, 2008). Babies with DS were placed in institutions where, due to general misunderstanding of the genetic implications and a lack of appropriate

care, many of their needs were neglected and their lifespans were ultimately reduced (Dixon, 2008:17; Silvers, 1998:23). The average lifespan of an individual with DS living in the USA in the 1930s was only about nine years old (Bauer, 2008).

In 1866, Professor Langdon Down properly diagnosed the condition through his identification of collective symptoms displayed in the facial features of such individuals (Moeller, 2005). Continuous research led to an increase in medical intervention, including successful congenital heart operations (Van Cleeve, 2006b:198). In addition, more literature and support services became available to parents, which had a positive impact on the lifespan of their children (Leonard *et al.*, 2000; Dixon, 2008:9). The lifespan of children with DS doubled from 25 to 50 years (“Down Syndrome”, 2001; Moeller, 2005).

2.3 IMPLICATIONS OF DS ON CHILDHOOD DEVELOPMENT

Children with DS frequently present with many medical conditions and a variety of congenital defects, and it is therefore essential that they receive routine assessments and ongoing medical management (Lampret & Christianson, 2007:2; Van Cleve & Cohen, 2006a:47). The congenital defects are due to the genetic implications which present at birth; as many as 50% of babies with DS are born with a heart problem, of which half are serious and require surgery (Van Cleve & Cohen, 2006a:47). Other congenital problems include narrow airway passages which pose breathing problems and tongue hypotonia, the latter of which causes low mobility in the movement of the tongue, impacting on the baby’s ability to suckle (Van Cleeve & Cohen, 2006a:49). Furthermore, the genetic defect of DS means all such individuals face a developmental delay, with the average age for sitting being 6 to 13 months, walking being 1 to 4 years, and first words being 1 to 3 years (Moeller, 2005).

In SA it has been reported that two out of three children with DS die before the age of two (Christianson *et al.*, 2002:179). However, despite the many congenital defects, the life expectancy of people with DS has been increasing since the 1920s due to better healthcare in terms of the treatment of these specific medical problems as well as chronic disabilities in general (Coppus *et al.*, 2008:2313; Wexler *et al.*, 2009:656). Wexler *et al.* (2009:656) argue that there is also a greater recognition that with appropriate and early medical, rehabilitative and educational interventions, individuals with DS can lead relatively normal and productive lives. Coppus *et al.* (2008:2314) agree, suggesting that there is today better education and

provision of services for rehabilitation of persons with DS. Chen (2009) concurs with their comment that individuals with DS living in today's world are generally healthier and better integrated into society than their predecessors. For more than two decades studies have been pointing to a significant improvement in the development of children with DS when afforded repetitive and consistent stimulation, effective management by a multi-disciplinary team of healthcare professionals, and a variety of other supportive services (Marder & Dennis, 1997:2). Globally, children with DS are ideally referred to the early intervention programmes run by various hospitals as well as to the Down Syndrome Association (DSA). Some of the specialised programmes and related resources available to children with DS as a part of the early intervention programme include occupational, physical and speech therapy, special education, nutritional advice, and social work support (Van Cleve & Cohen, 2006a:52).

2.4 MOTHERS' EXPERIENCES OF HAVING A CHILD WITH DS

Research focusing on the experiences of mothers of children with DS is limited and researchers highlight that more research is required with regard to the mothers' experiences (Docherty & Reid, 2009:460). The following experiences seem to be the most common as reported by the mothers themselves.

2.4.1 Support during pre- and postnatal screening of the diagnosis

Over the past twenty years the pre- and postnatal diagnoses of DS have increased globally by 71% due to a general rise in maternal age (Gammons, Sooban & Heslam, 2010:701; Staff, 2008:5). However, internationally the number of babies born with DS has not really changed, even in spite of pre-screening for DS and the many subsequent abortions. In Britain, between the years 2007 and 2008, there were 743 live births of DS babies (Morris & Alberman, 2009:701).

According to Gammons *et al.* (2010), the experiences of the support given from the time of pre-natal screening to post-diagnosis as reported by the mothers and then by the professionals involved do not correlate. Although the professionals, the majority of whom were midwives, reported that they followed the National Institute for Health and Clinical Excellence (referred to as NICE, 2008) guidelines during this process, the majority of the mothers surveyed disagreed, feeling they were not properly supported by health professionals. Furthermore, the

mothers claimed that the professionals expressed negative views and shared outdated information with them on DS. Lalvani (2008:440) supports the finding from the study by Gammons *et al.* (2010:701) that medical professionals reveal negative attitudes toward disabilities. The mothers that did receive the national screening leaflets from the healthcare professionals at the hospital said that the leaflets were unhelpful in terms of delivering information on what it is like to have a baby with DS. In addition, these mothers reported that they felt ‘alone’ after having been told of the diagnosis, and also experienced limited counselling or preparation on how to care for their baby with DS; they felt it was “overall a very lonely and tough experience to go through” (Gammons *et al.*, 2010:704).

During the period of diagnosis, the way in which the diagnosis was offered was described as “awkward”, because staff members seemed uncomfortable or reluctant to discuss the challenges that lay ahead for a parent with a child with DS. There were those who were also “disgusted” to have received the diagnosis over the phone. One parent shared that although the midwives suspected the diagnosis at birth, she was not told at the time, and furthermore, when asked about the explanation that eventually came, this woman said: “it was skated over and left me wondering” (Gammons *et al.*, 2010:710).

A finding common to many studies has been the prevailing negative perception amongst healthcare professionals of what it means to have a child with DS. The perception of this negative attitude was obtained primarily through the manner in which the diagnosis was given; for example, a healthcare professional using a negative tone when disclosing the diagnosis. Specific examples of negatively expressed diagnoses as reported by mothers – which correlate to descriptions given by Dixon (2008:4) – include phrases such as “unfortunately”, “there is a problem”, “your child is not normal”, “Mongol” and “something is wrong”. The emotions the mothers reported they experienced after the diagnosis include initial shock, hopelessness, uncertainty, concern over their child’s development, health and lifespan, and fear with regards to the possible lack of acceptance of the child by the family and society. These family stressors and emotions correlate with international literature (Gupta & Singhal, 2004:22; Lam & Mackenzie, 2002:225; Saloviito, *et al.*, 2003:300; Sari, *et al.*, 2006:29; Van Riper, 2007:116).

Skotko (2005:64) found that in mothers’ reflections on postnatal support, physicians speak very little about the positive aspects of DS (Gulli, 2006:39). Skotko, Capone and Kishnani (2009:754) strongly recommend that doctors make use of positive words and a positive tone when delivering the news about DS; they note that there are mothers who have reported

remembering those first negative words for over twenty years after the initial discussion. An American mother, who had decided to abort her baby, expressed that her doctor did not paint the brightest picture of the child's future, something that prompted her decision to terminate the pregnancy (Dixon, 2008:4). Her concern was that many mothers are making a similar decision based on misinformation.

Additional implications of the spread of a negative perception of DS include the development of a negative attitude by parents about their situation and their child. In turn that lack of parental acceptance results in further consequences for the child. Many mothers in the clinic surveyed for this study disclosed their grief over having the child's father abandon the family because he could not accept a child with a disability. Gupta and Singhal (2004:22) support this finding, stating that the stressors of having a child with a disability frequently lead to marital conflict as well as conflict amongst other relationships within the family.

Mothers' experiences at the time of their 'high risk' screen result tend to be similar to mothers' experiences during the diagnosis of their child when it comes to the level of information and support they receive. The mothers interviewed in this study reported unhelpful and unsatisfactory interactions with health professionals when receiving the test results. This situation of limited support to mothers of children diagnosed with DS has led to many court cases (Gammons *et al.*, 2010:714). In an article by Pancsensi (2006:168), we are told that the mother of a child with DS took her gynaecologist to court to pay for child support as a consequence of his failure to warn her of the possibility of her baby being born with a disability. This mother claimed she would have aborted the baby had she known of the condition in time. Another mother said that "Sherry [their child with DS] totally disrupted our plans", and that she would have wanted to abort the baby had she known the diagnosis before birth; she received payment from her doctor (Pancseviski, 2006:168). Fiano (2012a) reports that increasingly more parents are suing their doctor on the basis of the doctor's failure to inform them of or accurately diagnose their child's condition. Nicol (2008:145) says that "inadequate diagnosis fails to serve the needs of pregnant woman who feel anxious, pressured and frightened for their child's welfare". Staff (2008:5) explains this statement by arguing that some mothers "fear for their children's well-being in a world where there are fewer people like them".

The researcher suspects these mothers felt fear and anxiety over their child's life and that that is the real reason why the one mother said her child with DS disrupted her plans (Panscevski, 2006:168). This mother might have felt she needed to prepare herself and her family for raising a child with differences but was not given the opportunity. Unfortunately many mothers who receive a negative response to the diagnosis from doctors are sometimes pressured into aborting the baby (Fiano, 2012b).

Brown (2012) informs us that 90% of mothers in the USA with an unborn baby diagnosed with DS are choosing to have an abortion, while in the UK three babies with DS are aborted every day. Robin Steel, the coordinator of Cincinnati Adoption Awareness Program, reports that "some birth parents fear their child won't live long or achieve milestones" (Gulli, 2006:39).

2.4.2 Stress

Salvitto *et al.* (2003:300) found that the behaviour of children with DS is less of a contributing factor to a mother's stress than is the mother's own psychological well-being. Congruently, Norizon and Shamsuddin (2010:992) as well as Dabrowska and Pisula (2010:276) argue that maternal depression and failure to accept a child with DS are the most important predictors of stress in these mothers rather than any possible behavioural problems on the child's part. This claim is also supported by Lloyd and Hastings (2007:37), who discovered in their longitudinal study that mothers' acceptance of children with a disability is related to anxiety and depression, and furthermore that avoidance coping is positively associated with depression. Dabrowska and Pisula (2010:277), in concurrence with Nicol (2008:145) and Staff (2008:5), argue that the emotional predictor of stress is related to the mother's feelings of anxiety concerning her child's condition and her uncertainty over the future, and they also contend that the mother's loss of control over these stressors has a further effect on the mother-child relationship. Reichman *et al.* (2008:998) highlight the following stressful factors associated with raising a child with a disability: financial cost, emotional demands, and logistical complications. Another predictor of stress is the number of children within a family; raising normally developing children as well as a child with a disability increases the stress experienced by parents (Dabrowska & Pisula, 2010:276; Taylor *et al.*, 2007:373).

Most *et al.* (2006:507) suggest there is a pattern of maternal stress amongst mothers of children with DS in comparison to mothers of children with mixed aetiology developmental disabilities, and furthermore they argue that these changes in stress are connected to various child and family characteristics. Most *et al.* (2006) undertook a three-phase qualitative study that looked at DS infants' development at 15 months, 30 months and 45 months. The study considered differences in variables relating to demographics, income, and maternal education and age. In addition, child development outcomes were assessed at each of the three phases. Similar to the findings in a concurrent study by Eisenhower *et al.* (2005:665), Most *et al.* (2006:507) found that there was a major increase in the stress level of the mothers observed at phase 3 (i.e. the mothers who had been dealing with a child with a disability for a longer period of time) when compared with the average stress level observed in the group of mothers at phase 2. Predictors of change in stress in both groups were related to characteristics of the child in terms of his or her cognitive and language functioning and behavioural patterns (also referred to as phenotype behaviour) as observed during the 3 different phases of early child development assessments. Thus a child with DS's phenotypical behaviour of cognitive and language delay and maladaptive behaviour is only presented during the first three years of development, which is associated with an increased maternal experience of stress. Eisenhower *et al.* (2005:667) argue that the stress levels of mothers deferred at the different age groups of children with DS and additional contributing factors (i.e. other than behaviour and cognitive ability) include the following: availability of intervention services, and characteristic personalities, specifically characteristic stubbornness in children with DS. A recent study on mothers' perceptions of their own worth and capabilities revealed that they have negative beliefs about their ability to control their child's behaviour as well as their own emotional wellbeing (Kandari & Qashan, 2009:21). The feeling these mothers experience of not having any control of the situation correlates as a result of a predictor of stress in the studies on mothers of children with DS.

Most *et al.* (2006:512) suggest that professionals should increase their knowledge and skills so as to better support and prepare parents to understand their child's condition and then seek the relevant support in conjunction with their child's challenging behavioural patterns. Better knowledge and skills on the part of healthcare professionals would almost certainly help parents to adapt emotionally to their child's development, thereby decreasing the parents' level of stress in the long term (Most *et al.*, 2006:512). The parents' stress could perhaps be reduced by informing them during the diagnosis, which usually happens before or shortly

after the birth. Most *et al.* (2006:513), in support of the negative experiences expressed by mothers in Lalvani's study (2008:436), propose that informing parents during the diagnosis is essential in helping them to prepare for the challenges that lie ahead. Furthermore, they argue that adequate awareness of a child with DS's behavioural phenotype could contribute to supporting the families' experiences from an early stage (Most *et al.*, 2006:513).

Gupta and Singhal (2004:27) believe that the many stressors (medical complications, financial strain, care-giving demands, concern for the future, including the negative reactions from others) connected with raising a child with a disability have helped to create the prevailing negative perception of what it means to have a child with a disability. Gupta and Singhal (2004:30), in concurrence with the findings on coping strategies made by Hastings and Taunt (2002), argue that parents of children with disabilities do experience many stressors, and they suggest that there becomes a shift from only describing these stressors and their adverse effects to "exploring the ways that such families cope with varying degrees of success".

2.5 ATTACHMENT BETWEEN MOTHER AND BABY WITH DS

2.5.1 Emotional Availability

According to Venuti *et al.* (2008:135), attachment theory refers to the emotional exchanges between a parent and the child. According to this theory the focus is on one's ability to read and respond to the other's communications. Furthermore, because this perspective is based on attachment theory, it refers to the quality of these interactions in terms of the attitudes, involvement and behaviours (sensitivity, structuring, non-hostility and non-intrusiveness) on the part of the parent and on the child's ability to respond to and involve the parent, highlighting emotional understanding and expression as key roles in a two-way relationship (Biringen, 2000:104; Venuti *et al.*, 2008:135). Venuti *et al.* (2008:135) argue that this relationship construct does not consist of a one-way parent-to-child bond, where there is only the effect of the parent on the development and growth of the child. Rather their view entails a transaction where signs and behaviours from the parent as well as the child affect the other in a two-way exchange (Bornstein, 2003:136; Trevarthen & Aitken, 2001:23). Venuti *et al.* (2008:136) state that this construct of parent-child emotional availability (EA) has to date only been investigated in typically developing children, but not in children with DS, and they

thus argue that research into the mother-child emotional availability, could be important to understand the cognitive development of children with DS.

Researchers concur that the level of affective engagement of a parent or carer in play both in a child with or without a disability, has a pivotal role in the quality of the child's play thereafter (De Falco *et al.*, 2010:597; Venuti *et al.*, 2008:133). Venuti *et al.* (2008:133) discovered that the aspect of a mother's presence during the time of play with their child is crucial to increasing the child's ability to explore during play. Mundy *et al.* (1988:107) believe in the importance of maternal emotional availability as nonverbal communication for the foundation of language development in a child with DS.

Hart and Risely (1999:107) claim that there exists "an intimate social dance between children and parents" where communication is concerned. The dance is symbolic of the parent or caregiver leading the child in skills of listening and speaking, while the child follows and imitates this leadership style and content in communication with others. In concurrence, Bruner (1983:107) emphasises that the nature of exchange in communication that occurs within the dance between parent or caregiver and child, marks the effectiveness of communication with others. Furthermore, Greenspan and Wielder (1998:107) believe that in addition to the child's ability for relating and interacting the nature of the exchange within this dance between parent or caregiver and the child, determines the motivation and ability of the child to achieve. These definitions reflect attachment at its core, the importance of relating to your child with quality presence (as it has an immense impact on your child's future regarding relationship building skills), and interacting and performing at their peak capacity.

