

**EXPLORING THE WELL-BEING OF CAREGIVERS OF A FAMILY MEMBER  
WITH DOWN SYNDROME IN NAMIBIA**

**THESIS SUBMITTED IN PARTIAL FULFILMENT OF**

**THE REQUIREMENTS FOR THE DEGREE OF**

**MASTER OF ARTS IN**

**CLINICAL PSYCHOLOGY**

**OF**

**THE UNIVERSITY OF NAMIBIA**

**BY**

**Tanya A. Byleveldt**

**NOVEMBER 2013**

**Supervisor: Prof. S. Rothman**

## **ABSTRACT**

There is silence on Namibian families who have a member with Down syndrome (DS). Hence, research is needed regarding the experiences, stress and well-being of families who are caregivers of a family member with Down syndrome. This is important to parents who begin their married lives with a Down syndrome child in the family since it will provide them with a balanced perspective of what to expect. In addition, most studies on the experiences of caring for a Down syndrome were conducted outside the African context. No scientific information is available regarding the experiences and well-being of families as caregivers of Down syndrome children in Namibia. Furthermore, while studies have been carried out regarding the experiences of caregivers by utilising the disease model, no studies could be traced regarding the well-being of caregivers using a positive psychological paradigm.

The aim of this study was to explore the experiences and well-being of caregivers of a family member with Down syndrome in Namibia. A qualitative research design was used. The caregivers of children with Down syndrome were interviewed. The responses of participants were transcribed verbatim and themes were analysed.

Various themes emerged from this study about the caregivers' experiences and well-being when taking care of a family member with Down syndrome. The study further revealed that caregivers are faced with a variety of challenges such as having to dress, feed, bath and carry around their child because of delayed motor development. Some caregivers experience difficulties with finances, employment, differences with partners and claimed that they receive insufficient support from their families and the community, which affects their well-being. Despite the challenges and difficulties, caregivers accepted their child and learnt

through their experience compassion, humanity, patience, kindness, and forgiveness. Ultimately caregivers endure the hard times by relying on their spiritual beliefs.

The Ministry of Health and Social Services (the planning and policy division) should plan and implement programmes to promote the well-being of families who are giving care to a member with Down's syndrome. It is important that support groups be established in Namibia to provide friendship and emotional support to the caregivers.

Recommendations for future research were made.

## TABLE OF CONTENTS

<b>ABSTRACT.....</b>	<b>i</b>
<b>TABLE OF CONTENTS.....</b>	<b>iii</b>
<b>AKNOWLEDGEMENTS.....</b>	<b>ix</b>
<b>DEDICATION.....</b>	<b>x</b>
<b>DECLARATION.....</b>	<b>xi</b>
 <b>CHAPTER 1-INTRODUCTION.....</b>	 <b>1</b>
1.1 Background and Orientation of the Study.....	1
1.2 Problem Statement.....	3
1.2.1 Research Questions.....	10
1.3 Study Objective.....	10
1.4 Significance of the Study.....	10
1.5 Methods.....	11
1.6 Overview.....	12
1.7 Chapter Summary.....	13
 <b>CHAPTER 2-LITERATURE REVIEW.....</b>	 <b>14</b>
2.1 Introduction.....	14

## **TABLE OF CONTENTS (continued)**

2.2 Definition of Down Syndrome.....	16
2.3 Detection of Down Syndrome.....	16
2.4 Causes of Down Syndrome.....	18
2.5 Incidence of Down Syndrome.....	18
2.6 Profile of Individuals with Down Syndrome.....	19
2.6.1 Medical Profile.....	19
2.6.2 Psychological Profile.....	21
2.6.3 Social and Behavioural Profile.....	23
2.7 Prognosis.....	24
2.8 Chapter Summary.....	27
 <b>CHAPTER 3 - CARE AND WELL-BEING.....</b>	 <b>29</b>
3.1 Introduction.....	29
3.2 Definition of Care and Caregiver/Caregiving.....	30
3.2.1 Care.....	30
3.2.2 Caregiver/Caregiving.....	31
3.3 Prevalence of Caregiving.....	32
3.4 Formal Versus Informal Caregiving.....	33
3.5 The Effects of Caregiving.....	34

## TABLE OF CONTENTS (continued)

3.5.1 Financial Strain.....	35
3.5.2 Physical Strain.....	35
3.5.3 Emotional Strain.....	33
3.5.4 Caregiver Strain.....	36
3.6 The Benefits Associated with Caregiving.....	36
3.7 Caregiving for Down Syndrome.....	37
3.8 The Benefits of Caregiving for a Person with Down Syndrome.....	38
3.9 Dealing with Caregiving.....	41
3.10 Well-being of Caregivers.....	42
3.10.1 The concept Well-being.....	43
3.10.2 Hedonia and Eudaimonia.....	44
3.10.3 Positive Psychology.....	46
3.11 Challenges of caring for an Individual with Down Syndrome: Effects on Well-being...	49
3.12 Chapter Summary.....	52
 <b>CHAPTER 4 - METHODOLOGY.....</b>	 <b>53</b>
4.1 Research Design.....	53
4.2 Population and Sample.....	57
4.2.1 Participants.....	59
4.3 Data Gathering.....	60

## TABLE OF CONTENTS (continued)

4.3.1 Interview.....	60
4.3.2 Conducting of Interview.....	61
4.3.3 Reliability and Validity.....	62
4.4 Data Analysis.....	63
4.5 Ethical Issues.....	63
4.6 Chapter Summary.....	65
<b>CHAPTER 5-RESULTS.....</b>	<b>66</b>
5.1 Results.....	66
5.1.1 Knowledge of Down Syndrome.....	68
5.2 Challenges that Caregivers Experiences.....	69
5.2.1 Caregivers' Challenges with Child.....	69
5.2.2 Caregivers Ways of Coping with Situation in Everyday Life.....	72
5.3 Realization that Child has Down Syndrome and Ways of Coping.....	73
5.3.1 Caregivers realize for the first time that their Child has Down Syndrome.....	73
5.3.2 Caregivers' feelings when realized Child has Down Syndrome.....	75
5.4 Spiritual Beliefs and Lessons Learned.....	76
5.4.1 Spiritual Effects it has on the Caregiver.....	76
5.4.2 Special Lessons Caregivers Learned by having a Down Syndrome Child.....	77

## TABLE OF CONTENTS (continued)

5.5 Expectations.....	79
5.5.1 Future Expectations of Caregiver.....	79
5.5.2 Caregivers' expectations before learning Child has Down Syndrome.....	81
5.6 Economic Effects.....	81
5.6.1 Financial Effects on the Caregiver.....	82
5.7 Emotional Effects.....	83
5.7.1 Caregivers' Fear of Dying and not knowing what will happen to Child.....	83
5.7.2 Caregiver feels that she will always have a Companion.....	85
5.8 Spousal Relationship.....	86
5.8.1 Spousal Relationship is Affected.....	87
5.9 Effects on Social Life: Family Relations.....	88
5.9.1 Family Support is Minimal.....	89
5.10 Effects on Social Life: Social Reactions.....	90
5.10.1 Feelings of Shame when out in Public.....	90
5.10.2 Caregivers' Negative Experiences within the Community.....	92
5.10.3 Social Support from other Parents.....	93
5.11 Effects on Work.....	94
5.11.1 Caregivers' Work is Affected.....	94
5.12 Sexuality.....	96
5.12.1 Caregiver feels Hysterectomy is and/or were needed.....	96



## **TABLE OF CONTENTS (continued)**

5.12.2 Caregiver feels Child need to be on Contraceptives.....	97
5.13 Chapter Summary.....	98

## **CHAPTER 6 – DISCUSSION, CONCLUSION, LIMITATIONS AND /**

### **RECOMMENDATIONS.....99**

6.1 Discussion.....	99
6.2 Conclusion.....	106
6.3 Limitations.....	110
6.4 Recommendations.....	111
6.5 Chapter Summary.....	113

### **References.....114**

## **APPENDICES**

Appendix A.....	129
Appendix B.....	131

## **ACKNOWLEDGEMENTS**

First, I thank my heavenly Father for giving me the opportunity to complete my master's degree which I have longed to do ever since I have completed my bachelor's degree. I want to thank Him for providing me with the wisdom and grace to have completed this research project and showing me what was important in order for this research project to take place.

I thank you, all the caregivers who were willing to participate in this research. Thank you for your time and for a friendly welcome at your homes. Without you, this research project would not have been possible.

I thank you my supervisor, Professor Ian Rothmann for your guidance, encouragement and quick feedback whenever I needed an answer to a question. I thank you for your vote of confidence in me as well as believing in this research project and for just being a brilliant Professor. Prof. without you this would not have been possible, so thank you!

Lastly, I would like to thank my family. My husband for his patience and love, for my mother and father for their prayers and words of encouragement as well as my sisters for praying, quickly printing a PDF file or fixing my computer to finish my project in time. Thank you guys!

## **DEDICATION**

This thesis was inspired by my aunt, Hertha Maria Wohler and I dedicate this thesis to her. Aunty Hertha has Down syndrome. She is 57 years of age and has been living with us for 21 years. Through all these years I have learned so much from her and how to live with someone like her. This journey of 21 years has touched my life in many ways and I will always be thankful for that.

## DECLARATION

I, **Tanya A. Byleveldt**, hereby declare that this study is a true reflection of my own research and that this work or part thereof has not been submitted for a degree at any other institution of higher education.