According to a study on mother-child play by Venuti *et al.* (2008:135), mothers contribute towards their child's play development by adapting to their child's limitations and potentialities. Greenspan (1997:136) further specifies that it is the quality of the parent-child interaction that plays an especially critical role in the development of a child with special needs.

2.5.2 Possible barriers to attachment between mother and baby with DS

In terms of the understanding of attachment theory proposed by Venuti *et al.* (2008:135), attachment requires a quality involvement of emotional availability and interaction through presence, language and play. The implications of the diagnosis of DS may pose barriers to mothers forming an attachment to their babies with DS. The major factors that may act as barriers to this quality involvement include: good communication, encouraging autonomy, breast feeding, and acceptance of the diagnosis.

An attachment barrier may occur as a result of the concerns and difficulties involved in adapting to the news and accepting the child's diagnosis (Venuti *et al.*, 2008:136). This corresponds with the studies discussed under the section on maternal stress, which have highlighted that a mother's stress is mostly augmented by her anxiety and uncertainty over the child's development, which ultimately impacts on the mother-child relationship. Acceptance of the diagnosis may play a critical role in the mother's emotional availability and presence during the formation period of an attachment between mother and baby. Ross and Deverell (2010:43) emphasise that grieving is critical; parents need to mourn the loss of the dream they had for their child and separate themselves from that lost dream in order to ultimately reach a place of acceptance of their child as he or she actually is. Worden (2009:37), in agreement with Ross and Deverell (2010:44), share this understanding of the mourning process as a journey of working through tasks so as to process the loss. This journey entails acknowledging the reality of the loss, experiencing the pain of the loss, and, lastly, adjusting to the new environment without the loss. These theorists recognise that not everyone goes through the emotional phases in the same way or at the same speed (Ross & Deverell, 2010:39; Worden, 2009:52).

The implications of DS on childhood development with regards to delays in responsiveness and engagement may impact parental interaction style (Venuti *et al.*, 2008:136). Graham and Scudder (2007:109), in concurrence with the conclusions reached by Gilmore *et al.* (2009:1023), argue that mothers of children with low functioning abilities (i.e. in comparison with normally developing children) are more directive in their communication style, assuming the role of teacher and manager more often when interacting with their child with DS. Gilmore *et al.* (2009:1023) claim that the pattern of maternal support for autonomy during play with a child with DS (as opposed to maternal directiveness) developed

persistence in their child during problem-solving. Encouraging autonomy has been reported as a struggle by mothers of children with DS due to the barrier of being over-protected by parents. Parents said they are less inclined to seek physical activities for their child because of their protective instincts; “I don’t want him to get disappointed or hurt by society that is probably my weakness, I am protecting him too much” (Barr & Shields, 2011:1028). Seventy seven parents of young adults with DS were interviewed by Cunningham *et al.* (2000:47) and the following were found: 43% had tried not being open with their child about their diagnosis; 53% felt that their child would not grasp the information because of their diagnosis; 32% felt that it was not an issue that affected their lives therefore they need not discuss it; and 5 participants said they deliberately avoid any such discussion.

Another possible barrier to attachment is the complication involved in breastfeeding babies with DS due to the associated medical problems of DS individuals (Sooben, 2012:187). Sooben (2012:187) argues that little support is being provided in terms of guiding new mothers of a baby with DS on how to breastfeed despite these difficulties and so suggests that further research should be conducted into understanding the support necessary in such a situation. The originator of the attachment theory describes the period of breastfeeding as being critical in forming a long-term bond between mother and baby with DS. (Mahler, 1972:333).

2.6 POSITIVE EXPERIENCES OF MOTHERS OF CHILDREN WITH DS

Literature studies on the experiences of mothers of children with DS describe these mothers’ coping strategies and means of finding support structures that help them experience their situation more positively. Norizan and Shamsuddin (2010:992) conclude that maternal stress can be reduced through the adoption of positive coping styles. In addition, results from this study suggest that, through awareness, mothers gain a better understanding of their situation and this up-to-date knowledge helps them to view their situation more positively. The following studies reviewed in this section on positive experiences of mothers of a child with DS, offer examples of situations that can help mothers to cope better by gaining more support and knowledge, which aid them in viewing their situation differently and ultimately experiencing their situation as mothers of children with DS more positively.

2.6.1 Advancement and awareness

An international phenomenological study by Steward, Einfeld and Brown (2010:2525) reports that the prevalence of DS births is on the increase, and that fewer mothers choose to terminate such births owing to their greater awareness of the longevity of persons with DS. Sheets *et al.* (2011:432) similarly argue that the life expectancy and anticipated quality of life for individuals with DS has progressed due to advancements over the past 30 years in healthcare, education opportunities and societal integration. Two comparative studies (Eisenhower *et al.* 2005:227; Most *et al.*, 2006:501) highlight that parents of children with DS are in a slightly better situation than are parents of children with autism because the former enjoy greater access to professional assistance and other forms of support.

Extended support is offered to mothers of children with DS through the role of a genetic counsellor who is trained to explain the genetic causes of the diagnosis with relevant information on intervention, as well as offer emotional support through their professional counselling background (Sheets *et al.*, 2011:432). Cunningham (2006:2) correlates that parents felt they were able to cope with the news about the diagnosis by talking to someone. Parallel to Gulli (2006:39), Flaherty and Glidden (2000:407) conclude that both families and adoptive families are adjusting to the challenges of raising a child with DS. Reports have been on overcoming challenges that include: the success of the cardiac operation commonly required for the baby's weak heart at birth (Van Cleeve & Cohen, 2006a:47); improvement in the development of gross motor milestones, particularly regarding the baby's low body tone and consequent struggle with feeding, crawling and walking (Ulrich *et al.*, 2001); and children being successfully integrated into a crèche (Moeller, 2005).

In support of these mothers, the medical field continues to conduct research on the medical condition of DS. Articles on the many scientific studies completed include: "New hope for DS" (Staff, 2008:5); an article on the positive effect of blood pressure drugs in improving the mental skills of a child with DS (Macrae, 2011). Although this is recent, increased medical advancement in the 20th century has led to hopeful circumstances that the effects of DS on intellectual disability can be reversed through a drug that balances the high levels of GABA, known to cause high energy activity and prevent the ability to learn (Saheli, 2009). Thus the intellectual disability can be reversed through a neurotransmitter; cognitive intervention for babies with DS to slow the progression or onset to the predisposition of Alzheimers; and

successful eye-operation intervention to treat the disease, keratoconus, which is common in people with DS as well as improved diet of folic acid (Norton, 1999; Salehi, 2009). This ultimately supports the positive experience of mothers of a child with DS, who gain hope for their child's life span and healthy development through awareness and intervention of this medical advancement.

2.6.2 Temperament

Eisenhower *et al.* (2005:657) in correspondence with Most *et al.* (2006:501) discovered that mothers of children with DS experienced lower levels of behaviour problems with their children in comparison to parents of children with autism, Cerebral Palsy and intellectual disability. In agreement, Hastings *et al.* (2009: 616) reveal that mothers of children with DS have lower anxiety, lower depression, greater life-satisfaction and positive affect than mothers of children from other intellectual disabilities. Eisenhower *et al.* (2005:657) shares their reasoning that children with DS are reported to be more compliant, have better self-regulation, be less emotionally reactive and have fewer psychiatric problems than other syndromes. Mothers experienced their children to have more positive personality traits than children with other types of IDs, as they experienced them as happy, cheerful, loveable and sociable which contributed to the mothers positive experience of their child with DS (Farah & Dillah, 2004:1000; Patterson, 2002:215; Roizen, 2001). In agreement, results from (Fidler, *et al.*, 2001:317) show that parents of a child with DS are finding less stress and more rewards relating to their child, than children of other disabilities. An Italian Renaissance painter, Andrea Mantegna drew a painting of a little boy with DS for a Museum of fine arts in Boston in 1952 (Nicol, 2008:143). Nicol's (2008:143) view is that Mantegna believed that children with DS are more of a reflection to Christ through their gentleness, love, forgiveness and innocence. The mother of 25-year-old daughter with DS who is a special Olympian in swimming, skiing, cycling and swimming whilst also a college student and tutor, comments on the compassion that they as parents have learnt from their daughter with DS, and furthermore: "We see her as perfect and beautiful" (Taylor, 2011). Furthermore, this report highlights the results of studies interviewing 2,044 parents or guardians of children with DS, showing that 79% felt that their child with DS has improved their outlook on life (Taylor, 2011). Skotko *et al.* (2011b:2348) showed that 88% of their participants were convinced that they because of their sibling with DS they were better people.

2.6.3 Information

According to Fiano (2012b) the increased rate of mothers aborting is due to the prenatal testing and negative attitudes of society and the medical community. However, Fiano (2012b) reports on the new Massachusetts law that stands for pro-information through ensuring all doctors must inform mothers of up-to date details on DS, including resources that are available. Skotko *et al.* (2009:751) together with a more recent study by Sheets *et al.* (2011:432) have released articles on the guidelines for a more supportive manner in delivering the news with up-to date information about DS, which has led to more positive experiences of mothers. A mother shares her experience with a doctor who informed her of her baby's diagnosis of DS, with a very positive, hopeful attitude, with up-to-date information and supportive resources including parent support groups (Fiano, 2012b). She further highlights that she did not realise how fortunate she was, until he shared such a positive view without pressurising her to terminate her pregnancy. The doctor informed her that now is the best time to have a baby with DS because they are living "richer, longer, fuller healthier lives" due to early intervention and improved medical health care. Cunningham (2006:4) has also contributed to the awareness of the need for a positive manner in disclosing the news, through highlighting in his study that parents' felt their experience would have been more positive from the beginning if they knew from the start, what a joy their child would bring; instead they experienced a "tragedy", because of the sad and depressed manner it was portrayed, which evoked thoughts and feelings of "wanting to run away".

The findings of mothers adjusting to the many challenges of the condition correspond with Gupta and Singhal's (2004:27) finding on the successful development of positive perceptions in numerous families of a child with a disability. A mother in Cunningham's (2006:1) research expressed her experience that became positive: "You just have to get as many answers to the questions that go around your head as you can...you need to do this as soon as you can so you can get through the worrying and puzzling...you find when you get some information, you can see just how silly the worrying was...you know once I got over all the shock and worrying and just helped him, things changed. I got to know him and I can truthfully say I've had a lot of joy these last few years". Cunningham (2006:2) highlights the challenge of being "clouded" by the knowledge of the disability, which fades away once one is able to get past the grief the shock and ultimately see the baby not the condition. Furthermore, Cunningham (2006:2) emphasis the need for mothers to receive information

which helps them experience their situation more positively. A mother reported that as she gained more knowledge about her baby's condition, she felt she understood her better which brought her closer to her baby. Cunningham (2006:2) further recognises that parents have needed knowledge about their child's condition to feel prepared to answer about their child to people, friends and family. Mothers in Lam and Mackenzie (2002:223) concur as they highlight that they were supported by friends who looked for information about DS for them, and this information helped them accept the condition more easily.

Skotko (2011b:2348), a genetic researcher and the brother of a sister with DS, highlights the importance of families receiving accurate, unbiased information together with the encouragement that one can have a fulfilling and rewarding experience while rearing a child with DS. Skotko (2011b:2348) further shares that many people have spread misperceptions about what it means to have DS, but that research is now showing that many families have felt and experienced life with an individual with DS as positive and rewarding.

2.6.4 Inclusion

A psychosocial study focused on mothers' experiences of the attitudes from society toward their child with DS (Lenard *et al.*, 2007:98). This study was repeated 30 years after it was initially done. Results from the past revealed low levels of mothers who felt guilt in having a child with a disability, however the more recent study revealed that mother's feelings are less around guilt and more around being involuntarily segregated in society. Furthermore, there were reports that mothers more often experienced support and respect from outside through self-support groups and in addition, there were lower levels of withdrawal from society in the recent study (Lenard *et al.*, 2007:98). This may reflect the move toward inclusion of children in society as described in the stories below. A more recent corresponding article reveals the belief in the inclusion approach from a famous fashion designer, Dolores Cortes, who chose a baby with DS to be the face of her Spanish swimwear brand. The mother of this baby reports her experience in feeling excited as this gave such a clear message of inclusion. She expresses her belief that all children, regardless of their, economic, racial, social or medical condition, deserve the same opportunities (DSAOM, 2012). The campaign was described to highlight inner beauty, and celebrate the differences that make each individual unique, with a focus on the positive experiences of each day and not the challenges: "They teach us much more than we will ever teach them" (DSAOM, 2012). This rise in inclusion has great

meaning for the respondents in a study on the maternal meaning of disability. Results revealed that the meaning of DS is culturally embedded and that mothers of children with DS find their meaning and develop perceptions of their child's disability from the social environment (Dabrowska & Pisula, 2010: 276; Hastings *et al.*, 2009:610).

2.6.5 Belief system

Mothers in Norizan and Shamsuddin (2010:1001) reported coping styles of acceptance, religion, optimism, and active coping. In addition, they specify that in the acceptance process, mothers accepted their child as part of their fate; they had to actively seek help from others through communication and awareness of others in similar situations, where they realised their child's condition was not the worst (Lam & Mackenzie, 2002:223; Norizan & Shamsuddin, 2010:1001). Mothers who were more accepting experienced less psychological adjustment problems, while mothers who hid their children and isolated themselves had limited coping resources and they experienced more stress (Loyld & Hastings, 2008:37; Norizan & Shamsuddin, 2010:1001). Suhail and Fatima (2010:461) measured the impact of a mothers' belief system on their emotional experience and concluded that one's personal belief system is supportive of a personal resource when facing both normal and adverse life circumstances. Literature studies throughout the years, illuminate participants expression of faith as a meaningful coping mechanism that has contributed to the positive experiences of mothers of a child with DS. Bennett (1995:301) share a mothers comment in this regard: "So it's really been the biggest thing that has helped us cope" as he recognises that prayer and faith in a "higher power" is supportive of upholding a positive outlook for their child's future.

2.6.6 Development

A testimony was given by a mother, Linda, about her encounters after her child was diagnosed with DS. Linda highlights the many challenges she went through with her child, and expresses her relief and joy in Nia's speedy recovery thereafter. She further explains that her source of coping was seeing Nia overcome the difficulties of her condition with a beaming smile and being able to attend the same school as her brothers, which far outweighs the 'downs' (Phillips, 2007:28).

Another contributor toward mother's positive perceptions about their child with DS is that the focus of children with DS seems to be more on their abilities than their disabilities, which is evident in the reported positive experiences, medical intervention, rate of adoption and acceptance by society (Phillips, 2007:28). This has an impact on mother's perceptions of their child with DS, as it develops hope, increases coping and acceptance of their child. According to Docherty and Reid (2009:459) the parents attitudes and expectations may sustain the relationship between parent and child and thus contribute to the restraint of a transition to independent adulthood for the child.

Results in Venuti *et al.* (2009:198) on the emotional attachment between parents and children with special needs, specifically DS, correlate with Fidler (2005:93). They found that although children with disabilities may be delayed in their emotional development and response, parents are still able to read their responses and parents respond appropriately. More specifically they discovered that despite the delay in the child's responsiveness due to the condition, "parents may be doing an exquisite job in drawing him or her out" thus there does exist a process of connecting emotionally to the child (Fidler, 2005:93).