No part of this thesis may be reproduced, stored in any retrieval system, or transmitted in any form, or by means (e.g. electronic, mechanical, photocopying, recording or otherwise) without the prior permission of the author, or The University of Namibia in that behalf.

I, **Tanya A. Byleveldt**, grant the University of Namibia the right to reproduce this thesis in whole or in part, in any manner or format, which it may deem fit, for any person or institution requiring it for study and research; providing that the University of Namibia shall waive this right if the whole thesis has been or is being published in a manner satisfactory to the University.

..... [Signature]      Date.....

Tanya A. Byleveldt

## **CHAPTER 1**

### **INTRODUCTION**

This thesis explored the experiences and well-being of caregivers of a family member with Down syndrome in Namibia.

In Chapter 1, an orientation of the current study is provided. This is followed by the problem statement, the objective and significance of the study as well as the theoretical framework on which the research is based. The methodology is briefly addressed to give an overview of what research design was used.

#### **1.1 Background and Orientation of the Study**

For most parents, one of the most exciting experiences in adult life is expecting a child. During this time parents usually imagine what the child will be like and what the future holds for them as parents. King and Patterson (2000, p. 17) state that for most parents, some or even many of these positive fantasies may become a reality, but for others the birth of a child may require a substantive revision of these rosy expectations. To hear that a child has an intellectual disability is a major life event. Those future-oriented fantasies parents imagined for themselves and their children no longer exist (King & Patterson, 2000). This means the image of a bright and happy future of the parents with children who are physically and mentally healthy no longer exists for parents with a Down syndrome child. The parents (and the family) as caregivers are faced with many challenging responsibilities which can either have a positive or negative influence on their well-being.

Intellectual disability, according to the American Association on Intellectual and Developmental Disabilities (2008), is characterised by significant limitations, both in intellectual functioning and in adaptive behaviour, as expressed in conceptual, social and practical adaptive skills. The disability starts before the age of 18. Down syndrome is the most common genetic cause of intellectual disability delaying the mental and physical development of a child. The syndrome is caused by the presence of an extra 21<sup>st</sup> chromosome and is, therefore, occasionally referred to as Trisomy 21. The characteristics of Down syndrome include small flattened skull, decreased muscle tone, chronic ear infections and hearing loss, short stature, cardiac defects, small mouth with protuberant tongue, depressed nasal bridge, speech and developmental delays, small hands and feet and mental retardation (Christianson, 1996).

Cunningham (1996) studied the effects of Down syndrome on the families and their functioning and found that there are families that function normally and that they have adapted to their child with Down syndrome. However, he has found that families do experience trauma following the birth and, that they now face a society with little understanding and prejudice (Cunningham, 1996). A study by Eaves, Ho, Laird, and Dickson (1996) focused on information and services that would help parents in raising a child with Down syndrome. Although extensive research was done on individuals with Down syndrome and their families, no studies were undertaken within the Southern African context (Molteno, Smart, Viljoen, Sayed, & Roux, 1997). Therefore, a need exists to explore the well-being of caregivers of a family member with Down syndrome.

## 1.2 Problem Statement

For many parents the birth of a child with Down syndrome comes as unexpected. However, raising the child with Down syndrome can be described as worthwhile but also as a stressful experience (Hedov, Anneren, & Wikblad, 2002). Families face ongoing challenges that affect their lives as well as that of the child with Down syndrome. Van Riper (1999) states that a family can be defined as two or more individuals who depend on one another for emotional, physical, and/or economic support (p. 358). Families having to take care of a member with Down syndrome experience increased demands on their time, energy, and resources as well as dramatic shifts in their enactment of social roles (Van Riper, 1999).

A caregiver can be referred to as a layperson, trained professional, friend or family member involved in the physical, psychological, emotional, and/or spiritual caregiving to individuals who are in need (Van Dyk, 2005). Dulin and Hill (2008, p. 4) define caregiving as an activity that focuses on providing needed support to another individual who is disabled to the extent that he or she is not capable of independent functioning. The reason for this study is that there is very little data on the experiences and well-being of families who care for a family member with Down syndrome within Namibia; hence no programmes are in place for family support services, for instance to provide the necessary assistance and guidance to families.

According to Freedman and Boyer (2000), family support includes services, resources and other types of assistance that enable individuals with developmental disabilities of any age to live with their families and to be welcome, contributing members of their communities (p. 59). In South Africa, an organisation known as Down syndrome South Africa (DOWNSA) is

available to families who need information regarding their child with the syndrome. However, currently this is not the case in Namibia. Freedman and Boyer (2000) found that family support enhanced the well-being of individuals with disabilities and their families. Although organisations such as the church and family friends are there to be used as support systems, the question one needs to consider is whether caregivers avail themselves of these support systems to enhance their well-being?

Caring for a person with Down syndrome is frequently associated with stress and suffering (see Cichetti & Beeghly, 1990). Focusing on stress and suffering of family members who are caring for a member with Down syndrome is in line with the assumptions of the *disease* model. Indeed psychologists have long been concerned with the psychopathological underpinnings of suffering and ill health (Peterson & Seligman, 2004; Seligman, 2008; Snyder & Lopez, 2005). From the perspective of the disease model, well-being was defined as the absence of distress and psychopathology (Seligman & Csikszentimihalyi, 2000). Only focusing on and re-emphasising pathology reinforces low expectations, creates dependency on outside resources and discourages people's optimal development. Decades of research focusing on the disease model has overshadowed efforts to enhance the states which make life worth living (Peterson & Seligman, 2004; Seligman & Csikszentimihalyi, 2000).

According to Seligman and Csikszentimihalyi (2000), psychologists who are interested in promoting well-being need to move away from the disease model. Positive psychology is a fairly new paradigm which refers to the science of subjective experiences, positive institutions and individual traits which improve the well-being of people and prevent the onset of psychopathology and suffering (Seligman & Csikszentimihalyi, 2000). Two



approaches towards well-being can be distinguished, namely subjective well-being and psychological well-being (Waterman, 2008). Subjective well-being refers to a person's assessment of his/her own life and it includes general satisfaction and satisfaction with specific domains (Kashdan, Biswas-Diener, & King, 2008). Psychological well-being is an objective approach to understanding well-being in terms of the presence of an array of psychological qualities indicative of mental health (Ryff & Singer, 1998). Psychological well-being consists of six dimensions, namely autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance.

The birth of a child with Down syndrome is likely to affect the family as a whole. Parenting and caring for a child with a disability such as Down syndrome is associated with various challenges. Caregivers often experience anxiety concerning the child's abilities, skills and appearance and the social response of friends and of the community at large. Caregiving to a family member with Down syndrome is also associated with increased caretaking burdens, potential major changes in family life-style and worries about short and long-term care provision (Cicchetti & Beeghly, 1990).

Kim, Greenberg, Seltzer, and Krauss (2003) state that the behaviour problems of the member with the disability have been proven to increase the stress associated with caregiving. Research has been conducted on parental adaptation to a child with Down syndrome which mainly focused on stress (Cuskelly, Hauser-Cram, & Van Riper, 2008). In this scenario, stress can be referred to as: "an emotional response of parents when it comes to the demands of the parenting role for example, feeling isolated, entrapped, overwhelmed with responsibility while others focus on the demands brought about by the child's temperament

and behaviours, for example their demandingness, soothability, and activity level” (Cuskelly et al., 2008). Lastly, it also looked into the parent’s mental health and psychological functioning which include depression, anxiety, self-acceptance and mastery. This shows that parenting responsibilities as well as the child’s demands and psychological outcomes are all connected.

Cunningham (1996) found that most parents associated stress with the behavioural problems of the child. This is appropriate to the topic to be researched, since the child’s behaviour and functioning influence the well-being of the caregiver. Olsson and Hwang (2006, p. 963) found that mothers of children with intellectual disability display lower levels of well-being, or more depressive symptoms, when compared with those of fathers. This is because mothers tend to have a more demanding parenting role compared to fathers. The fact that fathers are more involved in paid work and other roles after the birth of a child with intellectual disability makes the fathers more prone to lower levels of depression than is the case with the mothers (Olsson & Hwang, 2001). Gender difference also plays a role in paid work and child care because this could also explain why there is a difference in well-being between mothers and fathers of children with intellectual disability (Olsson & Hwang, 2001). This is especially relevant when a masculine, patriarchal culture exists in society.

Disability is typically viewed as a burden, and the general community holds fairly negative views concerning parenting a child with Down syndrome (Cuskelly et al., 2008). In the past, professionals had low expectations regarding the development and community involvement of children and adults with Down syndrome (Buckley, 2002). The parents were often advised to institutionalise their children as they were seen as a burden to the entire family (Buckley,

2002). Some people believe that it is “a disgrace to have a child with a disability born into the family” (Cuskelly et al., 2008). Raising a child within a community that sees disability as a tragedy can be stressful. Gordon, Feldman, Tantillo, and Perrone (2004) point out that ancient Roman and Greek cultures viewed persons with physical disabilities as burdens on society and as less than human. Buckley (2002) adds that some communities have not progressed as far as others in changing negative beliefs and negative attitudes, and parents and families will be influenced profoundly by these views. As the Namibian population contains different ethnic groups this would be relevant to the topic in terms of how each caregiver experiences raising a family member with Down syndrome within a society of diverse cultures.

Hodapp, Fidler, Ly, and Ricci (2001) state that parents of children with Down syndrome generally report less stress than do parents of children with autism and other psychiatric disorders. Research showed that stress among mothers who have a child with Down syndrome experience less stress than those who have autistic children (Hodapp et al., 2001). It appears that parenting Down syndrome children is less stressful than parenting children with other types of disabilities. This information is relevant because it merely indicates that taking care of a Down syndrome family member is not that stressful compared to taking care of or raising a child with another form of disability; thus illustrating that caregivers of a Down syndrome have a better sense of well-being. However, the level of well-being is still affected.

Ryff's (1989) approach to psychological well-being has six characteristics which are self-acceptance, personal growth, autonomy, positive relations, environmental mastery, and purpose in life. The different domains of psychological well-being are associated with

specific maternal coping styles as well as with offspring maladaptive behaviour and diagnoses (Dykens, 2005, p. 361). Mothers of children who experience their child as a source of fulfilment by promoting familial strength and closeness used reframing coping strategies (Dykens, 2005).

Seligman (2003) introduced positive psychology which is focused on the study of optimal human functioning that is interested in the conditions that allow individuals to flourish. Seligman (2003) outlined three ways of increasing one's well-being, namely pleasure (the pleasant life), engagement (the engaged life), and meaning (the meaningful life). Peterson and Seligman (2004) pointed out that people need to cultivate work, social relationships, and activities that best tap their core virtues and strengths. By applying virtues such as humanity, justice, wisdom, and transcendence when providing care to a member who is intellectually disabled, family members can increase their subjective and psychological well-being (Dykens, 2005). In the past, most research only focused on the negative side of what it was like to raise children with Down syndrome. Research now shows that the challenge in caring for a Down syndrome individual leads not only to negative consequences for the families (Van Riper, 1999) since many studies show that parents find a sense of meaning when caring for their Down syndrome child. For instance, families tend to be more in harmony with their "situation" at hand, mothers are found to stress less and fathers experience a better relationship with their offspring (Hodapp, 2007). Studies found that families generally cope better when they include a person with Down syndrome (Hodapp, 2007, p. 280). It is not clear why this is the case, but children with Down syndrome tend to have a more sociable nature combined with an outgoing personality.

Families are the largest single providers of support to people with developmental disabilities (Freedman et al., 2000, p. 59). Having no form of support, for example social support, which is important in terms of coping as it satisfies the need for attachment, relieves stress, and bolsters a sense of self-worth; trust and life-direction, can have a major effect on the caring responsibility as well as on the psychological well-being of a caregiver (Chambers, Ryan, & Connor, 2001). This is of relevance to the topic of this study, since having no support has an effect on the caregivers well-being.

Scientific information is needed regarding the experiences, stress and well-being of families who are caregivers of a family member with Down syndrome. This is important to those parents who begin their married lives with a Down syndrome child within the family and it will provide them with a balanced perspective of what to expect. In addition, most studies which were conducted on the experiences of caring for a Down syndrome child were carried out within foreign countries. No scientific information is available regarding the experiences and well-being of families as caregivers of Down syndrome children residing in Namibia. Furthermore, while studies have been carried out regarding the experiences of caregivers by utilising the disease model, no studies could be traced regarding the well-being of caregivers from a positive psychological paradigm. Based on the information gathered in this study, the Ministry of Health and Social Services (the planning and policy division) could plan and implement programmes to promote the well-being of families who are giving care to a member with Down syndrome.

### **1.2.1 Research Questions**

The following research questions arise, based on the description of the problem:

- What are the challenges faced by families as caregivers of a family member with Down syndrome?
- How do families as caregivers in Namibia experience having a family member with Down syndrome?
- Which factors affect the stress and well-being of families who are caregivers of a family member with Down syndrome in Namibia?
- What forms of support do family caregivers need to sustain their well-being in Namibia?

### **1.3 Study Objective**

The general objective of this study was to explore the experiences and well-being of caregivers of a family member with Down syndrome in Namibia.

### **1.4 Significance of the Study**

At the time of the research no information regarding the manifestation of Down syndrome in Namibia was available. Consequently no scientific information is available regarding the experiences and well-being of families who are caring for a family member with Down syndrome. Through this study, the Ministry of Health and Social services (planning and policy division) can benefit by obtaining information that can be used to plan and implement interventions which can assist caregivers. The study will provide information and will be a

valuable contribution to families and societies that provide care to a member with Down syndrome. Others who can benefit from this study include future parents expecting or who have given birth to a child with Down syndrome, health professionals who provide emotional and mental well-being, support and care services as well as family researchers. Families within the Namibian society with a Down syndrome child will benefit greatly from this study.

### **1.5 Methods**

This research can be classified as qualitative research from a phenomenological approach. This means caregivers was observed and questioned by making use of a questionnaire compiled by the researcher to understand their experiences in caring for a Down syndrome child. This method was deemed most appropriate, as the researcher aimed to explore the experiences and well-being of caregivers of a child with Down syndrome. Furthermore, it allowed the researcher to study the meaning caregivers hold in relation to their experiences of their world.

The research population was the caregivers who are either the parents or the guardians responsible for the raising and caretaking of the child with Down syndrome. No specific age group was focused on as the well-being of a caregiver changes according to the development of a child's age. A study by Eisenhower, Baker, and Blacher (2005) was conducted on families of children aged 36 months and then again when the children were between 48 and 60 months. Within this study they found an increase in problem behaviour in the children, which was associated with an increase in maternal stress.

The analysis procedure which was applied was content analysis. Content analysis stands for categorizing answers into different types and the number of each type is counted. This means, identifying the general themes mentioned in the interviews and then counting the number of times they are mentioned (Hayes, 2000). Themes are topics or ideas which occur recurrently during the course of a qualitative analysis. Each interview was transcribed by the researcher and various themes from the interviews emerged which were used to understand the experiences of the caregivers.

## **1.6 Overview**

The study explores the experiences and well-being of caregivers of a family member with Down syndrome in Namibia. The thesis consists of six chapters.

Down syndrome is a genetic condition in which a person has 47 chromosomes instead of the usual 46. Within *chapter 2*, the history of Down syndrome and what it entails in its entirety is discussed. *Chapter 3* is about care and well-being. It looks at what caregiving entails, how the caregivers' well-being is affected and what well-being is all about. In *chapter 4* the methodology of the research is discussed. *Chapter 5* contains the results of the study and this is discussed in full. The chapter also indicates the various themes that came out of the interviews regarding the well-being of caregivers. In conclusion, *chapter 6* presents the limitations of the study. Recommendations are made concerning intervention strategies and in addition suggestions for future research are made.



## **1.7 Chapter Summary**

This chapter introduces the background and orientation of the study, the problem statement followed by the research questions, the objective of the study, and significance of the study.

The research method was introduced and the reason why this method was deemed most appropriate. A brief overview of what can be expected in the following chapters was given.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter is about the history of Down syndrome and how individuals were treated in the past, followed by a definition of Down syndrome. This chapter also looks at the different ways in which Down syndrome is detected, the causes of Down syndrome and its incidence.

#### **2.1 Introduction**

The history of Down syndrome dates back as far as human beings have existed. According to Margulies (2007, p 6), medical historians have identified cases of Down syndrome in children depicted in European paintings as early as the 15th century. Although Down syndrome has existed for most of human history, nobody singled out the condition and gave it a name (Margulies, 2007).

During the past families would often place their children within institutions because there was no other form of support for them within the community. Not only were people with Down syndrome placed within institutions, but also were they lumped together with robbers, murderers, orphans, or those too poor to pay their bills. Doctors believed that people with Down syndrome could never learn, and therefore children received little education (Brill, 2006, p. 24). These children were left to do nothing for most of the day. The positive aspect of placing people with Down syndrome within institutions was that these institutions offered a lifetime of care but the negative aspect of these institutions was that people with disabilities

held little hope of getting out or seeing their families and the care they received was in unclean or dangerous settings (Brill, 2006).

In the late nineteenth century, doctors began to look more closely at the people within the institutions and found that patients had similar features. Eduard Seguin, a French doctor, wrote a paper in 1866 in which he described children with “milk-white, rosy, and peeling skin... truncated (shortened) fingers and nose; with cracked lips and tongue... skin at the margin of the lids” (Brill, 2006, p. 26). Seguin was describing those with Down syndrome as having an uneven walking, smaller head size, and other physical features (Brill, 2006). Like Samuel Gridley Howe, an American, Seguin also encouraged institutions to open up so that these children could receive education and training. Seguin believed that these children can advance beyond what was expected of them in the past.

In 1859, John Langdon Down, an English physician, was appointed as a superintendent of the Earlwood Asylum for Idiots in Surrey. “The term ‘idiot’ was still used as a serious medical label for people with severe intellectual disabilities within the 1800s” (Margulies, 2007, p. 8). During this time he observed the patients and wrote a scientific paper in which he identified a set of patients at the hospital who bore the same physical and mental characteristics – the indicators of what we now call Down syndrome. These indicators were as follows: “...The face is flat and broad, and destitute of prominence. The cheeks are roundish, and extended laterally. The eyes are obliquely placed, and the internal canthi more than normally distant from one another. The palpebral fissure is very narrow... The lips are large and thick with transverse fissures. The tongue is long, thick, and is much roughened...” (Nespoli, 1996, p. 625).

Down, however, did not name the condition Down syndrome, but rather called it 'mongolism' because he had a theory that these patients were a throwback to the Mongols, common ancestors of many Europeans and Asians (Margulies, 2007, p. 8). The words 'mongolism' and 'mongoloid' were used for many years. In 1960, Asian doctors opposed these terms, calling them racist. These doctors demanded a change of thinking about the condition in both Europe and the United States and the medical community agreed (Brill, 2006). It was then that scientists named the condition Down syndrome after John Langdon Down, the man who had described a century earlier.