Pino (2000: 136) highlights a common thread in literature that the development of a child with DS, depends on the degree to which parents provide appropriate stimulation and social enrichment. Barr and Shield's (2011:1028) study concur with Venuti *et al.* (2008:134) as one of their four main findings on barriers to children with DS participating in physical activity include parents reporting that they themselves act as a barrier to their child's participation in activity. They expressed that their child's need for activity was not a priority as raising a child with a disability requires an increase in finances as well as an increase in supervision during physical activities, which they do not always find time for (Barr & Shields, 2011:1028). Their results therefore reflected that the facilitator of the child with DS participation in activity is the positive role of the family, encouragement and involvement themselves, that had a huge influence on the child with DS's physical activity, participation, cognitive functioning, social interaction and self-esteem. The findings under section 2.6.7 (entitled Family Relationships and Perceptions) highlights the willingness of siblings to be involved with their brother or sister with DS.

2.6.7 Family relationships and perceptions

Young people with DS have a say in a quantitative study undertaken by Skotko, Levine and Godlstein (2011a:2360). A total of 284 respondents with DS who are 12 years old were interviewed about their self-perceptions, with the aim being to share their experiences with new parents of DS babies. Of the DS persons interviewed, 99% expressed that they were happy with their lives and expressed love for their families; 97% conveyed that they liked their brothers and sisters, they liked who they are, and they liked how they look. The qualitative results of the same study indicated babies with DS must be loved by their parents. The participants also encouraged professionals to value them (DS children) because their hopes and dreams are the same as those people without DS. (Skotko *et al.*, 2011a:2360).

This experience correlates with statistics in literature on siblings of a child with DS. Family cognitive processes of DS persons, is revealed through a parallel study which was conducted on 822 siblings of DS people. The majority of these siblings highlight their feeling of affection toward their sibling with DS and expressed a feeling of pride in their sibling with DS; while very few expressed a feeling of embarrassment, and a minority communicated that they would rather have a sibling without DS. The majority of older siblings expressed a sense of being a better person as a result of having a sibling with DS, and shared that they want to continue being involved throughout their sibling's life (Skotko *et al.*, 2011b:2349).

In correspondence, findings in recent international research into the self-perceptions from people with DS and siblings of people with DS by Skotko *et al.* (2011a:2362) and Skotko *et al.* (2011b:2348), revealed a majority of positive perceptions people describe in having DS and positive perceptions children describe in growing up with a sibling who has DS. Gupta and Singhal (2004:30) explain that the positive perceptions not only benefit the parents and siblings in coping with the child but benefit the family unit as a whole. Their understanding through research has led to the view that the development of positive perceptions is a process that occurs through coping, and that these positive perceptions continue to act as a coping strategy in the face of stressors in parenting a child with a disability.

The researcher agrees with this as literature in this chapter highlights that at present there exists many positive changes in the world of having a child with DS. These factors have led to a positive change in people's perceptions which has increased the support of having a child

with DS and ultimately, contributed to the positive experiences of mothers of a child with DS.

Stoneman (2007:1006) examines income between families of children with DS and families of children with intellectual disabilities. The results revealed that a majority of mothers give birth to babies with DS when they are older in age and more financially stable. This factor of income does have an impact on the experience of parenting a child, which is more advantageous to the well-being of children with DS than children who are diagnosed with any other intellectual disability (Adnams, 2010:436; Dabrowska & Pisula, 2010:266; Hasting *et al.*, 2009:615; Stoneman, 2007:1006). There is more warmth and wellness in relation to the child as opposed to an increase in depression from parents of lower socio-economic backgrounds who relate to their child with less warmth.

2.7 AN OVERVIEW OF POSITIVE PSYCHOLOGY

2.7.1 What is Positive Psychology?

The theoretical perspective of this research approach is rooted in positive psychology. Positive psychology in no way dismisses that we encounter hardships, rather it is premised on the idea that although one is faced with adverse circumstances which may never change, one can choose to identify qualities in that situation or in oneself that can serve as strengths with which to deal with the adversity or view the adversity positively (Peterson, 2013:4; Seligman *et al.*, 2000:5). This view correlates with that of the National Dissemination Centre for Children with Disabilities (hereafter referred to as NICHCY), which suggests that although children with DS differ from non-disabled children in their abilities, families and healthcare professionals should place fewer limitations on the capabilities and achievements of children with DS and instead seek to recognise the capabilities of the latter and reinforce them (NICHCY, 2010:1). In addition, the NICHCY (2010:2) views children with DS as being very much the same as other children and it highlights that one should strive to provide them with the same opportunities enjoyed by other children.

2.7.2 The background to Positive Psychology

Positive Psychology is very new in its emergence yet has been growing for the past decade (Cherry, 2013). Positive psychology was founded by theorist Martin Seligman who built on the works of humanistic psychologists Carl Rogers, Abraham Maslow, Erik Erikson, Burton Singer and many others who shifted the interest of psychology from treating abnormal behaviour and mental illness after World War II, to the original goal of psychology which included addressing two other aspects, namely to make the lives of all people more productive and to identify and nurture talent (Cherry, 2013; Seligman, 2005:410). Co-founder, Christopher Peterson, describes positive psychology as the study of what goes right in life and furthermore what makes life worth living (Peterson, 2013:1, 3, 8).

This approach encompasses the study of “positive emotions, character traits and enabling institutions” to understand how one prospers in work, love and play (Seligman *et al.*, 2005:410). Peterson (2009:8) refers to the “positive emotions, character traits and enabling institutions” not as pillars but as psychological states, traits, mechanisms, and contexts. Positive psychology has its focus on the emotional state of happiness, using measurable and skill-based constructs of three realms that underpin their approach, namely: “hedonic”, which entails having life led around as many positive emotions as one can, to experience a “pleasant life”; “a state of flow”, which entails experiencing “an engaged life” if one’s life is led by this state. Flow is measured by using your highest strengths and talents to meet the challenges that come your way, and furthermore flow facilitates learning. The last realm in positive psychology is “the meaning of life”. The meaning of life is viewed as knowing your strengths which positive psychologists view as consisting of knowing what your highest strengths are and using them to belong to and serve something you believe is larger than yourself (Seligman, 2009:296). Seligman *et al.* (2005: 413) reports that the most satisfied people are those who orient their lives toward all three constructs of happiness, especially meaning and engagement.

Some of the major findings through their studies include conclusions that most people are happy, resilient and maintaining good social relationships which act as a buffer against setbacks (Peterson, 2010:5). Research describes a psychologically healthy person to have these components which make up a good life: experiencing more positive feelings than negative feelings; being satisfied with life; identifying and using talents and strengths; being engaged

in activities; having close relationships with neighbours, colleagues, friends, and family members (Peterson, 2013:19).

2.7.3 The application of positive psychology

Seligman (2005:413) highlights that positive psychology intervention that builds happiness is not epi-phenomenon, rather it is causal. This means that the intervention does not merely evoke a good feeling, rather that there are on-going benefits as a result of the intervention, which include happy people being healthier, more successful and more sociably engaged (Seligman, 2005:414).

The application of positive psychology may be used in various ways, for example exercises that include instructions to focus on three good things for the week, with a reflection on each good thing mentioned (Peterson, 2013: 289; Seligman et al., 2009: 301). The application of positive psychology can further be used to address various issues in areas such as education, therapy, self-help, stress management and workplace issues, ultimately to increase individual happiness through motivating, and helping individuals understand and develop their personal strengths (Cherry, 2013).

Gupta and Singhal's (2004) research has led to the view that the development of positive perceptions is a process that occurs through coping, and that these positive perceptions continue to act as a coping strategy in the face of the stressors involved in parenting a child with an ID. They emphasise that although there are no reports on the positive perceptions held by families of children with IDs, an awareness of these positive perceptions could serve to reframe the situation in a more positive light, creating a coping strategy in the face of the stressors associated with parenting a child with an ID. Seligman *et al.* (2005:5) in accordance with other positive psychology theorists, share evidence that positive strategies and beliefs can serve as a resource in the face of adversity as they fuel psychological resilience and also decrease depressive symptoms.

2.8 SUMMARY

This chapter focused on reviewing the literature on the phenomenon of DS, including its history and implications in terms of childhood development. In addition, a review of the literature was given in terms of its commentary on the experiences of mothers of children with DS, specifically with regard to external support both before and after the diagnosis, stress, and the impact of the diagnosis on family relationships. An explanation and the importance of attachment between mother and baby with DS, including barriers to attachment, were discussed. Lastly, the chapter highlighted the positive experiences, as recorded in the literature, of mothers of a child with DS in terms of learning to cope with the diagnosis and its reality and also finding relevant support structures.

The ensuing chapter discusses the theory underpinning this research study, namely positive psychology, and what this perspective entails.

CHAPTER 3

DATA ANALYSIS AND FINDINGS

3.1 INTRODUCTION

The following chapter presents the research findings in a table format as well as through a discussion that integrates relevant literature with quotes from the participants. Participant profiles are discussed, as well as the process of collecting the data.

The goal of this study was to explore *the positive experiences of mothers of a child with DS*, which was achieved through a qualitative approach and the data analysed according to the objectives of the study. The specific objectives of this study were as follows: (1) to ascertain how the participating mothers relate to their babies with DS; (2) to highlight and share the positive experiences of these mothers of children with DS; (3) to describe the experiences of these mothers; and (4) to make suggestions on how to help future mothers of a child with DS.

3.2 PROFILE OF PARTICIPANTS

The profile of each participant is given in Table 3.1 below.

Table 3.1: Participants' particulars

Participant number	Hospital of birth	Time of diagnosis	Child's present age	Attended TL Clinic*
1	Groote Schuur	Birth	5	Yes
2	Mitchell's Plain	Birth	4	Yes
3	Bonteheuwel	Birth	5	Yes
4	Groote Schuur	Birth	4	Yes
5	Mowbray	Birth	2	Yes

* The TL Clinic is part of Toy Library Clinic

This table indicates that all participants' children are in the toddlerhood age group and they therefore have indeed had a relevant period of experience with their child to contribute to this

study. Furthermore, the commonality of having the diagnosis at birth reveals that a respective time has been given to the participants before addressing the sensitive nature of this topic.

3.3 DATA COLLECTION

The researcher gathered data by way of individual interviews with the participants, during which time the mothers' experiences of having a child with DS were explored. To support this exploration, the researcher used the following questions to guide and focus the interviews:

- What was your initial experience like with your baby?
- Would you like to share what your experience was like relating to your baby?
- How would you describe your experience of your child now?
- Tell me more about the relationship between you and your baby, and between your child with DS and his/her siblings?
- Can you tell me about how your relationship with your husband may have been affected by having a child with DS?
- How have you experienced the community's perceptions toward your child with DS?
- Is there anything you would like to share with other parents of a child with DS about what you have experienced in the last few years as the mother of a child with DS?

The data received from the participants were then analysed according to the step process advocated by Tesch (1990:251), which includes transcribing, coding and analysing the data. Although the aim of this research was to explore the positive experiences of mothers of a child with DS, the data inevitably revealed that these mothers also have had negative or difficult experiences. In order to give a holistic view of the positive experiences of the mothers, the discussion of the research findings begins with looking at the difficult experiences of these mothers. The findings on the negative and positive experiences of the mothers of a child with DS are tabulated in Table 3.2 below.

Table 3.2: Table of findings

Main theme	Sub-theme	Categories
DIFFICULT EXPERIENCES	Adjustments to having a child with DS	Unpredictable health implications
		Developmental delay
		Perceptions
		Perceived unprofessional conduct
	Emotional experiences	Fear
		Aloneness
		Grieving
POSITIVE EXPERIENCES	Coping mechanisms	Support
		Resources
		Faith in God
		Acceptance of the condition
		Positive attitude
		Bonding
	Changes in perception through experience	Knowledge
		Development of child
		Positive approach of others

The above table depicts the collective feedback from the participants on the questions asked by the researcher and the discussion that follows is in accordance with these two over-arching themes as well as the sub-themes and categories. The researcher found that there were both positive and negative experiences described by the mothers of a child with DS in this study. Participants described their experiences as the mothers of a child with DS as being **difficult**, because it required enduring many challenges, while they discovered **positive** experiences through their coping and overcoming of these challenges.

* Any asterisks used in the discussion are there in placement of confidential names.

3.4 DIFFICULT EXPERIENCES OF BEING A MOTHER OF A CHILD WITH DS

3.4.1 Adjustments to having a child with DS

Participants reported on the following common factors that were difficult adjustments to being the mother of a child with DS:

- Unpredictable health implications
- Developmental delay
- Perceptions
- Perceived unprofessional conduct

3.4.1.1 Unpredictable health implications

The participants shared a similar difficulty in their initial experiences after giving birth to their babies as this period posed many *unpredictable health implications* for their babies, who suffered from chronic illnesses. Some of the participants shared that their babies had heart complications. One participant described her baby as having two 12 mm holes in her heart as well as limited valves, which required urgent surgery. Some of the participants shared that their babies had near-death experiences because their lungs were very weak and they struggled to breathe. Some of the participants shared that their babies struggled to latch on during breastfeeding, which meant they had to be incubated as they were not obtaining the nutrition they needed and were thus not gaining enough weight. In a study by Phillips (2007:28), a mother called Linda related how she had to endure watching her child undergo six hours of open heart surgery.

These experiences are classic examples of what the current literature lists as the frequently presented medical conditions and congenital defects of babies with DS (Lampret & Christianson, 2007:2; Van Cleve & Cohen, 2006a:47). Van Cleve and Cohen (2006a:47) explain, in detail, that the congenital defects are due to the genetic implications which present at birth and include as many as 50% of babies with DS being born with some form of heart problem, of which half are serious and require surgery. Other congenital problems include narrow airway passages posing breathing problems and tongue hypotonia, in which case there

is low mobility in the movement of the tongue, impacting on the babies' ability to suckle (Van Cleeve & Cohen, 2006a:48). Van Cleeve and Cohen (2006a:48) and Lampret and Christianson (2007:2) say that due to these complications it is essential that children with DS have routine assessments and on-going medical management.

Participants commented as follows on how they experienced these unpredictable health implications:

P1: *"That was a real experience, a real adjusting, up and down, in and out of hospitals."*

P3: *"It was for me, the first year was for me under a lot of stress, it was, but I think after the operation, I just could see progress – I got more relaxed and relaxed and today I think of her and I forget about the word Down Syndrome because I see her as one of my other kids."*

Similarly, all participants in this study described their role as a mother of a child with DS as requiring much sacrifice, especially regarding the health implications, which necessitate regular hospital visits.

These sacrifices are further highlighted in the following quotes from the participants:

P1: *"I felt sad because I had to leave my job because my child was laying here and I couldn't go to work and she is here. I went home every day and came here every morning; it was very difficult for me because I didn't sleep here."*

P2: *"And we will stay there for three days, we go home for a week, then we go in and stay for another two days. That was for three months and for me that was – it took a lot out of me, emotionally."*

P1: *"From the start actually I couldn't build a relationship with her because she was in hospital."*

The advancement of medical intervention has sought to understand and discover a means of supporting these health implications, therefore despite the many congenital defects, the life expectancy of people with DS has been increasing since the 1920s due to better healthcare in treating these medical problems and what may be lifelong chronic disabilities (Coppus *et al.*, 2008:2313; Dixon, 2008:9; Leonard *et al.*, 2000; Wexler *et al.*, 2009:656). Moeller (2005)

confirms what the literature has been reporting about the increase in life expectancy through factual data showing a doubling in life expectancy from 25 to 50 years.

This may explain that although Christianson *et al.* (2002:179) reported that two out of three children with DS die before the age of two years, all five participants' children with DS in this study survived the complications after birth. Furthermore, one participant's baby had no health complications at all. Even still, to date, hope for children with DS increases as health professionals continue to advance in medical research and intervention for the correction of the chronic and birth complications caused by the diagnosis (Macrae, 2011; Saheli, 2009; Staff, 2008:5).