## **2.2 Definition of Down Syndrome**

According to the Oxford Dictionary of Psychology (Colman, 2006), Down syndrome can be defined as a disorder linked to a chromosomal abnormality resulting in a broadened and flattened face and nose, short stubby fingers, skin folds at the edges of the eyes, mental retardation, and the premature development of Alzheimer's disease, usually in middle age.

## **2.3 Detection of Down Syndrome**

Down syndrome is usually diagnosed shortly after the birth of the baby. However, today there are many procedures which can be used to diagnose the condition of the baby before birth. There are two kinds of tests which can be made use of to determine whether an individual will have a Down syndrome baby. The first test is the screening test; these are blood tests and/or sonograms that will indicate the chance that the baby has Down syndrome. The second

test is the diagnostic tests which consist out of amniocentesis and chorionic villus sampling (CVS).

Amniocentesis is a procedure in which amniotic fluid is collected in the womb. According to Leshin (2007), a needle is inserted through the mother's abdominal wall into the uterus, using ultrasound to guide the needle. One ounce of fluid is then taken for testing. The fluid contains the foetal cells which are used to examine the chromosome test. Once this test is done it takes about two weeks to determine if the foetus has Down syndrome or not. Amniocentesis is done between the 14<sup>th</sup> and 18<sup>th</sup> week of pregnancy. Some of the complications for the mother which can occur because of this test are cramping, bleeding, infection and leaking of amniotic fluid.

The chorionic villus sampling (CVS) is when a small amount of tissue is taken from the young placenta (also called the chorionic layer). These cells that contain the foetal chromosomes are then tested for Down syndrome. "The cells can be collected the same way as the amniocentesis, but another method is to insert a tube into the uterus through the vagina. The method depends on the mothers' anatomy" (<http://www.ds-health.com/prenatal.htm>). CVS are undertaken between the 10<sup>th</sup> and 12<sup>th</sup> weeks of pregnancy. The complications for CVS are the same as those for amniocentesis.

According to the Journal of Midwifery and Women's Health (2005), a small number of women (about 1 in 100 of those women who have a CVS test and about 1 in 200 of those women who have an amniocentesis) who have one of these tests will have a miscarriage. These two diagnostic tests, however, provide an individual with a firm diagnosis.

## **2.4 Causes of Down Syndrome**

Down syndrome is the most common chromosomal malformation in new-borns and which is associated with mental retardation. Down syndrome is caused by the presence of an extra chromosome 21. According to Davis (2008, p. 271), there are three possible aetiologies for the extra chromosome associated with Down syndrome. One, when the egg or sperm develops with an extra chromosome and the resulting fertilized egg has three chromosome 21s instead of just two. This is then referred to as non-disjunction (meaning that one of the paired chromosomes failed to separate during meiosis) and this process is more common in older women, provided that women's eggs are present before birth. "When the embryo develops, the extra chromosome is repeated in every cell" (Davis, 2008, p. 271). The second aetiology takes place in about 2% to 4% of individuals with Down syndrome as the result of 'mosaic trisomy' (Davis, 2008). This aetiology is almost the same as the first condition; it is only that some cells have 46 chromosomes whereas others cells have 47 chromosomes. The third aetiology of Down syndrome occurs in about 3% to 4% of cases, as "translocation trisomy" (Davis, 2008, p. 272). This is when "material from one chromosome 21 gets stuck or translocated onto another chromosome, either before or at conception. Cells from individuals with Down syndrome have two normal chromosomes 21, but also have additional chromosome material on the translocated chromosome" (Davis, 2008, p 272).

## **2.5 Incidence of Down Syndrome**

Down syndrome occurs in all races, social classes and in all countries. According to research studies done by Harvey (2004), of every 1,000 babies born within the UK, one will have

Down syndrome. This means that within the UK about 600 babies are born annually with Down syndrome. “Throughout the world, the overall prevalence of Down syndrome is 10 per 10,000 live births, although in recent years this figure has been increasing” (Weijerman & Winter, 2010, p. 1445). Sometimes the prevalence of Down syndrome depends on a country’s socio-cultural variables. For instance, in countries like Ireland and the United Arab Emirates where abortion is illegal, the Down syndrome prevalence is higher (Weijerman & Winter, 2010). Down syndrome is recorded as 1.8 and 2.01 per 1 000 live births in urban and rural black population within South Africa (Lampret & Christianson, 2007). These babies with Down syndrome were born to women of advanced maternal age.

## **2.6 Profile of Individuals with Down Syndrome**

### **2.6.1 Medical Profile**

Individuals with Down syndrome tend to have a number of health problems and this means that they have an “increased risk of concomitant congenital defects and organic disorders like congenital heart and gastrointestinal defects (celiac disease)” (Weijerman & Winter, 2010). Congenital heart defects (CHD) and respiratory infections are the most common medical disorders found in individuals with Down syndrome. The prevalence of CHD in neonates with Down syndrome is about 44-58% worldwide (Weijerman & Winter, 2010, p. 1447). Heart defects are treatable and surgery often takes place at the age of 2-4 months, sometimes even earlier. In terms of respiratory infections, constant wheezing is common among individuals with Down syndrome and this is related to respiratory syncytial virus (RSV). The clinical picture may sound like asthma but it is not equivalent to asthma (Weijerman &

Winter, 2010). According to Grech (2001, p. 865), studies indicate that 7% to 16% of individuals with Down syndrome may have the celiac disease which is part of gastrointestinal defects. Common symptoms of this are diarrhoea, vomiting, weight loss, malnutrition, irritability and decreased appetite.

Owing to the fact that Down syndrome is characterized by several dysmorphic features, individuals with Down syndrome also tend to have problems with their vision as well as with their ears, nose and throat. In terms of their vision, most individuals with Down syndrome have ocular abnormalities. These ocular features which are related to Down syndrome are those like “epicanthal folds, narrowed or slanted palpebral fissures (the mongoloid slant) and Brushfield spots, but can also include strabismus (20-47%), nystagmus (11-29%), congenital cataract (4-7%), acquired cataract (3-15%), blepharitis (7-41%), refractive errors (43-70%) and glaucoma (0.7%)” (Weijerman & Winter, 2010, p. 1447). It is, therefore, important that vision is checked at birth.

Hearing loss within individuals with Down syndrome is also prevalent and this may have an influence on educational language and emotional development which in turn can have an influence on the individual’s articulation skills. It is important, therefore, that the hearing of an individual with Down syndrome is assessed annually. Grech (2001, p. 865) states that half of children with Down syndrome suffer from obstructive sleep apnoea and this may be caused by the flattened midface, narrowed nasopharynx, hypotonic upper airway muscles and enlarged adenoids and /or tonsils found in these individuals. Their lack of sleep this could bring about behavioural problems.



Although most individuals with Down syndrome tend to have a variety of medical problems, their life expectancy has improved considerably from what it was in the past. It is believed that the total population of individuals with Down syndrome is expected to grow substantially. According to Weijerman and Winter (2010, p. 1446), in the Netherlands, the infant mortality rate in children with Down syndrome dropped from 7.07% in 1992 to 4% in 2003 (this is in contrast with the 0.48% infant mortality of the reference population in the Netherlands in 2003). The reason for the drop in mortality rate is due to the successful treatment of CHD as well as to the treatment of congenital anomalies of the gastrointestinal tract. Elkins and Brown (1995, p. 18) states that individuals with Down syndrome have a life expectancy of 55 years if they do not die in infancy from untreatable heart defects (a situation that occurs in less than 2% of infants with Down syndrome).

Advances in treatment and increased access to medical care now means that people with Down syndrome are living much longer.

### **2.6.2 Psychological Profile**

Down syndrome not only affects the physical development of individuals but it also affects their psychological development and learning. Their learning shows characteristic patterns that can be different from those of children with other developmental delays (Harvey, 2004, p. 44). For example, they have difficulty with their gross motor skills. A child with Down syndrome takes much longer to walk (up to 24 months) unaided than a child that does not have Down syndrome who is expected to walk between nine and 17 months.

Down syndrome also affects the neurocognition which results in impairment in communication (oral motor skills), language and memory (Davis, 2008). Because individuals with Down syndrome have a narrow high arched palate, irregular dentition and a large tongue that protrudes forward as well as poorly differentiated muscles, hyperextendable joints, and nerve innervations differences their speech intelligibility is affected. “There are also reports of drooling, open mouth posture, large tongues, hypotonia, velopharyngeal insufficiency, and compromised respiratory support as well as apraxia (difficulty in execution of the motor programming of speech movements) and dysarthria (weakness or lack of coordination of the articulators that results in slow, weak, imprecise or discoordinated speech)” ( Roberts, Price, & Malkin, 2007, p. 27).

When children start to learn a language, it is communicated by making use of prelinguistic language. Prelinguistic language is the period before children use language to communicate. This occurs between 12 to 18 months of age. This language involves communicating through gestures, vocalizations, facial expressions and other movements. According to Roberts, Price, and Malkin (2007, p. 27), this period can last several years for individuals with Down syndrome or for all their life for individuals with severe motor speech disorders.

Individuals with Down syndrome also have poor speech intelligibility which can be a major barrier in their daily activities (Roberts, Price, & Malkin, 2007).Whereas typical developing children are often intelligible at 48 months of age, producing intelligible speech it is a lifelong challenge for those with Down syndrome (Roberts et al., 2007, p. 28).

Besides communication and language difficulties, verbal memory, a common cognitive impairment, is another challenge for individuals with Down syndrome. Possible causes for verbal short-term memory in individuals with Down syndrome includes rapid storage decay, less storage capacity of the phonological store, encoding deficits, and poor hearing (Davis, 2008).

It is therefore, necessary and important that individuals who are responsible for interventions are familiar with the specific nature of the child's syndrome, especially with regard to age-related changes and processing strengths and weaknesses (Davis, 2008).

### **2.6.3 Social and Behavioural Profile**

Social and behavioural development is seen as a strength within individuals with Down syndrome compared to other groups of individuals with neurodevelopment disorders. This is because parents of children with Down syndrome view these children as joyful and possessing more social competence than are children with mental retardation with an unknown aetiology or Williams or Prader-Willi Syndrome (Davis, 2008, p. 276).

Over the last years behaviour problems within individuals with Down syndrome have been partly investigated. When compared to other individuals with genetic disorders and mental retardation, individuals with Down syndrome portray fewer and less severe behaviour problems. According to Roizen and Patterson (2003, p. 1286), 17.6% of individuals with Down syndrome aged less than 20 years have a psychiatric disorder, most frequently a disruptive behaviour disorder such as attention deficit hyperactivity disorder (ADHD) which

comprises 6.1%. Conduct/oppositional disorder comprises 5.4%, and aggressive behaviours 6.5% while 25.6% of adults with Down syndrome have a psychiatric disorder, most frequently a major depressive disorder of 6.1% and aggressive behaviour of 6.1% (Roizen & Patterson, 2003).

Down syndrome children are like any other child who at times displays disobedience and stubbornness. When individuals with Down syndrome show behaviour problems, errorless compliance training can be used as an intervention, especially within schools (Davis, 2008).

Older individuals with Down syndrome are at risk of behaviour and psychiatric problems which are also prevalent with those suffering from Alzheimer's disease. These problems consist of agitation, depression, anger as well as other personality changes. "Clinical signs and symptoms of Alzheimer's disease are noted in 75% of such individuals over 60 years of age, and are most frequently seizures 58%, change in personality 46%, focal neurological signs 46%, apathy 36%, and loss of conversational skills 36%" (Roizen & Patterson, 2003, p. 1286). When a diagnosis is made with an adult in terms of Alzheimers, a complete medical assessment should be done to see whether treatable disorders like thyroid malfunction or depression are prevalent.

## **2.7 Prognosis**

Research on Down syndrome has been conducted over a long period of time and our knowledge of what the condition entails has improved sufficiently well so that researchers, educators, psychologists, and medical doctors now have information on evidence-based care,

therapies and interventions which could be used when working with individuals with Down syndrome.

In recent years there have been major changes in attitudes towards individuals with Down syndrome so much so that “parents are thinking more carefully before opting for prenatal screening and termination – so that being born with Down syndrome is being seen in a different light today” (<http://mhtodayexhibition.co.uk>). People have become more accepting and individuals with Down syndrome have become more part of the community than in the past. Infants and children are no longer institutionalized and separated from their families and community. According to research undertaken by the Down Syndrome Association (<http://mhtodayexhibition.co.uk>), some parents now state that they know people with Down syndrome or other disabilities and that this influenced their decision to continue with the pregnancy, other respondents said that they felt supported by their family and friends. Individuals with Down syndrome now have the benefits of living in loving, stimulating environments (homes) where health problems are addressed locally and they live longer.

Medical care has also improved considerably in recent times, especially in terms of individuals with Down syndrome. For example, one medication that can help with the cognitive problems in Down syndrome is piracetam. This drug belongs to the group of medications thought to enhance cognitive function in instances of brain dysfunction (Roizen & Patterson, 2003, p.1286). Not only has medical care improved but individuals with Down syndrome can now have facial reconstruction since the “vast majority of individuals with Down syndrome have extra skin at the inner corners of the eyelids (‘epicanthal folds’), slanting rather than horizontal eye openings (‘slanted palpebral fissures’), and a flattened

nasal bridge” (Leshin, 2000). Sometimes they have flattened mid-facial region and a down turned lower lip. These factors are all reasons why individuals are now privileged to undergo facial reconstruction. The sole purpose of this in individuals with Down syndrome is to not only improve their appearance but to make them more socially acceptable. According to Leshin (2000), one study indicated that people with Down syndrome are subject to decreased acceptance by their peers on the basis of their facial features alone. Having facial reconstruction increases their opportunities for success within society.

Besides facial reconstruction, individuals with Down syndrome can also have tongue reduction since a protruding tongue is a common feature to such individuals. Tongue reduction is also referred to as ‘partial glossectomy’, and it consists of removing a wedge of the tongue to make it smaller and shorter (<http://www.ds-health.com/psurg.htm>). Doctors, according to Leshin (2000), recommend it for aesthetic reasons as it helps the child to keep his or her mouth closed while breathing and eating.

Developmental and educational research has also increased over the past years in terms of the learning difficulties of those individuals with Down syndrome. Research has improved with teaching techniques and this has transformed education for many thousands of young people with Down syndrome. Today they also have the privilege of enjoying education in schools unlike in the past. Programmes like early intervention education systems are implemented to stimulate the development of children with Down syndrome from the first months of life and especially in the preschool period (Weijerman & Winter, 2010).

Another research intervention which now promotes the developmental functioning within children with Down syndrome is the Responsive Teaching (RT) strategy. This intervention

develops the following three domains within developmental functioning, namely cognition, communication and social-emotional functioning. Mahoney, Perales, Wiggers, and Herman (2006, p. 18) state that Responsive Teaching is a child development early intervention curriculum that was designed to be implemented by parents and other caregivers who spend significant amounts of time interacting with and caring for young children. This intervention was developed to help parents and caregivers to increase their potential when interacting with their children so that they support and enhance the children's development and well-being. The following important behavioural skills that are learned within Responsive Teaching are social play, initiation, problem solving, joint attention, conversation, trust, cooperation, persistence and feelings of competence. The instructional strategies that are at the heart of Responsive Teaching are easy to remember suggestions that adults can incorporate into daily routines with children (Mahoney et al., 2006, p. 8).

Many such interventions have been implemented that will help with the development and education of individuals with Down syndrome. Research continue to progress whether it is within the medical field or within the development and education of individuals with Down syndrome. All these new effective interventions and teaching strategies now help young people with Down's syndrome to achieve much more today than in the past.

## **2.8 Chapter Summary**

Historically, individuals with Down syndrome were placed within institutions and families were often ridiculed. In the past, their survival as infants was discouraged especially when they experienced heart problems or intestinal blockages (Brown, 2004). However, today such

discriminatory practices have led to campaigns which fight for the rights of individuals with Down syndrome.

Since Down syndrome is a disorder that has so many aspects, it would be impossible for those with the condition to lead a normal life. As with many other disorders, individuals with Down syndrome need constant care and extra help is vital. Therefore, the next chapter will indicate the effects of providing care to a member with Down syndrome and what well-being entails.



## **CHAPTER 3**

### **CARE AND WELL-BEING**

This chapter deals with the effects, constraints and challenges for a caregiver and his or her family in the provision of care for the individual with Down syndrome. Various definitions are provided in terms of what the terms care, caregiver, caregiving means. The prevalence of caregiving is discussed as well as formal and informal caregiving. There are different ways in which caregivers can deal with caregiving which are also indicated in this chapter. Lastly well-being will be discussed in terms of positive psychology, hedonic well-being which indicates subjective well-being and eudaimonic well-being which reflects psychological well-being. The umbrella term for both the hedonic and eudaimonic measures of well-being denotes both psychological and subjective well-being.

#### **3.1 Introduction**

Two decades of research on the effects of family caregiving have shown that this is a stressful role with deleterious consequences for the person providing care (Seltzer & Li, 2000, p. 165). However, research indicates that there is heterogeneity in the effects of caregiving, with some caregivers showing patterns of adaptation while occupying this role, whereas others are characterized by wear-and-tear effects (Seltzer & Li, 2000).

Caregiving can be seen as a physically and emotionally exhausting job, but it can also be viewed as a special, rewarding experience (sometimes even called labour of love) whether it is for a family member or client. Caregiving varies from situation to situation and can last for

a few short months, sometimes three to five years and at times caregiving can be a lifetime commitment (Mintz, 2008).

The health and well-being of caregivers who provide constant caregiving to individuals in need of 24/7 care are greatly affected. Caregivers tend to suffer either from exhaustion, family dysfunction, or social isolation owing to the continuous caregiving that they have to provide. Caregiving comes in different forms to many different families. For example, some families or caregivers have to provide care to adults or children in any of the following categories:

(a) schizophrenia and other severe and persistent mental disorders, (b) children with pervasive developmental disorders, (c) elderly adults with Alzheimer's and dementia, (d) adults and children with HIV and AIDS, (e) children with developmental disabilities, (f) children with chronic diseases; and more recently (g) children with emotional and behavioural disorders (Brannan, Heflinger, & Bickman, 1997).

### **3.2 Definition of Care and Caregiver/Caregiving**

There are various definitions for care and caregiver/caregiving.

#### **3.2.1 Care**

The term care is a broad definition which can include emotional and administrative support as well as physical and domestic tasks. Caring responsibilities may include regular help or supervising someone with everyday activities like shopping, cooking, laundry, bathing,

dressing and providing emotional support and advocacy (<http://www.merton.gov.uk/health-social-care/adult-social-care/coresupport>). The person being cared for can have either irregular mental health problems or serious illness.