3.4.1.2 Developmental delay

Moeller (2005) explains that the genetic defect involved in DS means all individuals with the diagnosis face intellectual disability as well as developmental delay. The average age for such persons is 6 to 13 months for sitting, 1 to 4 years for walking, and 1 to 3 years for first words (Moeller, 2005). According to the participants, as time went on, they did notice that their children with DS in fact did have a *delay in their development* during their toddlerhood milestones.

P3: "I am not feeling right. By the time she grow, started walking, and even coming to sitting, I notice that something wasn't right. She was trying to walk only at 2 years old. But as time went on, I noticed something by the eyes and he's not like the other children, by the time he must sit and walk."

P5: "I see it now actually. When he's laughing and his tongue hangs out."

P1: "She didn't walk by three years old, she just stand up. That was for me the hardest part because by that time my other child walked already."

The participants realised that this developmental delay would indeed require sacrifices and patience from their side.

P5: "So it's going to take double the time than a normal child to grow up. Always when I have a baby then I think okay, it takes two years then it's fine, until you can walk and talk and

I can potty train you. You basically big, if I can say so, you can at least do things for yourself. And now I think, it's not going to be two years; it's gonna be four / five years of my time."

The importance of stimulating the child for them to progress through their developmental delays was also highlighted by the participants.

P4: "So they need a lot of stimulation, you can't let a child just be."

Wexler *et al.* (2009:656) confirm this participant's statement, as they found a greater recognition that with the appropriate early medical, rehabilitative and educational interventions, individuals with DS can lead relatively normal and productive lives.

In the literature we see that there has been a great advancement in the resources and intervention available to children with developmental delays (Dixon, 2008:8; Leonard *et al.*, 2000). Other than the fact of having a child diagnosed with DS in common, the participants in this study were commonly referred by professionals (either a doctor or genetic counsellor) to the early intervention programme run in a hospital by a Down Syndrome Association (DSA). Van Cleve and Cohen (2006a:52) highlight the importance of this referral as a resource in support of the development delay and furthermore that occupational, physical and speech therapy as well as special education, nutritional and social work support are some of the specialised programmes available to children with DS as part of the early intervention programme.

3.4.1.3 Perceptions

Participants shared that they felt their negative experiences were due to misperceptions about the diagnosis of their child having DS. Some of the participants explained their initial misperceptions of having a child diagnosed with DS as follows:

P5: "I didn't really know much about DS, but I can tell you how I looked at DS children. I was always scared of them always. I never liked them, because I didn't know what they were capable of. You know, I hardly saw them, it was like, 'Oh my word, don't touch me'. I was honestly like that. Because I wasn't sure they were gonna hurt me or hit me with something, cause I didn't know their state of mind, they didn't look all there."

P2: "The image I had of Down Syndrome, I did not know the positive things."

P1: "For me I was thinking the people will think she is really bad, but she is not bad that I or the people thought so. If I had known I would have taken her long time to a crèche."

This particular factor of misperceptions relates to the categories of family, community and personal *perceptions* that participants felt had an influence on their experience of being a mother of a child with DS. This was with particular reference to perceptions or views that participants had already developed about DS from what they had seen on television, in their community, and in some cases extended family. Participants felt that their perceptions were outdated and had changed after experiencing what it was actually like to be a mother of a child with DS. Hence they felt that their initial negative perceptions about having a child with DS, was linked to unawareness of what it is actually like to-date. Mothers commented on the differences they experienced to what they were told and had seen.

*P3: "They changed when they saw * crawling in church. It changed when they see * walk in church. It changed when she go to them and talk to them."*

*I think the community see that Down Syndrome is not really that bad when they see * or when they see other Down Syndromes, it's not really that bad."*

*P3: "And then I think most, or everything changed of my thinking, of Down Syndrome the day I walked in by the toy library and the day I walk in by the toy library, I think * was one month and then I saw all the mothers with babies with Down Syndrome and there I saw that I'm not the only one."*

P2: "I was thinking that she is not going to talk, I was very, very angry, because I was having imagined when I was always walking with that child in the chair or on my back. And I had to do everything on the bed, when he was not walking, I must change him on the bed. And God was good to me because she is walking and talking and I can understand what she says. I was also thinking she would have no sense. Yes, I see my child growing. Yes she is developing now."

Mothers also reported that this negative perception and lack of awareness about what DS actually was and meant, contributed to their difficult experience with regards to the emotions and acceptance of their child's condition.

Gupta and Singhal (2004:27) understand that the many stressors (medical complications, financial strain, care-giving demands, concern for the future, including the negative reactions from others) of raising a child with a disability, has contributed to a negative perception of having a child with a disability. Gupta and Singhal (2004:30), in concurrence with the findings on coping strategies made by Hastings and Taunt (2002), argue that parents of children with disabilities do experience many stressors, and they suggest that there becomes a shift from only describing these stressors and their adverse effects to and rather focus on the successes that these families experienced.

3.4.1.4 Perceived unprofessional conduct

In correspondence Gammons *et al.* (2010:701) and Lalvani's (2008:440) studies revealed that mothers did not feel supported by health professionals, and furthermore they emphasised that professionals, like doctors and nurses, shared negative views and attitudes toward disabilities including outdated information that was shared with them. Similarly the participants in this study reported similar behaviour by the professionals which they (the mothers) perceived as unprofessional behaviour by the professionals during their stay in the hospital. This began with a delay in the period of receiving a confirmed diagnosis that their babies are DS. For example their babies were taken away from them for up to four days and during that time, nothing was said to them about their child's condition or why they were taken away. This left the mothers with anxiety and uncertainty about what may be happening.

Participants described their experiences as follows:

P4: "It was horrible! The whole time I was in hospital with her, the whole time she was never by me, only when she was discharged on the Friday was the first time we were together and she was born on the Tuesday. I only saw her once, twice, because when she was under the lights her eyes were closed, so I haven't seen her also, so I didn't know which one was mine. And they also found something. They thought something may be wrong with her heart. That is why they sent her to Red Cross. They didn't explain none of that to me."

P3: "But I notice one day when he said he was going to check the brain, but he didn't tell me anything. But the one sister said there was something wrong with this child, but the doctor said that he is fine."

*P5: "Dr * he was supposed to tell me actually but he couldn't. I was anxious, I wanted to know but I didn't want to know. So that morning the sister she came around and gave me my*

*papers I could go home later that afternoon after seeing Dr *, so I asked her if it was positive and she said 'unfortunately, it is true'. When she answered I was so shocked."*

In addition, mothers in the study by Gammons *et al.* (2010:704) disclosed that they felt alone after hearing the diagnosis and also experienced limited counselling or preparation on how to care for their baby with DS. Similarly, participants in this study experienced having a lack of information because it is only once an appointment is made for the genetic counsellor at a different hospital where they find out more about DS and thereafter referred to the Toy Library Clinic for further support. This may be months after they have given birth.

P2: "because I know of the lack of knowledge about Down Syndrome. People will say the wrong thing because I, myself did not know much about Down Syndrome. At that moment I wanted to gain knowledge about Down Syndrome. What one sister did at church, she got me a lot of information on the internet about Down Syndrome and I went through everything and so when people ask me something I will know what to answer them. That is what I wanted. I wanted to prepare myself."

Another perceived unprofessional conduct by professionals was the *manner in which the diagnosis was delivered* to them.

P5: "Then an hour or two later, they said I must come along with them, they want to take a look at my baby. So I went with them to the other side of the hospital. They took a look at him, I wasn't aware of what was happening, but I thought, ok they just want to look at him. They looked at his eyes, his legs, his feet. Then they got the opinion of another doctor. And I was just wondering what is wrong, there must be something wrong if they have one doctor after another, usually that happens when something is wrong. And then the one doctor was very abrupt and said, 'we checking your child for DS' and I was just so shocked, that was not even on my mind, not even the last thing, it wasn't there at all."

P2: "One sister saw my child and she took him from me, but not in a nice way and she just said in front of everyone, 'this child must come under the light, there is no time for Downs queries'. Now I ask her excuse me, what are you saying? 'Didn't they tell you your baby is Down Syndrome?' in front of everyone. It was really, really sad, it was very emotional."

Gammons *et al.* (2010:704) further support these findings. Mothers in their study described that during the period of diagnosis, the way in which the diagnosis was offered was described as “awkward” because staff seemed uncomfortable or reluctant to discuss the challenges that lay ahead for a child with DS. In accordance with parallel studies, a common report has been on the negative perception of having a child with DS. This was mostly portrayed through the manner of the diagnosis, for example a negative tone used by professionals involved in the disclosure of the diagnosis. Specific examples reported by the mothers in this study, that correlate to descriptions from Dixon (2008:4) include phrases such as: ‘unfortunately’; ‘there is a problem’; ‘your child is not normal’; ‘Mongol’; ‘something is wrong’. The emotions the mothers reported they experience after the diagnosis include initial shock, hopelessness, uncertainty and concern about the child’s development, health and lifespan and fear with regards to the possible lack of acceptance from family and society. These family stressors and emotions correlate with international literature (Gupta & Singhal, 2004:22; Lam & Mackenzie, 2002:225; Saloviito *et al.*, 2003:300; Sari *et al.*, 2006:29; Van Riper, 2007:116).

3.4.2 The emotional experiences of being a mother of a child with DS

Mothers shared common emotions in being a mother of a child with DS like

- Fear
- Aloneness
- Grieving

3.4.2.1 Fear

Nicol (2008:145) expresses the idea that inadequate diagnoses fail to serve the needs of pregnant women who feel anxious, pressured and frightened for their child’s welfare. Staff (2008) may explain this statement further as mothers’ describing a feeling of fear for their child’s well-being in a world where there are relatively few people like them (i.e. disabled or Down Syndrome individuals). This feeling has been proven true by the participants of this study who shared a common emotional experience of *fear* for their child’s future after having been told the diagnosis. They explained that their former perception of what it is like for children with DS – namely being institutionalised and/or ostracised, and having limited

capacity and a short lifespan – had a strong influence on their emotions, which made the diagnosis of their children difficult to accept.

P2: “All you know, all you stare at or you mind focus on is fear, fear the unknown things, fear.”

Participants also described fear for not knowing whether their child would achieve or become independent in the future:

*P4: “You can’t sleep at night because you fear * needs to go to school. I would love for her to go to an inclusive school, but there I won’t be able to protect her and there it’s all children, not just babies.”*

P3: “I am afraid I don’t know how she is going to get into the school.”

P2: “I don’t know what he is going to learn maybe he can write her name her surname, knows her parents and then maybe something to do when she grows, then I can feel better. When she was sitting and looking and wanting something to eat and need the clothes, I don’t want her to be like that because her communication is not good.”

The participants also expressed their fear regarding the health implications of their child with DS:

P2: “And my fear was what if I’m going to love this child, what if I’m going to get so close to this child and the Lord decides to take this child from me- then my loss is going to be bigger than it is now.”

P5: “Somehow I looked at it like that, I didn’t know If there would be health implications. I was mostly worried about the medical side of it, but fortunately for me he had no medical, major medical problems.”

Silent fear of not being there for their child was expressed:

P4: “But when you go lie down at night and reality hits you, then you not positive. And when you look at this baby and you think, “What is going to happen to this child if I’m not there” and those are the worries. That is my biggest worry, what is going to happen to her if I am no longer there, or her daddy’s no longer there.”

3.4.2.2 Aloneness

Mothers in this study further related to the expression of loneliness, as described in Staff's (2008:5) description of mothers' "feeling of fear for their children in a world where there are fewer people like them". The participants shared their lack of knowledge about the diagnosis and that they were unaware of the existence of other mothers facing the same situation, which made them feel alone and isolated from the world.

P2: "Felt like I'm the only one in this world with a baby like mine and I felt so alone and there was really no one at that point of time that could encourage me, "listen here, I also have one and it is going to be all right now". I was on my own. Me and my husband was on our own"

P5: "When your child is born, you feel like you the only one, you hardly know of anyone who has a baby like that, you actually shocked to see there's so many and I'm not alone and it's not really something, at home it's something but here at the TL Clinic it's not."

3.4.2.3 Grieving

Participants disclosed their individual processes of grieving in having a child with DS. Mothers shared how helpful going through the stages of grieving was for them to get to the acceptance of their child's condition. Participant's distinguished the difference in their grieving process, as they emphasised that they were not grieving their child, but grieving the diagnosis and what this meant for their child. Participants disclosed what these specific things were that they were grieving for:

P5: "And now I think, it's not going to be two years, it's gonna be 4 or 5 years of my time."

P1: "That my child wasn't going to do everything."

P2: "Mourning- when you see other children then you realise it's not going to be like that, tears were just flowing- the loss of maybe she's not going to be like my other children, she's not going to go to school like them, she's not going to go to college like them but time really heals."

Ross and Deverell (2010:43) emphasise that grieving is critical for parents to experience in order for them to mourn the loss of the dream they had for their child and separate themselves

from that lost dream, ultimately to reach acceptance of their child as he or she is. Worden (2009:37) in agreement with Ross and Deverell (2010:44) shares their understanding of the mourning process to be a journey of working through tasks to process the loss. This journey entails acknowledging the reality of the loss; experiencing the pain of the loss, and lastly, adjusting to the new environment without the loss. These theorists recognise that there is great variation in the response to grieving and that not everyone goes through the emotional phases in the same way or at the same speed (Worden, 2009:52; Ross & Deverell, 2010:39).

Participants described experiencing feelings of *anger*:

P2: “ has a big, big heart problem and I was like, not only they must have Down Syndrome, they also gave us a sick child. It’s anger, it’s anger. I was very angry at the Lord.”*

Mothers also experienced many situations that highlighted their *denial* of the diagnosis specifically that they did not want to hear about it. The participants responded as follows when they expressed the emotion of denial:

P2: “I was hoping she was not Down Syndrome. I was very, very much in shock. I couldn’t, I just couldn’t face people. I couldn’t even tell my friends and I’m talking about the closest, I couldn’t, because I was not ready to tell them.”

P3: “I didn’t want to hear that my child was going to be stupid.”

P4: “So I didn’t want to hear anything. But it will only work for you when you ready to see it. Before that because you have boundaries, you sit there, everybody’s talking but I wasn’t listening because I had these walls. But when the walls came down, then I listened and everything was ok.”

The literature highlights similar experiences of mothers who initially experienced negative emotions towards their situation. Cunningham (2006:2) explains that these emotions may be due to the challenge of being “clouded” by the knowledge of the disability, which fades away once one is able to work past the shock and grief and so ultimately see the baby, not the condition.

It seems that the grieving process can lead to mothers experiencing their child with DS in a positive manner. The following section discusses the positive experiences of the participants, and so focuses on how they overcame the grieving process.

3.5 POSITIVE EXPERIENCES OF MOTHERS OF A CHILD WITH DS

Participants described their experiences as mothers of a child with DS as being “blessed” because there were many ways of coping with and overcoming the difficult adjustments. Their experiences changed their negative perception of children with DS to a positive one. So while the mothers mentioned their negative experiences, they also shared many positive experiences, and in light of the goal of this study the remainder of this chapter – the majority of it – focuses on the positives.

The researcher discusses the positive themes and various categories highlighted by the mothers when describing their positive experiences.

3.5.1 Coping mechanisms

The participants spoke of many similar as well as different coping mechanisms they employed while going through the many difficulties posed by having received a DS diagnosis. These included:

- Support
- Resources
- Faith in God
- Acceptance of the condition
- Positive attitude
- Bonding

3.5.1.1 Support

The participants spoke about the support they received during their experience of being a mother of a child with DS. Sources of support included: support from husbands and family, counselling support, support from professional intervention, and support from the community.

Participants emphasised how much their husband's involvement and positive attitude helped them to view their situation of having a child with DS more positively:

P5: "...he was positive, so I became positive, the healing process was a lot quicker."