### **3.2.2 Caregiver/Caregiving**

A caregiver can be referred to as a layperson, trained professional, friend or family member involved in the physical, psychological, emotional, and/or spiritual caregiving to individuals who are in need (Van Dyk, 2005).

Duxbury, Higgins, and Schroeder (2009) define a caregiver as an individual providing care or assistance to a family member in their home or the care recipient's home who has a physical or mental disability, is chronically ill, frail, or at the end of life.

According to Sloan Work and Family Research Network, "caregiving is the act of providing unpaid assistance and support to family members or acquaintances that have physical, psychological, or developmental needs. Caring for others generally takes on three forms: instrumental, emotional, and informational caring. Instrumental help includes activities such as shopping for someone who is disabled or cleaning for an elderly parent. Caregiving also involves a great deal of emotional support, which may include listening, counselling, and companionship. Finally, part of caring for others may be informational in nature, such as learning how to alter the living environment of someone in the first stages of dementia" (<http://wfnetwork.bc.edu/glossary>).

Dulin and Hill (2008, p. 4) define caregiving as an activity that focuses on providing needed support to another individual who is disabled to the extent that he or she is not capable of independent functioning.

### **3.3 Prevalence of Caregiving**

The National Alliance for Caregiving in collaboration with AARP (2009) states that an estimated 65.7 million people in the U.S. have served as unpaid family caregivers to an adult or a child. Within the survey which they conducted to determine the prevalence of caregiving they found that 28.5 % of respondents reported being caregivers. The National Alliance for Caregiving in collaboration with AARP (2009) state that in the U.S most caregivers are female (66%) and that they are 48 years of age on average. “One-third takes care of two or more people (34%).A large majority of caregivers provide care for a relative (86%), with over one-third taking care of a parent (36%).One in seven cares for their own child (14%).Caregivers have been in their role for an average of 4.6 years, with three in ten having given care to their loved one for five years or more (31%). Seven in 10 caregivers take care of someone 50 years of age or older, 14% take care of an adult age 18 to 49, while 14% take care of a child under the age of 18” (National Alliance for Caregiving in collaboration with AARP, 2009, p. 4).

The prevalence of caregiving varies at times depending on the sample being studied and how caregiving is defined. The General Social Survey (GSS) of 2002, Cycle 16 on Social Support and Aging states that over 1.7 million adults between the ages of 45 and 64 provide unpaid care to almost 2.3 million seniors with a long-term disability or physical limitation (Duxbury,

Higgins, & Schroeder, 2009, p. 28). This means that 1.2 million of these caregivers are employed. Since the GSS data does not count caregivers younger than 45 or older than 64, these figures probably underestimate the number of employed caregivers as they exclude older women who look after their spouses and younger adults (Duxbury, Higgins & Schroeder, 2009, p. 28).

### **3.4 Formal versus Informal Caregiving**

Formal caregiving is defined as paid or free of charge attention provided by public or private institutions and non-profit organizations; whereas informal care (unpaid caregiving) refers to the attention provided by family members, friends and neighbours (Martin & Prieto, 2008, p. 2). Care that is provided within a home can be either formal or informal caregiving. Since most informal caregivers are employed, they sometimes have limited time in between caregiving and maintaining a household and a job (<http://www.articlebase.com>). This is when formal caregiving comes into place since family members need rest for themselves or to allow them have some kind of employment.

When family members are unable to remain the caregiver of the care recipient, formal caregiving comes into place on a full-time basis. This may be in the form of a congregate living arrangement, assisted living, a continuing care retirement community or a nursing home (<http://www.articlebase.com>). Having to make use of formal caregiving can be quite costly to family members or to the care recipient as care facilities are expensive and because formal caregivers provide hands-on assistance which can either be full-time or part-time

which is provided through an agency or hired privately. These expenses sometimes rob the family members of a home and adequate standard of living (<http://www.articlebase.com>).

Informal caregivers derive great satisfaction and fulfilment by providing care to those whom they love, often at great cost to their own health and well-being. However, because of the increasing need for physical and emotional support which often goes unrecognized, informal caregivers tend to burn themselves out with the workload in terms of the number of hours they work. These hours and the number or intensity of activities in providing care can sometimes increase without the caregiver realizing it (<http://www.articlebase.com>).

### **3.5 The Effects of Caregiving**

Pearlina and Aneshensel (1994), as quoted by Seltzer and Li (2000, p. 165), explain that, unlike most careers, caregiving is unplanned, unexpected, and not entered into by choice. As a result many caregivers report relationship and financial difficulties, decreases in social support and leisure time, and career and family disruptions (Pearce, 2005). They also tend to have poorer physical health, impaired immune functioning, exacerbation of medical conditions and elevated levels of depression and anxiety.

A number of terms have been used to refer to the added strain of caring for a relative with special needs. These are: family burden of care, caregiver burden, physical strain, financial strain, emotional strain, and caregiver strain. The following concepts like physical strain, financial strain, emotional strain and caregiver strain will be explained in short, in terms of the effects they have on the caregiver.

### **3.5.1 Financial Strain**

Financial strain according to Duxbury, Higgins, and Schroeder (2009, p. 11), is associated with poorer physical and mental health, greater work-life conflict, increased absenteeism, lower job satisfaction, and a higher number of visits to the emergency room at the hospital. These financial strains are caused by living in a family where the financial resources are limited. This is because the caregiver who is an employer has to spend a lot of time with caregiving demands which are heavy and time-consuming and, therefore, they (the caregiver/employer) have less time to devote to work, which in turn reduces their earning potential (Duxbury et al., 2009).

### **3.5.2 Physical Strain**

Physical strain has to do with the physical effort required to provide care to an elderly dependent like lifting and cleaning. Duxbury et al. (2009, p. 11) state that physical strain is associated with poorer mental health, increased work-life conflict, and increased absenteeism owing to problems of caring for the elderly and is also associated with lower levels of family satisfaction.

### **3.5.3 Emotional Strain**

Emotional strain is defined as feelings of being overwhelmed and worried about how one will cope (Duxbury et al., 2009, p. 12). When providing care, emotional strain is associated with poorer physical and mental health, increased work-life conflict, higher job stress, increased

absenteeism due to caring for elderly relatives and emotional fatigue, lower levels of family well-being and reduced fertility. Emotional strain is caused when living in a family where financial resources are limited, physically and emotionally heavy caregiving demands become more, lower levels of control at work like family responsibilities that limit advancement opportunities and gender - women are more predisposed to experiencing this form of strain than men (Duxbury et al., 2009).

#### **3.5.4 Caregiver Strain**

According to Brannan, Heflinger, and Bickman (1997, p. 212), caregiver strain refers to the demands, responsibilities, difficulties and negative psychic consequences of caring for relatives with special needs. Caregiver strain is a multidimensional construct which includes financial, physical and emotional strain. Caregiver strain also includes the effect on family life, schedules and routines, effect on physical and mental health of family members and restrictions on personal freedom, time, and privacy (Brannan et al., 1997).

#### **3.6 The Benefits Associated with Caregiving**

Providing care to a disabled family member often places a burden on the caregiver, but it can also involve rewarding components like enabling the caregiver to feel useful, important and competent (Boerner, Horowitz, & Schulz, 2004). Most research focuses only on the negative aspects of the caregiving experience; however, a few studies have emerged which focus on identifying the positive benefits of caregiving.



The following positive experience associated with caregiving was found. Neal and Wagner (n.d., p. 9) state that the positive benefits of caregiving include increased self-esteem and self-respect, satisfaction with having fulfilled one's obligations, a sense of competence and mastery in managing caregiving tasks, feeling needed or useful, and having resolution of previously unresolved issues or feelings.

Positive aspects of caregiving (PAC) have been identified in a variety of ways, but are defined as the rewards and satisfaction derived from the caregiving relationship (Hilgeman, Allen, DeCoster, & Burgio, 2007, p. 2). Hilgeman et al. (2007, p. 2) state that satisfaction with caregiving and rewarding appraisals of caregiving may reduce caregiving stress and improve emotional outcomes. A study done by C.A. Cohen, Colantonio, and Vernich (2002) in which they asked 289 Canadian caregivers if they could identify and describe positive aspects within their caregiving relationship (PAC) found that 73% of caregivers identified at least one PAC, mentioning a range of positive experiences from feeling fulfilled, important, and responsible, to finding a sense of companionship and meaning within the relationship (Hilgeman et al., 2007). The ability to identify positive aspects within the caregiving relationship can serve as a buffer against negative consequences (Hilgeman et al., 2007). Caregiving in the end can be viewed as a growth-enhancing experience.

### **3.7 Caregiving for Down Syndrome**

Each family caregiver responds to his or her situation in a different way. Some families tend to cope better or worse with having a child with Down syndrome and other families will do really well. The birth of a child with Down syndrome has many effects on the family (Abery,

2006, p. 3). In fact, it is likely to affect the whole family system in many ways. According to Abery (2006), research shows that families of children with developmental disabilities often have added stress, social isolation, and more marital discord, more tension among siblings, greater caregiving burdens and poorer physical and mental health. Siblings have been found according to Sari, Baser, and Turan (2006, p. 29) to be affected positively, while other studies report behavioural disorders, poor school performance and antisocial relations of siblings. According to Cunningham (1999) siblings also tend to have a high anxiety trait and low perceived support and regard from their parents. Since the child with Down syndrome is given most attention within the family, parental caregivers tend to neglect the rest of the family and place high parental expectations and demands upon siblings.

Parental caregivers who have a child with intellectual disability or mental illness often have to face a lifetime of caregiving responsibility (Kim, Greenberg, Seltzer, & Krauss, 2003). As a result, it takes a toll on their mental health, especially the mothers who take on the caregiving role. Another aspect of having to provide care to a child with an intellectual disability such as Down syndrome is that it often occurs that parental caregivers tend to have a feeling of loss and grief, and having concerns about their child's future when they will no longer be able to provide the needed care or supervision (Kim et al., 2003). Family well-being is also affected by a lack of resources to provide care for a child with Down syndrome. For example, financial problems and a lack of a car were associated with the stress levels of mothers and poorer family relationships (Cunningham, 1999, p. 90). Cunningham (1999) also found that the child's disability restricted the mother's own employment opportunities.

Another aspect which has an influence on parental caregivers is external stressors, which are linked to the disability and include lack of progress and development, negative public opinion, pressures from spouse or other family members, pressures from members of parent support groups, financial needs, lack of relief, frustration from interactions with helping professionals, loneliness, and concerns for the future welfare of the child (Greaves, 1997). With these stressors parental emotions are raised and this causes them to display mourning, anger, fear, depression, self-pity and guilt.

Having a lack of resources to cope with a situation are likely to increase strain or stress on the family (Cunningham, 1999, p. 88). If informal supports and resources are made available to families with a child with Down syndrome, family interaction can be promoted and maintained.

### **3.8 The Benefits of Caregiving for a Person with Down Syndrome**

There are many caregivers who derive positive benefits from their care role. One of the findings by Green (2007, p. 158) on what benefits mothers derive from having a child with a disability was a response to the nature of Down's syndrome itself. The mother of the child with Down syndrome talked about the sense of peace and joy her son seemed to exude, even as an infant, and the value of that peace and joy in their lives (Green, 2007).

Another finding on the positive benefits of providing care for children with Down syndrome was that families with children and adults with this syndrome report less stress than families with children with similar levels of intellectual disabilities from other causes

(<http://www.down-syndrome.org/information/family/overview/?page=3> ). There is some evidence that ageing parents who have adults with Down syndrome still living at home have better physical health and life satisfaction than ageing adults in the typical population (<http://www.down-syndrome.org/information/family/overview/?page=3>). Other positive aspects to providing care for a Down syndrome child is an increased feeling of empowerment by parents, personal growth, and a rearrangement of priorities as examples of the positive changes they attribute to their experience of parenting a child with a disability (Cuskelly, Hauser-Cram, & Van Riper, 2008).

Other positive benefits to provide care for a child with an intellectual disability were findings by Green (2007). One of the findings was that most mothers of children with disabilities come to the experience having had very little prior contact with individuals with disabilities. This all changed when they had to take their children for health care and other services where they came into contact with other individuals with disabilities. This exposure increased their level of comfort with other people with disabilities (Green, 2007, p. 158). Green (2007) found that mothers believe that because they have a child with a disability it gives them the necessary strength and courage to face anything. Other positive experiences associated with caregiving are those caregivers who reported an increased awareness of what's important to them. They focus on those things which give life meaning and let other things slide (Green, 2007).

Caregivers who provide care for an individual with a disability have reported that this makes them much stronger, better, more competent people with a greater appreciation of the

important things in life and stronger and deeper relationships with friends and family are fostered (Green, 2007).

### **3.9 Dealing with Caregiving**

Because of the financial, physical and emotional strain as well as other unmet needs which impede a caregiver's ability to function effectively, caregiver support services can be introduced to provide information access, caregiver education and training, and respite and supplemental services (Chen, Hedrick, & Young, 2010). Research findings according to Chen et al. (2010, p. 117) have shown that counselling and education services are effective in helping caregivers to deal with their own psychological needs and in improving caregivers' relationships with care recipients. These counselling and education services can also help caregivers to avoid burnout through attending support groups which will also make them feel better by having someone to talk to. Caregivers can attend financial support services where they get cash support which can help benefit them in the end.

Caregivers who provide care for to a family member with a mental illness should try to follow coping patterns such as the following: maintaining family cooperation and having an optimistic view of their social support, self-esteem, and psychological stability as well as understanding the medical situation through communication with other family members and consulting with medical staff (Liu, Lambert, & Lambert, 2007, p. 87). By making use of these coping patterns family cohesion, family conflict and neglect of other family members can be prevented. Establishing a sense of coherence is regarded a cornerstone of successful adaptation for parents of children with Down's syndrome (King et al., 2005). With time and

experience, parents of children with disabilities may come to regain a sense of control over their circumstances and a sense of meaning in life by seeing the positive contributions of their children with respect to personal growth and learning what is important in life (King, et al., 2005, p. 354). If parents and caregivers are filled with feelings of hope and spiritual beliefs which are important to many people, then they will be able to overcome these life challenges.

It would also be good if the caregiver can get all the support they need from their families to help them cope with the situation at hand and not only provide sympathy and understanding. Caregivers, especially those who are employed, could be offered alternative work arrangements and flexibility with respect to time off (Duxbury, Higgins, & Schroeder, 2009). Support services to caregivers are of importance and these services should be able to empower the parents/caregivers to make informed decisions regarding their disabled child; they should be available and open to the entire family; and should be flexible in accommodating the unique needs of individual families (Siklos & Kerns, 2006).

In essence, if proper assistance is offered to caregivers which will reduce the demands made on them then caregivers will be able to survive and cope without forgetting and neglecting themselves.

### **3.10 Well-being of Caregivers**

In the past, most research documented the negative outcomes associated with caregiving which includes a decrease in both psychological and physical health (Semiatin & O'Conner, 2012). It is, therefore, important that one should not only focus on the caregiving experience

from a negative perspective but also look at the positive aspects to caregiving since this may help protect and enhance caregivers' well-being (Semiatin & O'Conner, 2012). So it is essential that one has an understanding of what well-being entails in its totality.

### **3.10.1 The Concept Well-being**

Well-being according to Seifert (2005) is a dynamic concept that includes subjective, social and psychological dimensions as well as health-related behaviours. Well-being refers to optimal functioning and experience (McMahan, & Estes, 2011) and applying and developing oneself to the fullest (Huta & Ryan, 2010). Well-being is not just about the lack of disease or illness or the absence of anxiety or depression but it is a state of complete physical, mental and social health.

Research has shown that caregiving is associated with a considerable amount of burden, depression and in some cases poor health (Marks, 1997), but nowadays research not only focuses on the negative aspect of caregiving but also looks at its positive side. One's well-being can be related either positively or negatively, but they do not form a bipolar continuum (Marks, 1997). This means that positive well-being and negative well-being are rather independent dimensions; a person can experience aspects of negative well-being but at the same time experience aspects of positive well-being (Marks, 1997, p. 5). For example, while a parent may worry and experience distress at times caring for a child with Down syndrome, other parents may find caring for a child with Down syndrome gives meaning and is a frequent source of pleasure.

### **3.10.2 Hedonia and Eudaimonia**

Hedonia and eudaimonia are two distinct philosophical traditions in the conceptualization and measurement of well-being. Hedonic well-being focuses on happiness and defines well-being in terms of increased pleasure and decreased pain. It defines well-being as the presence of positive affect and the absence of negative affect. Hedonism has its roots in Greek philosophers and Epicurus was its principal exponent (Vasquez, Hervas, Rahona, & Gomez, 2009).

Bauer, McAdams, and Pals (2008, p. 82), state that hedonic well-being is more individualistic and based upon how good one feels about one's life. Hedonic concepts are based on the notion of subjective well-being.

Subjective well-being (SWB) is a scientific term that is commonly used to denote the 'happy or good life'. SWB involves happiness and life satisfaction (Ozmete, 2011). Ryan and Deci (2001, p. 144) state that SWB consists of three components: life satisfaction, the presence of a positive mood, and the absence of a negative mood, together often summarized as happiness. SWB is seen as fluctuating daily in terms of one's life experiences. One of the main components of SWB is people's affect; this involves their pleasant and unpleasant moods and emotions. When people react with pleasant emotions they perceive what happen to them as good and when bad happens to people and they react with unpleasant emotions it is perceived that bad has happened to them. Moods and emotions of people are not only pleasurable or painful, but also provide an indicator of whether an event is perceived by the individual as desirable or not (Ozmete, 2011). Schwarz and Strack (1991). as quoted in



Ozmete (2011, p. 55), maintain that these judgements of people concern their enduring mood (e.g. happiness) as well as their evaluation of the self (e.g. satisfaction with one's physical and mental health and functioning) and its relation to the material and psychosocial environment (e.g. life satisfaction, work satisfaction).

The core meaning of eudaimonic well-being is based on self-realization and it defines well-being in terms of the degree to which a person is fully functioning. "Eudaimonic well-being involves pleasure but emphasizes meaningfulness and growth – a more enduring sort of happiness. It tends to be more humanistic and based upon how meaningful one's life feels in addition to simply how good it feels" (Bauer, McAdams, & Pals, 2008, p. 83). An example is Ryff's measure of Psychological Well-being which assesses feeling good about one's life in six ways: a positive attitude toward oneself and one's past life (self-acceptance), high quality, satisfying relationships with others (positive relations with others), a sense of self-determination, independence, and freedom from norms (autonomy), having life goals and a belief that one's life is meaningful (purpose in life), the ability to manage life and one's surroundings (environmental mastery), and being open to new experiences as well as having continued personal growth (personal growth) (Springer & Hauser, 2003).