*P4: "my husband didn't miss one visit with *, he was there every time."*

P3: "Me and my husband, I think it brought us closer. It brought us closer it brought me and my in-laws closer."

In addition family members were involved and showed much positive acceptance toward the situation:

P5: "So I tell you the family support is very important, they didn't look at you any different, they actually praised you, they blessed you. I felt as if I was more important, if I can say so. Because they were like I wouldn't mind having a baby like that, that's no lies. Even my sisters everybody would say, 'this is the best thing, this is so nice'. My sister has three daughters, they come here every day, they would phone, what is he doing now, what is he wearing, they have more photos of him than I have. They captured when he was crawling, I don't even have that. They have like every little stage on camera. So for the children to accept it was easy for them."

Extended support is offered to mothers through the role of a genetic counsellor who is trained to explain the genetic causes of the diagnosis with relevant information on intervention, as well as offer emotional support through their professional counselling background (Sheets *et al.* (2011:432). Cunningham (2006:2) correlates that parents felt they were able to cope with the news about the diagnosis by talking to someone.

Participants mentioned that hearing about what causes DS and the support from the genetic counsellor was such a relief because it helped with blame and fear felt toward their child's diagnosis.

P4: "Because somehow even though you know it's not your fault, you still feel guilty. So that was sorted, it disappeared, I didn't feel guilty anymore, I understood clearer."

P1: "Ok, the counselling was very nice because it was for me and my husband, we were both there and they explained to us how it's one out of a hundred children who are born with holes in their heart with DS. I am actually sure because they explained it to me, what is the facts now for the DS. I understand it well. The only thing I say nowadays is that the children don't turn out like those days, now it's just maybe the delay."

P2: "It is not the end of the world, they explained to us what is Down Syndrome and what it's all about...baby is going to be slow, delayed and baby can be like other children, it is just that baby's going to be delayed in certain developments or fields."

Positive responses and support from the community was a surprise for participants:

*P4: "Before she was somehow covered, even if they pick her up, she was covered. But by 6 months I decided no more, it's a lekker day and I take her out. I went to the butcher here with her on my arm. I knew this butcher here and when he saw * his eyes lit up and I wondered why he is so happy to see me, because I know his wife but I don't know him. It wasn't for me, it was for *, he started kissing her and said "you know, we lost our one three years ago" he called his wife and said "come look here" and they hugged her and kissed her because their one is no longer there. Whenever that man sees * or any child with DS he hug them because he misses his own child. I didn't even know at that time. I thought to myself, 'yoh', we are blessed with this child and he is longing for his child who is no more."*

Participants felt that much support on professional intervention was received for their child's development:

P2: "If that support wasn't in place at the TL clinic, I wouldn't be here where I am now. Because you needed support and people to talk to who are positive. My husband can tell me to be positive but that's one person, all the little bits help."

The participants had a positive experience in attending the TL clinic because they had support from other parents who were going through the same experience and who could share suggestions about difficulties they were facing. Participants shared how beneficial it was to see other children in the TL clinic as well as a particular a 35 year old adult with DS who works in the clinic and is very high functioning in her ability to converse with mothers, attend to children and fulfil her administration role in the clinic. Mothers reported that this gave them great hope as it altered their perception of a child with DS not being able to develop and function or achieve in life.

*P2: “The day I walked in by the Toy Library, I think * was one month and then I saw all the mothers with babies with Down Syndrome and there I saw that I’m not the only one. I realise that oh this mommy’s baby also don’t pick up weight and that one. I can relate to the other mommy’s and that bring peace of mind. It is not only * and I think hope really build up in the Toy Library.”*

P5: “If it wasn’t for the TL I wouldn’t have come to accepting really, if I look at it now. You know when you come to the TL, it’s like this is really nothing, everyone has a child like that.”

*P3: “Because she is growing up and up and I was blank, knowing nothing about what is happening to this child. This year when * was 5 years old, when I was open now, this child is going to be like this, I saw the others, that she is going to be like this one, like that.”*

3.5.1.2 Resources

Participants spoke about the importance and necessity of being resourceful. This included resources like pamphlets, the internet (for information and answers to questions), and the TL clinic (for learning about early childhood development and developmental delays in children with DS). This all contributed to the mothers’ positive experiences of their child with DS.

P2: “Because I know of the lack of knowledge about Down Syndrome. People will say the wrong thing because I, myself did not know much about Down Syndrome. I did not want to be in contact with other people. At that moment I wanted to gain knowledge about Down Syndrome. What one sister did at church, she got me a lot of information on the internet about Down Syndrome and I went through everything and so when people ask me something I will know what to answer them.”

P1: “Yes, because I explained to family what they tell me and the booklets they gave me, my family also read it too.”

This factor of being resourceful was essential as participants agreed that their initial experience in the hospital during the disclosure of the diagnosis was inadequate. They didn't feel they received sufficient knowledge and therefore it was beneficial for them to gain more information from other sources. Cunningham (2006:2) recognises that parents have needed knowledge about their child's condition to feel prepared to answer about their child to people, friends and family. This stress may be avoided by informing parents during the diagnosis which usually happens before or shortly after birth. Most *et al.* (2006:513) in support of the negative experience expressed by mothers responses in Lalvani's (2008:436) study, proposes that informing parents during the diagnosis is essential to preparing the parent for the coping process. Awareness of this need to be informed during the disclosure has been addressed internationally. Fiano (2012b) reports on the new Massachusetts law that stands for pro-information through ensuring all doctors must inform mothers of up-to date details on DS, including resources that are available.

Literature concurs with the importance of receiving resources to gain adequate knowledge for the purposes of making a difference to the families coping experience and adjustment.

3.5.1.3 Faith in God

Participants spoke about having faith in God through the difficult times, about praying for healing when your child is sick, and about praying for faith in general.

P1: “I pray to God for that child to believe, to make this child walk and talk. Every day I ask Him.”

P3: “Sometimes it is difficult, but then you must just ask God to give you the strength to hold on. I just get down on my knees and ask Him to give me that faith to hold on.”

P2: “As Christians we still believe that prayer can change everything.”

P5: “Cry about it and ask God to help you actually and then you get to the acceptance, and when you there you'll see it's just a breeze from there.”

Mothers in the research of Norizan and Shamsuddin (2010:1001) reported coping styles of acceptance, religion, optimism, and active coping. Suhail and Fatima (2010:461) measured the impact of a mothers' belief system on their emotional experience and concluded that one's personal belief system is supportive of a personal resource when facing both normal and adverse life circumstances. Literature studies throughout the years, illuminate participants expression of faith as a meaningful coping mechanism that has contributed to the positive experiences of mothers of a child with DS. Bennett (1995:301) shares a mother's comment in which she stated that prayer and faith in a "higher power" is supportive of upholding a positive outlook for their child's future.

Mothers also discovered meaning and purpose in life to be there for their child with DS through their faith:

P1: "I also think of the future, I ask God to just spare me through that, I don't want to miss it, because I want to see her future. And what I want for her for the future, it's not what I want, it's what God wants, so whatever he prepares for her, I want to see."

3.5.1.4 Acceptance of the condition

Participants felt that acceptance of the condition was a helpful and positive coping mechanism to embrace. One participant mentioned that if you just accept your child's condition, then you will easily do what needs to be done and it will not be difficult, but if you do not accept it, then going to the hospital, for example, as regularly as you need to will be a problem for you.

Participants spoke about how seeing other people's positive and accepting responses to their child with DS really helped them accept it themselves. They shared the wisdom they have developed through their experiences regarding acceptance of the child's condition and other people's responses to it:

P5: "If it is normal to you, then it will be normal to others."

P4: “I was like, ‘yoh’, what now, everybody now knows, because I wanted her to prove herself first, but now everyone knows? Ag man, we take it from there. Whatever their reaction, is their problem. My child, my daughter, I don’t have a problem with her, it’s fine, it’s ok.”

Similarly mothers in the study of Norizan and Shamsuddin (2010:1001) reported coping styles of acceptance, religion, optimism, and active coping. In addition, they specify that in the acceptance process, mothers accepted their child as part of their fate; they had to actively seek help from others through communication and awareness of others in similar situations, where they realised their child’s condition was not the worst (Lam & Mackenzie, 2002:223). Mothers who were more accepting experienced less psychological adjustment problems, while mothers in the study who hid their child and isolated themselves had limited coping resources and they experienced more stress (Loyld & Hastings, 2008:37).

3.5.1.5 Positive attitude

Mothers in this research study agreed that acceptance of the situation birthed a positive attitude in them toward their child with DS, which is helpful to supporting them and experiencing their situation more positively.

According to Docherty and Reid (2009:459) the parents attitudes and expectations may sustain the relationship between parent and child and thus contribute to the restrain of a transition to independent adulthood for the child. A mother of 25 year old daughter with DS who is both a special Olympian in swimming, skiing, cycling and swimming, while also a college student and tutor, comments on the compassion they have learnt from their daughter with DS and further comment: “We see her as perfect and beautiful” (Taylor, 2011). Furthermore, this report highlights the results of studies interviewing 2044 parents or guardians of a child with DS, showing that 79% felt that their child with DS made their outlook on life more positive (Taylor, 2011). Skotko *et al.* (2011b:2348) showed that 88% of their participants were convinced that because of their sibling with DS, they were better people.

*P2: "I like her words she said when people stare, she'll say, 'he's beautiful ne?' That's what I like to do, say hello to them and then people's whole attitude change and they will wave to * instead of staring at her. So we as parents, we must be there for our children."*

3.5.1.6 Bonding

Hart and Risely (1999:107) claim that there exists "an intimate social dance between children and parents" where communication is concerned. The dance is symbolic of the parent or caregiver leading the child in skills of listening and speaking, while the child follows and imitates this leadership style and content in communication with others. In concurrence, Bruner (1983:107) emphasises that the nature of exchange in communication that occurs within the dance between parent or caregiver and child, marks the effectiveness of communication with others. Furthermore, Greenspan and Wielder (1998:107) believe that in addition to the child's ability for relating and interacting the nature of the exchange within this dance between parent or caregiver and the child, determines the motivation and ability of the child to achieve. These definitions reflect attachment at its core, the importance of relating to your child with quality presence (as it has an immense impact on your child's future regarding relationship building skills), and interacting and performing at their peak capacity.

Participants in this study shared experiences of relating with their baby through interacting, reading, talking and holding which portrayed a presence of maternal emotional availability that describes the process of bonding or forming an attachment. Participants clarified that the initial grieving process after hearing the news about the diagnosis, did not impact on their bonding with their baby.

P5: "That's what helped me, made me more attached to him. He was cute and fat and helped me bond more with him. I could just overlook the emotions. I don't think that interfered with that. He was my baby. If I think about it, it didn't interfere with how I felt about him. Because he had all his fingers and toes. So it wasn't like, you know you couldn't see that he was Downs. He didn't look that bad. So for me it was just like a normal baby and that was something separate to accept, that he was Downs."

P4: "I mean whenever I gave her a bottle when she was smaller, I still kept her like I would if I breastfeed her, so we still had the hugging and the cuddling, the us time, you know that time, we still had that."

These mothers therefore disagreed with literature which notes that the barrier to attachment is the complication of breastfeeding between mother and baby due to the associated medical problems with DS (Sooben, 2012:187). This may be of particular importance according to the original author of attachment who described the period of breastfeeding to be critical in forming a long-term bond between mother and baby (Mahler, 1972:333).

P1: "It's great, because she understands me and I understand her. Yes because she shows me when she wants something, if she can't tell me, she shows me. She points."

*P3: "My husband will tell me every night, or most of the time, 'this child loves you, huh?'. I think he also realise that my connection with * and me is, I don't want to say but it is like that, is stronger than with her and her daddy. He will pick it up and it's so wonderful, he don't feel left out, he will just go with the flow, and he will tell me: 'you love that child, huh!' And I will tell him 'yes'. He sees and I think the reason he let me go on that thingy is because he see how much joy * really bring into my life, and he share that joy with us."*

This particular interaction represents the intimate dance that is theorised above:

*P2: "Wonderful, wonderful, it's so amazing that my daughter will come out of school and she will say 'hi mommy', she will just kiss me on my cheek. My son will come out of school, 'good afternoon mommy', walk past me but * will come out of crèche and she will, come in by the door and from the door, she will say 'mommy, hi mommy!' And she will come and she will hug me and if I'm busy baking and I can't bend to kiss her, she will kiss my leg and what more do you want from a child like that."*

Theorists have described how this particular pattern of bonding with your child, contributes to their future of relating, interacting and performing at their peak capacity (Greenspan and Wielder, 1998:107; Mundy *et al.*, 1988:107). Participants described their child's capacities in these areas which is a reflection of the attachment between mother and child:

*P4: "You can show * something once and she tries it immediately."*

Venuti *et al.* (2008:136) state that this construct of parent-child emotional availability (EA) has to date only been investigated in typically developing children, but not in children with DS, and they thus argue that research into the mother-child emotional availability, could be important to understand the cognitive development of children with DS.

Participants highlighted experiences of bonding between their child with DS and others:

*P4: “You won’t say there’s anything wrong with * when you see her with them. They hug each other and last week this grandmother stopped and picked us up and normally * takes her sisters hand, but she took her friend’s hand and they walked into school together.”*

*P4: “Last night her daddy didn’t come home, she calls him *, and says, ‘come now *, come now’”. The last evening he came home late, she sat by the window for an hour, ‘come now *, please come now’. When she saw the car in the distance, she jumped up, ‘*, come now, *, come come!’”*

Participants highlighted the relationship their child has with extended family and siblings:

P5: “My eldest son, he wasn’t at home, he was 16 then in JHB. He was all negative but now he calls to say ‘mommy what is he doing, what is he wearing? I can’t wait to get home, is he walking? I can’t wait to chase him and catch him’. You know he is supposed to start talking now, he calls his father and he calls me, but nothing else. My one son in JHB, he mentions his name, but the rest he doesn’t. That’s amazing because he only comes home thrice and he remembers his name but not the others.”

This experience correlates with statistics in literature on siblings of a child with DS. Family cognitive processes of DS persons, is revealed through a parallel study which was conducted on 822 siblings of DS people. The majority of these siblings highlight their feeling of affection toward their sibling with DS and expressed a feeling of pride in their sibling with DS; while very few expressed a feeling of embarrassment, and a minority communicated that they would rather have a sibling without DS. The majority of older siblings expressed a sense of being a better person as a result of having a sibling with DS, and shared that they want to continue being involved throughout their sibling’s life (Skotko *et al.*, 2011b:2349).

In addition, Barr and Shields (2011:1028) reflect that the facilitator of the child with DS participation in activity is the positive role of the family, encouragement and involvement themselves, that had a huge influence on the child with DS's physical activity, participation, cognitive functioning, social interaction and self-esteem. This may explain the impact that the son of participant 5 had on his sibling with DS, who remembered his name.

3.5.2 Changes in perception through experience

The benefits of having positive perceptions of DS according to Gupta and Singhal (2004:30) extend to benefiting the family unit as a whole. Their understanding through research has led to the view that the development of positive perceptions is a process that occurs through coping, and that these positive perceptions continue to act as a coping strategy in the face of stressors in parenting a child with a disability.

In relation to this positive psychology theory, participants in this study, expressed how their experiences of overcoming the many difficulties and challenges of the condition through the coping mechanisms discussed above, led to a change in their view or perception of what DS means for their child and what the experience of being a mother of a child with DS is like. The categories that led to this sub theme of changes in perception through experience are:

- Knowledge
- Development of child
- Positive approach of others

These categories are parallel to the categories under positive experiences which include receiving resources that increased their knowledge, receiving support from the TL for the development of their child and exposed them to seeing that there are other mothers whose children have DS, and lastly receiving the positive approaches from others through these sources of support.

These categories highlight a contribution to a change in the participants' perceptions as each contributor instilled hope and understanding in them, which became the positive lens for their situation.

3.5.2.1 Knowledge

In this section, knowledge correlates with “Resources” (page 19). Knowledge received through various media and through seeing their own child as well as others, has shown to equip mothers and develop hope.

P2: “When I got all the information, I realise there is hope for my child.”

*P3: “Because of * that changed...today you can handle it, today you can understand it”*

*P4: “So I said he must meet me at the TL. We were sitting down together and * came in and started to talk. He was so amazed, she is his beacon of hope. He is so over * because she gave him hope, that * can be like that, we don’t need to worry if she can be like that.”*

Robin Steel, the coordinator of Cincinnati Adoption Awareness Program, confirms the need for parents to receive this hope, as some birth parents fear that their child won’t live long (Gulli, 2006). Attaining this knowledge of up-to date information and hopeful, positive experiences has helped mothers view their situation differently. In agreement, Cunningham (2006:2) emphasises the need for mothers to receive information which helps them experience their situation more positively. A mother in his study reported that as she gained more knowledge about her baby’s condition, she felt she understood her baby better which brought her closer to her baby. Skotko (2011b:2348) himself, a genetic researcher and brother of a sister with DS, highlights the importance of families receiving the correct, unbiased information, with the knowledge that one can have a fulfilling and rewarding experience while rearing a child with DS. Skotko (2011b:2348) further shares that people do have misperceptions about what it means to have DS, but that research shows that families have shared that they feel and have experienced life to be positive with DS. A mother in Cunningham’s (2006:1) research expressed her experience that shifted from a difficult to a positive experience: “You just have to get as many answers to the questions that go around your head as you can...you need to do this as soon as you can so you can get through the worrying and puzzling...you find when you get some information, you can see just how silly the worrying was...you know once I got over all the shock and worrying and just helped him, things changed. I got to know him and I can truthfully say I’ve had a lot of joy these last few years”.

The findings of mothers adjusting to the many challenges of the condition correspond with Gupta and Singhal's (2004:27) finding on the successful development of positive perceptions in families of a child with a disability.

In correspondence, the participants in this study expressed that in retrospect if they knew then, when their child was diagnosed with DS, what they know now about DS, that it is merely a delay in their child's development, they would not have gone through the process of grieving.

P5: "But If I look back at it, it was totally unnecessary; it's only been a joy after that, after some time, obviously. It didn't take me long to accept it. You know the quicker you accept it, it's much better for you, I find. So it's really for me it's a waste of time, ok I think you need your grieving stages. Because first you get angry, because 'why is God doing this to me, why did this happen to me, it always happens to other people, why me this time?', you frustrated. So it's first the anger you deal with and then it's the, you have to go to your phases, and then the acceptance comes. Because you accept you can't do anything about it and then once you get there, everything becomes so much easier. You know cry about it, go there, get angry, I wouldn't say it's a waste of time, because it helps you to heal, you should have your grieving stages, just don't take too long."

Most *et al.* (2006:512) suggests that professionals should increase their knowledge and skills to support and prepare parents to understand and seek the relevant support regarding their child's behaviour. This may contribute to emotionally adapting to their child's development and ultimately decreasing levels of stress (Most *et al.*, 2006:512). Furthermore, they argue that adequate awareness of a child with DS's behavioural phenotype could contribute to supporting the families' experiences from an early stage (Most *et al.*, 2006:513).

In light of mothers' comments and findings by Most *et al.* (2006) gaining knowledge of up-to date information in a hopeful and positive manner, may eliminate the emotions of grieving for a mother of a child with DS who sees her situation through a positive perception, from the very beginning.

3.5.2.2 Development of child

Participants were surprised to see their child progress so well in all areas of their developmental milestones, despite having a delay. They felt a sense of achievement to witness their child overcoming the delay and achieving growth in each area. Participants spoke about how surprised they were to see their child being so intelligent when it came to understanding everything they said, and remembering such details and furthermore how they could actually be disciplined because they understood when teaching them manners. These factors changed perceptions because mothers had a perception that children with DS would be very limited in their development, would be “stupid” [quoted from participant 1] and would behave badly and out of control because it wouldn’t be possible to educate them with manners. These developmental stages of their child contributed to the mothers’ positive experiences of their child. This was very contrary to what they were told by professionals, specifically doctors who shared a negative perspective about having a child with DS, and the community perceptions, as well as what they saw from children with DS in the past.

P4: “...and seeing her grow just gave me hope....”

“I looked at the cover and thought oh my, she remembered this from last year, because the cover is “push chair”. I thought oh my child is so clever. She remembered this from last year. She remembers words, she can identify her name and she reads the magazines.

I think it’s mostly when you see how they progress and how they can do things. They themselves, fill you up. It’s like, “ can do that!” and you feel so ecstatic, so filled. It gets fuller and fuller every time they can do something new, or something on their own.”*

*P2: “but I think after the op, I just could see progress in * and I think the more the time was going by, I got more relaxed and relaxed and today I think of * and I forget about the word Down Syndrome because see her as one of my other kids. The word Down Syndrome, although we know, we are not in denial, we know she is Down Syndrome but we don’t use the word Down Syndrome in our house because she is growing up like her brother and her sister.”*

The mothers’ awareness of the child with DS’s ability to be disciplined in their development process, contributes to positive attitudes toward their child with DS.

P5: *“It is important to discipline them, that’s the most important, because you don’t want to go into public places and they embarrass you. Or you think it’s not an embarrassment, because they supposed to act like this, because you don’t know you can discipline them, but I can see you can discipline them.”*

P2: *“Even though I know a lot of Down Syndrome’s I get them in the mall where they 13, 14 and they walk with this teddy bear or thing and I said to myself I’m not going to let * do this. If you do have a special doll which she has and it’s Barney and a doll without hair, we call it pinky, they stay at home. She has to be on her own, she has to walk next to me. When we walk in the mall, I don’t keep her hand. I watch her but I want to let her grow up independent.”*

Another contributor toward mother’s positive perceptions about their child with DS is that the focus of children with DS seems to be more on their abilities than their disabilities, which is evident in the reported positive experiences, medical intervention, rate of adoption and acceptance by society (Phillips, 2007:28). This has an impact on mother’s perceptions of their child with DS, as it develops hope, increases coping and acceptance of their child. According to Docherty and Reid (2009:459) the parents attitudes and expectations may sustain the relationship between parent and child and thus contribute to the restrain of a transition to independent adulthood for the child.

3.5.2.3 Positive approaches of others

Literature reveals that the meaning of DS is culturally embedded and that mothers of a child with DS find their meaning and develop perceptions of their child’s disability from the social environment (Dabrowska & Pisula. 2010: 276; Hastings *et al.*, 2009:610).

Mothers in this study emphasised that gaining support and positive responses from others was important for their coping and perception of their situation of having a child with DS.

P5: *“You can see who’s positive, who acts positive toward him and be with them if you not positive, so that you can adopt that. Eventually it will get better.”*

P2: *“They will say when they see this child, this child is so clever and I will just say thank you. I think the community see that Down Syndrome is not really that bad when they see * or when they see other Downs Syndromes, it’s not really that bad.”*

P2: “If that support wasn’t in place at the TL clinic, I wouldn’t be here where I am now. Because you needed support and people to talk to who are positive. My husband can tell me to be positive but that’s one person, all the little bits help.”

Seligman *et al.* (2005:5), in accordance with other positive psychology theorists, share evidence that positive strategies and beliefs can serve as a resource in the face of adversity. They fuel psychological resilience and also decrease depressive symptoms. Literature in correspondence with the experiences of these participants, highlight that hope for this situation is needed and that coping with the condition can be achieved which ultimately can lead to a positive experience as these participants testify.

P2: “The first thing when I meet mothers who come, or come to Toy Library, and I’m here, I will tell them: ‘congratulations on this beautiful bundle of joy’. That’s my first words, I will always tell them and the second thing is I will tell them ‘don’t worry, there is hope for them, it’s gonna be alright’ and when I use that words I will see that mothers relax and they will start talking back to me.”

3.6 SUMMARY

This chapter discussed the method whereby the findings of the research were attained, compiled and then analysed. An examination of the themes and categories of the findings was presented; the overarching themes were that of the difficult versus the positive experiences of mothers of a child with DS. Quotes from the study’s participants were often deemed as best capturing the findings and so were presented and analysed together with extracts and commentary upon past and present literature on the topic (as introduced in Chapter Two).

The next chapter provides conclusions and recommendations from both the participants and author as based upon the study’s findings.

CHAPTER 4

CONCLUSIONS AND RECOMMENDATIONS

4.1 INTRODUCTION

This chapter offers conclusions derived from the findings presented in Chapter Three. Conclusions concerning both the difficult and positive experiences of mothers of a child with DS are given. Lastly, this chapter provides recommendations from both the participants as well as from myself, the researcher.

4.2 CONCLUSIONS WITH REGARD TO THE OBJECTIVES OF THE STUDY

The goal of this study was to explore and describe the positive experiences of mothers of a child with DS. I consider this goal achieved as I explored the topic through interviewing five participants who described their experiences as mothers of a child with DS. In light of the exploration I conclude that mothers of a child with DS experience many difficult experiences as well as positive experiences with regard to being the mother of a child with DS. I further conclude in accordance with positive psychology, that the findings on positive experiences of mothers of a child with DS, namely the strengths they discover through the challenges; the meaning they acquire to serve and sacrifice with their faith; the increased interaction the mothers have with people in support groups, TL Clinics, and family, and the increased joy they report to experience, all correlate with the three realms that positive psychologists use to measure happiness, specifically, meaning, engagement, and positive emotion. Positive psychology theorise that a life oriented around these three realms yields satisfied people. I would therefore make the conclusion, in accordance with this positive psychology theory, and in response to the research question, that mothers of a child with DS experience happiness. The goal of describing these positive experiences has been achieved through my presentation of these findings in Chapter Three. The conclusions, as rooted in the findings, that mothers of a child with DS experience both difficult and positive aspects, will be discussed next..

4.3 CONCLUSIONS WITH REGARD TO DIFFICULT EXPERIENCES

The findings of this study lead me to conclude that mothers of a child with DS experience difficulties with regard to having to adjust to a situation which includes: unpredictable health

implications; developmental delays; their and other people's perceptions; and perceived unprofessional conduct. The following bulleted list presents my conclusions in this regard:

4.3.1 Adjusting to having a child with DS

- It is apparent that mothers of a child with DS have to adjust to **unpredictable health complications** in terms of their child's health. These health implications include (but are not limited to) the heart problems; respiratory problems, and breastfeeding issues. These adjustments require many sacrifices on the part of the mother. She may well need to make a sacrifice of time, work and/or certain relationships in order to build a bond with her baby while the latter is being monitored in hospital.
- Children with DS face many developmental delays, which are generally noticed when they are toddlers. The **delays in development** place an additional demand on the mother, who will need to regularly attend early childhood intervention programmes and also display patience in stimulating her child more often than is required with a child without DS.
- There exists a **misperception** about DS, including the mental picture one may have of a child with DS, what DS is and what it means for your child, contributes to the difficulty of adjusting to having a child with DS. These misperceptions are drawn from outdated information on DS, past situations where people with DS had short life spans, uncontrolled behaviour, were institutionalised, chronically ill, and isolated with no future because they didn't develop properly. This lack of awareness about updated information on the diagnosis, contributes to mothers' emotional experiences and furthermore, the inability to accept the diagnosis.
- It is further concluded that sibling rivalry does occur in families containing a child with DS, generally because more attention and time is given to the baby with DS. It is important for the parents to allow the normally developing siblings the time to go through their own process of adjustment while also giving them attention as well as support in their acceptance of and involvement with their sibling with DS.

- Mothers perceive healthcare professionals as offering **limited and/or unprofessional support** after the birth of their baby with DS. This view is derived from the participants' claims that healthcare professionals: have negative attitudes about disabilities (making inappropriate remarks during the diagnosis as well as afterwards); deliver the news of the diagnosis in both an insensitive and unethical manner; delay too long in confirming the diagnosis (during which time there is uncertainty as to what is happening and why the baby has been taken away for so long after birth); and provide outdated information on the experiences of having a baby with DS and what interventions are available.

4.3.2 Difficult emotional experiences

It has been concluded that mothers of children with DS experience emotions towards their situations including the dominant emotions of fear, aloneness and grieving.

- Mothers experience **fear** for their child's future, which is influenced by: (1) the outdated perception that is promoted by healthcare professionals of what DS entails; (2) fear over their child's limited lifespan, over him/her being ostracised, dependent, and unable to achieve much in life because of having a limited capacity; and (3) fear over not being there for their child if they are no longer available (such as through death).
- Mothers often experience feeling **alone** after hearing the diagnosis due to having limited counselling and preparation with regard to having a child with DS. In addition, not knowing that there are other mothers of a child with DS left them feeling alone.
- Mothers frequently experience a **grief**-like emotion, which includes feelings of anger, shock and disappointment that their child will not develop at the same pace as other children. Mothers want to protect their child from a world that may hurt or discriminate against their child because of the disability. Feelings of guilt are often experienced because mothers sometimes think it is their fault for bringing such a child into the world. Sometimes they feel embarrassment over their perceived failure to

bear a normal child. Mothers' misperceptions of what DS means, specifically that the child will prove to be stupid and sick, can lead to their experiencing emotions of anger towards God. They may well also enter into a state of **denial** for a time, during which they do not wish to hear about the diagnosis.

4.4 CONCLUSIONS WITH REGARD TO POSITIVE EXPERIENCES

As a result of my research I have concluded that the difficult experiences of the mothers were temporary because the mothers also reported positive experiences with their child. These positive experiences are found through various coping mechanisms and the development of a positive perception about their child. The common coping mechanisms included support, being resourceful, having faith in God, accepting the condition, bonding with their child and having a positive attitude. Mothers' positive experiences can also contribute to their positive perception of their child with DS, which in turn can be attributed to factors of knowledge, seeing the development of their child, and the positive approaches of other people. These coping mechanisms and perceptions helped them discover and encounter the positive experiences in being a mother of a child with DS.

4.4.1 Conclusions with regard to coping mechanisms

- The mothers found **support** from different sources, including professionals, husbands, counsellors, their community, other mothers of a child with DS and professional interventions. Positive attitudes from these sources toward their babies with DS helped the mothers to view their situation as a blessing. The Toy Library Clinic's intervention was supportive in helping mothers to see others who are going through the same experience and who can therefore empathise and also offer relevant and helpful suggestions. Furthermore, seeing older children and adults with DS in the clinic who have developed and show independence and relationship abilities is helpful in cultivating hope and altering perceptions of what it means to have DS and what they can potentially achieve in life. Receiving advice from professionals in the TL Clinic challenges the instinct to protect and isolate your child, as this ultimately hinders and limits their opportunities to interact with others and progress socially and developmentally.

- It is concluded that **resources** like reading pamphlets, searching the Internet, and receiving information from the TL Clinic helped the participants with understanding the diagnosis and helped to answer other people's and their own questions. This understanding and hearing the explanation of the genetic cause from the genetic counsellor helped relieve any feelings of guilt and gave them hope for their child's development.
- Mothers found **faith** to be an important means of support and a way of coping through the difficult times. Praying was used to ask for healing, for an increase of faith, for strength to hold on, for help through the emotions, and for acceptance of the child's condition.
- It is concluded that **acceptance** of the condition acts as a coping mechanism through difficult times, and assists with the sacrifices that are required. In addition their acceptance supported the responses of others toward being a mother and toward their child with DS.
- The mothers experienced that having a **positive attitude** toward their child with DS, ultimately helps them to have a positive outlook on situations involving their child and to be supportive of their child with DS.
- It is concluded that the mothers experienced the process of **bonding** with their baby with DS, despite health implications and delays. Even though there may be medical complications with breastfeeding, mothers are still able to form attachments. The bonding process also occurred between fathers and babies with DS. The child's relational ability with siblings, extended family and friends from crèche, depicts the foundational bond with the mother.

4.4.2 Conclusions with regard to changes in perceptions through experience

- Gaining **knowledge** of up-to date information in a positive manner instils hope in mothers and equips them to inform others about their child. Furthermore the

knowledge gained about the meaning of DS, and the experience of the joy their child brings, changes the perceptions about the need to grieve.

- It is concluded that the mothers experienced their child in a positive way and their perceptions were challenged and changed by seeing their **child develop** in terms of their potential, despite the developmental delay that is common to children with DS. The mothers gained hope for their child's future and in their child's ability to become independent and care for themselves.
- The mothers' fears regarding the negative perceptions about how family and communities would respond to the baby with DS were challenged and changed to a more positive experience of their child when they received more **positive responses** than negative responses.

5.4 RECOMMENDATIONS

The following recommendations are derived from the conclusions in the previous section:

5.4.1 Participants' recommendations to mothers of a child with DS

The main theme that the participants had in common for suggestions for other parents was to accept their child's condition. Participants in retrospect shared the most helpful coping mechanisms they had drawn on that led to a positive journey through their experience. The suggestions that participants agreed on were; to have support, to bond with their child, to persevere and to have awareness about their condition.

- The participants recommended that mothers should be *hopeful* for their child's health and development and *persevere* through prayer and *have faith* during the difficulties of their experience as a mother of a child with DS.
- The participants recommended that mothers take *one day at a time* and have a *positive attitude* toward the challenges they will encounter.

- The participants recommended that mothers should have *awareness* about the diagnosis and know that the most impactful *meaning* of the diagnosis is that their child will have a developmental delay, and that they should be encouraged to have hope for their child as they go through their developmental stages.
- The participants recommended that mothers be *patient* with their child, *love* their child, enjoy them and make *sacrifices* for them through the challenges.
- The participants recommended that mothers should understand that *they are not alone*. *Talking about it* does help, and furthermore that *interacting with other parents* is helpful. Suggestions were made that counselling support should be available to fathers to support their adjustment.
- The participants recommended that mothers should *get support on guidance to care for their child* from professionals and early childhood intervention clinics and *attend* all their hospital and TL Clinic appointments *regularly*.
- The participants recommended that mothers should see their child with DS in a positive light and be *around positive people* in order to be positive for themselves.
- The participants recommended that mothers *take time* to grieve if need be, and suggested that this period not be too long, so that they can be in *every moment* of the *blessed* and *joyous* experience with their child.

5.4.2 Researcher's recommendations

- I conclude that if mothers' perceptions of their child with DS were to change based on their receipt of accurate, up-to-date information on DS, they would cope better and be in a position to experience their situation more positively. It is therefore recommended that future mothers of a child with DS receive updated knowledge from professionals like doctors, nurses and social workers in the pre- and post-natal phases of their pregnancies.

- I recommend an early intervention protocol for professionals who are involved in the process and for contact with mothers giving birth to babies. This early intervention protocol aims for all professionals being on the same page about: the manner of how to go about detecting the typical features of DS; the manner of ethical confidentiality; the manner of informing the parents - not just the mother, but ensuring that the father is present for disclosure; specifically if it is only a suspicion, the manner of informing the parents of why the baby needs to be taken away and for how long; the health implications of the diagnosis; the medical advances; adequate and up-to-date information about the diagnosis; the testing procedure and timing required to confirm the diagnosis; the period of hospitalisation estimated; the support available; the emotional counselling available for both parents; and the professional manner of disclosure.
- I also recommend that a research project should be undertaken in order to establish such a protocol seeing that this research indicates the absence of such an early intervention protocol.
- I advise future mothers to make the effort to be a part of a community as a means of finding support and ultimately experiencing the situation more positively. By being around others who are accepting, positive, resourceful, and empathic, one can better cope with the situation.
- Mothers seem to adjust and accept the diagnosis once they have discovered through their positive experiences that the medical problems are relatively short-lived (generally only the first year or two of life). They discover that the diagnosis thereafter only relates to delays in their child's long term development. The researcher recommends that new mothers with the diagnosis of having a child with DS should become aware of these positive experiences, as set out in Table 3.2 under the main theme "Positive experiences", and make them part of their daily life to gain perspective through their experiences.
- These positive experiences could also be recorded for future mothers to read when they receive the diagnosis. This could be in the form of a pamphlet with quotes from

mothers willing to share their wisdom and encouragement about the difficulties, leaving mothers with a sense of hopefulness in their situation, even with the difficulties.

- The mothers in this study reported positive connections between their children with DS and themselves, as well as the father, siblings and extended family. They also reported achievements and progress in their children's development and interactions, which highlights a very interesting link to the literature regarding emotional availability in attachment determining a child's capacity. Furthermore, I would like to recommend, in accordance with the literature, the need for more studies on this topic so as to level out the degree of knowledge and understanding pertaining to disabled children with that pertaining to typically developing children. Scholars in the field appear to concur that further research into the mother-child emotional availability, could be important to understand the cognitive development of children with DS.
- Regarding the limitation of this study, mentioned on page 14, I would like to recommend that further research be done on this topic in the South African context, specifically regarding the statistics on abortion of babies with DS. Due to the limitation of this study to the experiences of mothers of children of an older age group, I recommend that research be carried out on this same topic with a focus on an older age group.

BIBLIOGRAPHY

Adnams, C. 2010. Perspectives of Intellectual Disability in South Africa: epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry*, 23:436-440.

Aucamp, L. 2010. Understanding attachment. Gauteng: FACT.

Babbie, E. & Mouton, J. 2001. The practice of social research. Cape Town: Oxford University Press.

Barr, M. & Shields, N. 2011. Identifying the barriers and facilitators to participation in physical activity for children with Down syndrome. *Journal of Intellectual Disability Research*, 55(11):1020-1033.

Bauer, E. 2008. Tennessee woman among oldest with Down syndrome.
<http://www.patriciaebauer.com/2008/04/30/tennessee-woman-among-oldest-with-down-syndrome-2037> Date of access: 06 December 2012.

Biringen, Z. 2000. Emotional availability: conceptualization and research findings. *American Journal of Orthopsychiatry*, 70:104-114.

Bittles, A.H., Bower, C., Hussain, R. & Glasson, E.J. 2007. The four ages of Down Syndrome. *European journal of public health*, 17(2):221-225.

Bornstein, M.H. 2003. Parenting and child development: intracultural and intercultural perspectives. (In Venuti, P., De Falco, S., Giusti, Z. & Bornstein, M. H. 2008. Play and emotional availability in children with Down Syndrome. *Infant Mental Health Journal*, 29(2):133-152.

Botma, Y., Greef, M., Mulaudzi, F.M. & Wright, S.C.D. 2010. Research in Health Sciences. Cape Town: Pearson Education.

Bowlby, J. 1988. A secure base. Clinical applications of attachment theory. London: Routledge.

Brown, K.B. 2012. Baby with Down Syndrome becomes prestigious model for fashion designer. http://www.lifesitenews.com/news/baby-with-down-syndrome-becomes-model-for-prestigious-fashion-designer?utm_source=LifeSiteNews.com+Daily+Newsletter&utm_campaign=dfdb47950c-LifeSiteNews_com_Intl_Headlines_08_07_2012&utm_medium=email Date of access: 08 August 2012.

Bruner, J. 1983. Child's talk: learning to use language. (In Venuti, P., De Falco, S., Giusti, Z. & Bornstein, M. H. 2008. Play and emotional availability in children with Down Syndrome. *Infant Mental Health Journal*, 29(2):133-152).

Chen, H. 2009. Down Syndrome. <http://emedicine.medscape.com/article/943216-overview> Date of access: 25 October 2012.

Cherry, K. 2013. What is positive psychology: a brief overview of the field of positive psychology. *About.com Psychology Guide*.
<http://psychology.about.com/od/branchesofpsycholog1/a/positive-psychology.htm> Date of visit: 12 May 2013.

Christianson, A.L. & Kromberg, J.G.R. 1996. Maternal non-recognition in black South African infants. *Clinical Genetics*, 49(3):141-144.

Christianson, A.L. & Modell, B. 2004. Medical genetics in developing countries. *Annual Review of Genomics and Human Genetics*, 5:219-265.

Christianson, A.L., Zwane, M.E., Manga, P., Rosen, E., Venter, A., Downs, D. & Kromberg, J.G.R. 2002. Children with intellectual disability in rural South Africa: prevalence and associated disability. *Journal of Intellectual Disabilities*, 46:179-186.

Creswell, J.W. 2008. Educational research. 3rd ed. New Jersey: Pearson Education.

Coppus, A.M., Evenhuis, H.M. & Verberne, G.J. 2008. Survival in elderly persons with Down syndrome. *Journal of American Geriatrics Society*, 56:2311-2316.

Cunningham, C.C. 2006. Down Syndrome: an introduction for parents and caregivers. Souvenir Press, USA.

Cunningham, C.C., Glenn, S. & Fitzpatrick, H. 2000. Parents telling their offspring about Down Syndrome and disability. *Journal of Applied Research in Intellectual Disabilities*. 13(2):47-61. (Abstract).

Dabrowska, A. & Pisula, E. 2010. Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3):266-280.

De Falco, S., Esposito, G., Venuti, P. & Bornstein, M.H. 2010. Mothers and fathers at play with their children with Down Syndrome: influence on child exploratory and symbolic play. *Journal of Applied Research in Intellectual Disabilities*, 23:597-605.

De Vos, A.S. & Delpont, C.S.L. 2011. Professional research and professional practice. (In De Vos, A.S., Strydom, H., Fouche, C.B. & Delpont, C.S.L. eds. *Research at Grass Roots: for the social sciences and human service professions*. 4th ed. Pretoria: Van Schaik. p. 49-54).

Dixon, D.P. 2008. Informed consent or institutionalized eugenics? How the medical profession encourages abortion of fetuses with Down Syndrome. *Law and medicine*, 24(1):2-59.

Docherty, J. & Reid, K. 2009. 'What's the Next Stage?' Mothers of young adults with Down Syndrome explore the path to independence: a qualitative investigation. *Journal of Applied Research in Intellectual Disabilities*, 22:458-467.

"Down Syndrome". *A dictionary of nursing online*. 2008. Columbia: Encyclopedia.com. <http://www.encyclopedia.com> Date of access: 08 October 2012.

"Down Syndrome". *Gale Encyclopedia of psychology online*. 2001. Columbia: Encyclopedia.com. <http://www.encyclopedia.com> Date of access: 19 October 2012.

DSAOM (Down Syndrome Association of Miami). 2012. Designer Dolores Cortes chooses a Miami girl with Down Syndrome, Valentina Guerrero, for the cover of their catalogue. <http://www.dsaom.org/news-article/2012/07/designer-dolores-cortes-chooses-miami-girl-down-syndrome-valentina-guerrero> Date of access: 17 October 2012.

Eisenhower, A.S., Baker, B.L. & Blacher, J. 2005. Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, 49(9):657-671.

Farah, S. & Dilla, R. 2004. Socialization development of Down Syndrome children and its relationship with the parents and caregiver. (In Norizan, A. & Shamsuddin, K. 2010. Predictors of parenting stress among Malaysian mothers of children with Down Syndrome. *Journal of Intellectual Disability Research*, 54(11):992-1003).

Fiano, C. 2012a. More Parents Come Forward with a Wrongful Birth Suit, Would Have Aborted Their Daughter. *Live Action News*, 1 July. <http://liveactionnews.org/opinion/more-parents-come-forward-with-a-wrongful-birth-suit/> Date of access: 30 July 2012.

Fiano, C. 2012b. Now Down Syndrome is broken DNA? *Live Action News*, 28 May. <http://liveactionnews.org/human-rights/now-down-syndrome-is-broken-dna/> Date of Access: 30 July 2012.

Fidler, D.J. 2005. The emerging Down Syndrome behavioural phenotype in early childhood. *Infants and Young Children*, 18(2):86-103.

Fidler, D.J., Hodapp, R.M., Ly, T.M. & Ricci, L.A. 2001. Less stress more rewarding: parenting children with DS. *Parenting: Science and Practice*, 1(4):317-337.

Firth, H.V., Hurst, J.A. & Hall, J.G. 2007. Oxford desk reference: clinical genetics. New York: Oxford University Press.

- Flaherty, E.M. & Glidden, L.M. 2000. Positive adjustments in rearing a child with Down Syndrome. *Early Education and Development*, 11(4):407-422.
- Fouché, C.B. & Schurink, W. 2011. Qualitative research designs. (In De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. eds. *Research at Grass Roots: for the social sciences and human service professions*. 4th ed. Pretoria: Van Schaik. p. 307-327).
- Freedman, R.I. & Boyer, N.C. 2000. The power to choose: supports for families caring for individuals with developmental disabilities. *Health Social Work*, 25(1):59-68. (Abstract).
- Gammons, S., Sooben, R.J. & Heslam, S. 2010. Support and information about Down Syndrome. *British Journal of Midwifery*, 18(11):700-708.
- Gilmore, L., Cuskelly, M., Jobling, A. & Hayes, A. 2009. Maternal support for autonomy: relationships with persistence for children with Down syndrome and typically developing children. *Research in Developmental Disabilities*, 30(5):1023-1033.
- Gordon, A., Benda, C.E., Böök, J.A., Carter, C.O., Ford, C.E., Chu, E.H.Y., Hanhart, George Jervis, E., Langdon-Down, W., Lejeune, J., Nishimura, H., Oster, J., Penrose, L.S., Polani, P.E., Potter, E.L., Stern, C., Turpin, R., Warkany, J. & Yannet, H. 1961. Mongolism [letter to the editor]. *American Journal of Human Genetics*, 13(4):426.
- Graham, T.K. & Scudder, R.R. 2007. Parent interactions with twins who are developmentally different: a case study. *Communication Disorders Quarterly*, 28(2):107-115.
- Greenspan, S.I. & Wieder, S. 1998. The child with special needs. (In Venuti, P., De Falco, S., Z. Giusti, Z. & Bornstein, M. H. 2008. Play and emotional availability in children with Down Syndrome. *Infant Mental Health Journal*, 29(2):133-152).
- Gupta, A. & Singhal, N. 2004. Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal*, 15(1):22-3.
- Gulli, C. 2006. A demand for Down Syndrome. *Maclaens*, 119(15):39.

Hart, B. & Risley, T.R. 1999. The social world of children learning to talk. (In Venuti, P., De Falco, S., Giusti, Z. & Bornstein, M. H. 2008. Play and emotional availability in children with Down Syndrome. *Infant Mental Health Journal*, 29(2):133-152).

Hassall, R. & Rose, J. 2005. Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability. *Behavioural and Cognitive Psychotherapy*, 33:71-88. (Abstract).

Hastings, R.P. & Taunt, H.M. 2002. Positive perceptions in families of children with Developmental Disabilities. *American Journal on Mental Retardation*, 107(2):116-127. (Abstract).

Hastings, R.P., Griffith, G.M., Nash, S. & Hill, C. 2009. Using matched groups to explore child behaviour problems and maternal well-being in children with Down Syndrome and Autism. *Journal of Autism Developmental Disorder*, 40:610-619.

Kandari, H.Y. & Qashan, H. 2009. Maternal self-efficacy in mothers of children with intellectual disabilities, Down Syndrome and autism in Kuwait. *Child Adolescent Social Work Journal*, 27:21-29.

Kidder, C.S. & Skotko, B.G. 2001. Common threads: celebrating life with Down Syndrome. Rochester Hills: Band of Angels Press.

Klein, M. 1959. Our adult world and its roots in infancy. *Human Behaviour*, 12:291-303.

Lalvani, P. 2008. Mothers of children with Down Syndrome: constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities*, 46(6):436-445.

Lam, L.W. & Mackenzie, A.E. 2002. Coping with a child with Down Syndrome: the experiences of mothers in Hong Kong. *Qualitative health research*, 12(2):223-237.

Lampret, J.C. & Christianson, A. 2007. Reproductive choices made by South African mothers who have a child with Down syndrome. *South African Journal of Medicine*, 97(7):1-98.

Leedy, P.D. & Omrad, J.E. 2005. Practical research: planning and design. (In De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L., eds. Research at Grass Roots: for the social sciences and human service professions. 4th ed. Pretoria: Van Schaik. p. 64).

Lenard, W., Erwin, B., Harald, E., Joachim, S.H., Klaus, D.Z. & Wolfram, H. 2007. Attitudes of mothers towards their child with Down Syndrome before and after the introduction of prenatal diagnosis. *Intellectual and Developmental Disabilities*, 45(2):98-102. (Abstract).

Leonard, S., Bower, C., Petterson, B. & Leonard, H. 2000. Survival of infants born with Down's syndrome: 1980-96. *Paediatric Perinatal Epidemiology*, 14(2):163-71. (Abstract).

Lloyd, T. & Hastings, R.P. 2008. Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research*, 52(1):37-48.

Macrae, F. 2011. Hope for Down's Syndrome children as blood pressure drug shown to improve mental skills. <http://www.dailymail.co.uk/health/article-1228965/Hope-Downs-Syndrome-children-blood-pressure-drug-shown-improve-mental-abilities.html> Date of access: 14 November 2012.

Mahler, M. 1972. On the first three subphases of separation-individuation. *International Journal of Psychoanalysis*, 53:333-338.

Marder, E. & Dennis, J. 1997. Medical management of children with Down's syndrome. *Current Paediatrics*, 7:1-7.

Maree, K. 2007. First steps in research. Pretoria: Van Schaik.

Maree, K. & Van der Westuizen, S. 2007. Planning a research proposal. (In Maree, K. First steps in research. Pretoria: Van Schaik. p. 40-48).

Moeller, I. 2005. Just a bit different. *Scientific American Mind*, 16(3).

Molteno, C., Smart, R., Viljoen, D., Sayed R. & Roux, A. 1997. Twenty-year birth prevalence of Down syndrome in Cape Town, South Africa. *Paediatric Perinatal Epidemiology*, 11(4):428-435.

Morris, J.K. & Alberman, E. 2009. Trends in Down's syndrome live births and antenatal diagnoses in England and Wales from 1989 to 2008: analysis of data from the National Down Syndrome Cytogenetic Register. (In Gammons, S., Sooben, R.J. & Heslam, S. 2010. Support and information about Down Syndrome. *British Journal of Midwifery*, 18(11):700-708.

Most D. E., Fidler D. J., LaForce-Booth, C. & Kelly, J. 2006. Stress trajectories in mothers of young children with Down syndrome. *Journal of Intellectual Disability Research*, 50(7):501-514.

Mundy, P., Sigman, M., Kasari, C. & Yirmiya, N. 1988. Nonverbal communication skills in Down syndrome children. (In Graham, T.K. & Scudder, R.R. 2007. Parent interactions with twins who are developmentally different: a case study. *Communication Disorders Quarterly*, 28(2):107-115.

Naidoo, H., Aldous, C., Ramdhani, H., Winship, W., Henriques, N. & Kormuth, E. 2011. Down syndrome in paediatric outpatient wards at Durban hospitals: scientific letter. *South African Medical Journal*, 101(1):27-28. (Abstract).

National Institute for Health and Clinical Excellence. 2008. Antenatal care: routine care for the healthy pregnant woman. NICE, London.

<http://www.nice.org.uk/nicemedia/pdf/CG062NICEguideline.pdf>. Date of access: 24 January 2013.

Nicol, C. 2008. At home with Down Syndrome. *The new Atlantis, a Journal of Technology and Society*, 143-152. <http://www.thenewatlantis.com/publications/at-home-with-down-syndrome>. Date of access: 11 August 2012.

Norizan, A. & Shamsuddin, K. 2010. Predictors of parenting stress among Malaysian mothers of children with Down Syndrome. *Journal of Intellectual Disability Research*, 54(11):992-1003.

Norton, T. 1999. Nutrition study brings new hope for Down's syndrome mothers. <http://www.independent.co.uk/news/nutrition-study-brings-new-hope-for-downs-syndrome-mothers-1123181.html> Date of access: 13 November 2012.

NWU (North West University). 2012. Referencing guide. <http://www.nwu.ac.za/sites/default/files/files/library/documents/verwysings.pdf> Date of access: 12 March 2012.

Pancevski, B. 2006. Doctors must pay child support after inadequate warning of disability. *British Medical Journal (International Edition)*, 333(7560):168-168. (Abstract).

Patterson, B. 2002. Behavioral concerns in persons with Down Syndrome. (In Cohen, W. I., Nadel, L. & Madnick, M. E., (eds). *Vision for the 21st Century Down Syndrome*. Wiley-Liss Inc., New York: 215-219).

Pelchat, D., Lefebvre, H. & Perreault, M. 2003. Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care*, 7(4):231-247.

Peterson, C. 2013. *Pursuing the good life: 100 reflections on positive psychology*. Oxford University Press, USA.

Philips, L. 2007. Nia's Story. *Learning Disability Practice*, 10(5):28-35.

Pino, O. 2000. The effect of context on mother's interaction style with Down's syndrome and typically developing children. *Research in Developmental Disabilities*, 21:329-346.

Reichman, N.E., Corman, H. & Noonan, K. 2008. Impact of child disability on the family. *Maternal and Child Health Journal*, 12:679-83.

Roizen, N.J. 2001. Down Syndrome. (In Batshaw, M. L. & Paul, H., *ed.* When your child has a disability. Brookes Publishing, Baltimore, MD).

Ross, E. & Deverell, A. 2010. Health, illness and disability. *Psychosocial approaches*. 2nd ed. Pretoria: Van Schaik Publishers.

Saheli, A. 2009. Hopes high that Down Syndrome could be reversed.
<http://www.perthnow.com.au/news/special-features/hopes-high-that-down-syndrome-could-be-reversed/story-e6frg1ac-1225799618783> Date of access: 02 October 2012.

Saloviita, T., Itälinna, M. & Leinonen, E. 2003. Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. *Journal of intellectual disability research*, 47(4-5):300-312. (Abstract).

Sari, H.Y., Baser, G. & Turan, J.M. 2006. Experiences of mothers of children with Down Syndrome. *Pediatric nursing*, 18(4):29-32. (Abstract).

Schore, A. 2001. The effects of secure attachment on right brain development, affect regulation and infant mental health. *Infant Mental Health Journal*, 22(1-2): 7-66.

Seidman, I. 1998. Interviewing as qualitative research: a guide for researchers in education and the social science. (In De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L., *eds.* Research at Grass Roots: for the social sciences and human service professions. 4th ed. Pretoria: Van Schaik. p. 342).

Seligman, M.E.P. & Csikszentmihaylyi, M. 2000. Positive psychology: an introduction. *American Psychologist*, 55(1):5-14.

Seligman, M.E.P., Steen, T, Park, N. & Peterson, C. 2005. Positive psychology progress: empirical validation of interventions. *American Psychologist*, 60(5):410-421.

Seligman, M.E.P., Ernst, R.M., Gilham, J., Reivich, K. & Linkins, M. 2009. Positive education: positive education and classroom interventions. *Oxford Review of Education*, 35(3):293-311.

Sharp, K. & Frey, R. 2006. Down Syndrome. (In Gale Encyclopedia of Medicine. 3rd Ed. http://www.encyclopedia.com/topic/Down_syndrome.aspx Date of access: 19 Nov. 2011).

Sheets, K.B., Crissman, B.G., Feist, C.D., Sell, S.L., Johnson, L.R., Donahue, K.C., Masser-Frye, D., Brookshire, G.S., Carre, A.M., LaGrave, D. & Brasington, C.K. 2011. Practice guidelines for communicating in prenatal or postnatal diagnosis of Down Syndrome: recommendations of the National Society of Genetic Counsellors. *Journal of Genetic Counselling*, 20(5):432-441.

Silvers, A. 1998. Formal Justice. (In Silvers, A., Wasserman, D. & Mahowald, M.B. *Disability, Difference, Discrimination. Perspectives on bioethics and public policy*. USA: Rowand and Littlefield Publishers, 13-145)

Skotko, B. 2005. Mothers of children with Down Syndrome reflect on their postnatal support. *Pediatrics*, 115(1):64-77.

Skotko, B.G., Capone, G.T. & Kishnani, P.S. 2009. Postnatal diagnosis of Down Syndrome: synthesis of the evidence on how best to deliver the news. *Pediatrics*, 124(4):751-758.

Skotko, B.G., Levine, S.P. & Goldstein, R. 2011a. Self-perceptions from people with Down Syndrome. *American Journal of Medical Genetics. Part A*, 155(10):2360-2369.

Skotko, B.G., Levine, S.P. & Goldstein, R. 2011b. Having a brother or sister with Down Syndrome: perspectives from siblings. *American Journal of Medical Genetics. Part A*, 155(10):2348-2359.

Sooben, D.R. 2012. Breastfeeding patterns in infants with Down Syndrome: a literature review. *British Journal of Midwifery*, 20(3):187-192.

Staff. 2008. New hope for Down Syndrome. *New Scientist*, 199(2684):5. (Abstract).

Stewart, L., Einfeld, M.D. & Brown, R. 2010. Down Syndrome – New perspectives for an ancient disorder. *Journal of American Medical Association*, 303(24):2525-2526.

Stoneman, Z. 2007. Examining the Down Syndrome advantage: mothers and fathers of young children with disabilities. *Journal of Intellectual Disabilities*, 51(12):1006-1017.

Suhail, K. & Fatima, I. 2010. Belief in a just world and subjective well-being: mothers of normal and Down Syndrome children. *International Journal of Psychology*, 45(6):461-468.

Taylor, K.H. 2011. Down Syndrome rewards touted as new test looms.
NBC News. 29 Sept. http://www.nbcnews.com/id/44703812/ns/health-health_care/t/down-syndromes-rewards-touted-new-test-looms/ Date of access: 15 April.

Taylor, J.Y., Washington, O. G. M., Artinian, N.T. & Lichtenberg, P. 2007. Parental stress among African American parents and grandparents. *Issues in Mental Health Nursing*, 28:373-87.

Tesh, R. 1990. Qualitative research: analysis types and software tools. (In Creswell, J.W. 2008. Educational research. 3rd ed. New Jersey: Pearson Education).

Trevarthen, C. & Aitken, K.J. 2001. Infant intersubjectivity: Research, theory and clinical applications. *Journal of Child Psychology and Psychiatry*, 42:3-48.

Ulrich, D.A., Ulrich, B.D., Kinzler, R.M. & Yun, J. 2001. Treadmill Training of Infants with Down Syndrome: Evidence-Based Developmental Outcomes. *Paediatrics*, 108(5):84.

Van Cleve, S.N. & Cohen, W.I. 2006a. Part I: Clinical practice guidelines for children with Down Syndrome from birth to 12 years. *Journal of Pediatric Health Care*, 20(1):47-54.

Van Cleve, S.N. & Cohen, W.I. 2006b. Part II: Clinical practice guidelines for children with Down Syndrome for the adolescent and young adult with Down Syndrome. *Journal of pediatric health care*, 20(3):198-215.

Van Riper, M. 2007. Families of children with Down Syndrome: responding to “a change in plans” with resilience. *Journal of paediatric nursing*, 22(2):116-128. (Abstract).

Venuti, P., De Falco, S., Giusti, Z. & Bornstein, M. H. 2008. Play and emotional availability in children with Down Syndrome. *Infant Mental Health Journal*, 29(2):133-152.

Venuti, P., De Falco, S., Esposito, G. & Bornstein, M.H. 2009. Mother-child and father-child emotional availability in families of children with Down Syndrome. *Parenting: Science and Practice*, 9:198-215.

Wexler, I.S., Abu-Libdeh, A., Kastiel, Y., Nimrodi, A., Kerem, E. & Tenenbaum, A. 2009. Optimizing health care for individuals with Down syndrome in Israel. *Israel Medical Association Journal*, 11:655-658.

Winnicott, D.W. 1965. The family and individual development. London: Tavistock Publications.

Wordon, W.J. 2009. Grief counselling and grief therapy. A handbook for the health practitioner. 4th ed. Springer Publishing Company: New York, 37-52.

ADDENDUM A: ETHICAL CONSENT FORM

EXPLORING THE POSITIVE EXPERIENCES OF MOTHERS OF A CHILD WITH DOWN SYNDROME IN THE WESTERN CAPE

STATEMENT BY PARTICIPANT

I,, living at
(address)
confirm that:

1. I have been invited to participate in the above research project which has been initiated through the Centre for Child, Youth and Family Studies, North-West University, because I have a preschool child who has Down syndrome (DS) and attend the clinics and supportive services rendered at the Red Cross War Memorial Children's Hospital (RCWMCH).

2.1. I understand that the objective of this study is to investigate:

- The experiences of having a child with DS.

2.2. I understand that the interview will take place in room 9 of S6 at RCWMCH and that it may take one or two visits of an hour each.

2.3. I am aware that this is a once-off investigation that will take place between July to September 2012 at a time convenient to me and my family.

2.4. I understand that some of the questions may make me angry or sad, but the risks from the study are minimal. The researcher will refer me to a counsellor or they can ask for one, if necessary. She will show me respect, acceptance and empathy during the interview.

3.1. I have been assured that all information will be handled confidentially. Information may be used for a thesis, publication in scientific journals and presentations at professional congresses, but names will not be included.

3.2. I understand that the interview will be video-recorded so that the researcher does not have to write too much during the interview. The recordings will be stored in a safe until the research has been written up and will then be destroyed immediately.

4. I have been assured that the recorded and transcribed information discussed at the meeting will only be made available to the researcher's supervisors.

5. I have not been coerced to consent to taking part in the study and I have been informed that I may refuse to participate in this project and that I may stop participating at any stage, and that such refusal or stoppage will not negatively affect my current or future access to medical and counselling services to which I am entitled.

6. has explained the information of the study to me in English. I am proficient in that language and my questions have been answered satisfactorily.

7. I understand that there will be no medical benefits to me from this study.

8. I have been assured that participation in this project will not lead to additional costs for me or my family and I will not benefit from it financially.

I HEREBY DECLARE THAT I VOLUNTARILY AGREE TO PARTICIPATE IN THE ABOVE RESEARCH STUDY

Signed at: (address) on 2012

.....
Participant's signature

.....
Witness signature

I HEREBY DECLARE THAT I AGREE TO HAVE MY INTERVIEW VIDEO-RECORDED

Signed at: (address) on 2012

Participant's signature

Witness signature

ANNEXURE B: HOSPITAL RESEARCH APPROVAL



Dr TA Blake
Manager: Medical Services
Email: Thomas.Blake@pgwva.gov.za
Tel: +27 21 658 5788 Fax: +27 21 658 5166
3 August 2012

MS S CHETTY

RESEARCH APPLICATION

Dear Ms Chetty,

Your application to do research at the Red Cross War Memorial Children's Hospital is successful.
You may proceed.

Yours faithfully,

A handwritten signature in black ink, appearing to read "T Blake".

Dr Thomas Blake
Manager: Medical Services

www.westerncape.gov.za