Deci and Ryan (2008), as quoted by Winefield, Gill, Taylor, and Pilkington (2012), state that psychological well-being is usually conceptualised as some combination of positive affective states such as happiness (the hedonic perspective) and functioning with optimal effectiveness in individual and social life (the eudaimonic perspective). Psychological well-being is about lives going well. It is about feeling good and functioning effectively. Therefore, people with

high PW report feeling happy, capable, well-supported, satisfied with life and so on (Winefield, Gill, Taylor, & Pilkington, 2012).

### **3.10.3 Positive Psychology**

Caring for a person with Down syndrome is frequently associated with stress and suffering (see Cichetti & Beeghly, 1990). Focusing on stress and suffering of family members who are caring for a member with Down syndrome is in line with the assumptions of the *disease* model. It is important for people whether parents, caregivers, employers or employees to have concerns about how to achieve personal well-being. Psychological well-being is viewed as not only the absence of mental disorder according to Sin and Lyubomirsky (2009), but also as the presence of positive psychological resources that include components of hedonic or subjective well-being (e.g. positive affect, life satisfaction, happiness) as well as components of eudaimonic well-being (e.g. self-acceptance, positive relations, autonomy, purpose in life).

In order to strive towards optimal well-being and health, Slade (2010) suggests positive psychology as the science of what is needed for a good life. Positive psychology is a new field of psychology which seeks to understand positive emotions like joy, optimism and contentment (<http://www.blackdoginstitute.org.au>). It is a field in science which focuses on the positive aspects of human life like happiness, well-being and flourishing.

As well-being is all about the absence of distress and psychopathology (Seligman & Csikszentimihalyi, 2000), it would be best if caregivers were provided with appropriate intervention techniques on how to enhance their own well-being by making use of positive

psychology given that positive psychology is all about valued subjective experiences; that come from well-being, contentment and satisfaction, hope and optimism, flow and happiness (Slade, 2010). Seligman (2000), as quoted from Rothmann and Ekkerd (2007), suggests that the goal of positive psychology is to learn how to build the qualities that help individuals and communities not just to endure and survive but also to flourish (p 35). Caregivers should not only strive towards the idea of health as the absence of illness but they need to move towards achieving optimal physical, mental and emotional well-being as well as “psychological well-being which refers to the achievement of one’s full psychological potential” (Carr, 2003, as quoted in Rothmann & Ekkerd, 2007, p. 35). By making use of intervention techniques from a positive psychology perspective, caregivers can achieve lower rates of depression, reduced upset related to behavioural problems of care recipients and fewer burdens related to daily care activities (Semiatin & O’Connor, 2012).

Happiness which is part of positive psychology is just as important as optimal physical, mental, emotional and psychological well-being. Happiness according to Russell (1930/1958), is having an active interest and engagement in life, and affection, which means having meaningful bonds of love with significant others (Ryff & Singer, 2008, p 19). Psychologist Martin Seligman introduced the concept ‘authentic happiness’ which refers to fundamental strengths and using them every day in work, love, play and parenting (Huang, 2008). Authentic happiness is more than just having experiences of feeling good; it is about being engaged in some activity that is valued, regardless of the presence or absence of positive subjective feelings (Huang, 2008). Seligman’s theory of authentic happiness has identified different types of a good life:

- The Pleasant Life, which consists in having as much positive emotion as possible and learning the skills to prolong and intensify pleasures;
- The Engaged Life, which consists in knowing your character's highest strengths and recrafting your work, love, friendship, play and parenting to use them as much as possible;
- The Meaningful Life, which consists in using your character strengths to belong to and serve something that you believe is larger than just yourself; and
- The Achieving Life, which is a life dedicated to achieving for the sake of achievement (Slade, 2010, p. 5).

In order to enjoy the different types of a good life, approaches to promoting well-being need to be implemented. To enjoy an engaged life, psychologist Mihaly Csikszentmihalyi developed the concept of 'flow' which describes a state of joy, creativity and total involvement. This is when people feel completely engaged and have experiences of their problems disappearing as well as experiencing feelings of transcendence. To have a good life is one that involves complete absorption of what one does (Slade, 2010). This includes doing activities we like.

Caregivers need to seek out 'flow' experiences like taking more time to do leisure activities such as sport, art, games and hobbies which will create a more positive experience for them. In the end it is important to encourage a full life which is pleasant, good and meaningful.

### **3.11 Challenges of Caring for an Individual with Down Syndrome: Effects on Well-being**

Abbeduto et al. (2004, p. 237) state that parents raising a child with a developmental disability face challenges that are not shared by parents of typically developing children. Psychologically they have to face the loss of the expected “normal” child, accept the reality of having a “less-than-perfect” child, integrate the child into the family, and shoulder the lifelong process of rearing a child who is “different” (Lam & McKenzie, 2002, p. 224). The challenges of taking care of a child with Down syndrome come in many forms. It ranges from the medical conditions which includes congenital heart disease; congenital gastrointestinal tract malformations; ophthalmologic difficulties; ear, nose and throat problems; and musculoskeletal conditions to neurologic and neurodevelopmental disorders that consist of epilepsy; autistic disorders; attention deficit hyperactivity disorder (ADHD) as well as neurobehavioral disorders like oppositional-defiant disorder; disruptive disorder and stereotypic movement disorder (Cohen, n.d.). The various medical conditions associated with Down syndrome individuals lead parents to need more hospital appointments for their child which has a negative influence on the parents’ finances. The healthcare needs of the child with Down syndrome are more significant and serious than they are for the majority of children without Down syndrome and they can increase the family’s vulnerability (<http://www.down-syndrome.org/information/family/overview/?page=3>).

Lam and McKenzie (2002, p. 224), found that the long-term uncertainty of the child’s viability, future health, growth, and ultimate level of functioning and the family’s ability to meet the child’s needs are factors further adding to parents’ psychological stress. Because of

the child's delayed motor skills, physiologically the parents have to spend more time, energy and patience in taking care of their child. They have to manage their child's health and emotional and behavioural problems and train him or her in daily living skills (Lam & Mckenzie, 2002).

For this reason, they have limited time for themselves. Working mothers often have to give up their employment, and this has a profound effect on the financial security as a family. A parent who cares for a member with Down syndrome is faced with loss of various kinds and because of the child's handicap it creates crisis in the family, it creates potential for disrupting and adversely affecting the health status of its members (Lam & Mckenzie, 2002).

According to Lam and Mckenzie (2002, p. 224), parents of handicapped children report experiencing chronic sorrow, decreased self-esteem, and an increased level of depression. They tend to be less optimistic, and self-efficacious, more negative and self-blaming. The well-being of the parent decreases as time in the caregiver role increases. For instance, psychological well-being is how people evaluate their lives and this evaluation can be in the form of cognitions or in the form of affect (<http://www.grossnationalhappiness.com>). The cognitive part or cognitive well-being is an information based appraisal of one's life. This is when a person makes conscious evaluative judgements about his/her satisfaction with life as a whole (<http://www.grossnationalhappiness.com>). The affective part is a hedonic evaluation guided by emotions and feelings like the rate at which people experience pleasant/unpleasant reactions to their lives. People can experience moods and emotions which have a positive or pleasant affect (like joy, pride, happiness) or a negative or unpleasant affect (like sadness, depression, loneliness). All these components are conceptually and

empirically related yet they are distinct aspects of well-being ([http://nova.no/asset/5965/1/5965\\_1.pdf](http://nova.no/asset/5965/1/5965_1.pdf)). Caregiving comes with many facets (e.g. structural, social, financial, and existential) which have an impact on people's lives and can influence them in both a positive or negative way. The effects of caregiving on psychological well-being could vary substantially depending on the well-being aspect under scrutiny and the individual's other life circumstances (<http://nova.no/asset/5965>). Some caregivers may often experience emotional distress but nevertheless believe that their lives are highly meaningful and rewarding.

Having satisfaction with life (life satisfaction), satisfaction with self (self-esteem) and satisfaction with one's relationship (partnership relationship) can be viewed as aspects of cognitive well-being. Life satisfaction and partnership satisfaction refer to overall assessments of one's quality of life and relationship ([http://nova.no/asset/5965/1/5965\\_1.pdf](http://nova.no/asset/5965/1/5965_1.pdf)). Self-esteem has to do with a global evaluation of self-worth, self-acceptance, self-respect and self-satisfaction. Self-esteem and satisfaction judgements are believed to result from people evaluating their lives according to various standards like their earlier lives, personal goals and expectations, and the expectations of significant others (<http://nova.no/asset>). "Caregiving may thus depress positive self-evaluations because it usually represents a disruption of the expected and desired life course. Caregiving requires significant commitment of time and energy, which may cause marital discord, and lower marital and life satisfaction" ([http://nova.no/asset/5965/1/5965\\_1.pdf](http://nova.no/asset/5965/1/5965_1.pdf)). With caregiving comes more daily problems, worries, stress and poor sleep although caregiving can promote feelings of joy, fulfilment and pride. Caregiving thus increases psychological distress as well as having more positive affect

([http://nova.na/asset5965/1/5965\\_1.pdf](http://nova.na/asset5965/1/5965_1.pdf)). Extensive caregiving in the long run depletes the caregivers' energy, vitality and happiness which are aspects of affective well-being ([http://nova.na/asset/5965/1/5965\\_1.pdf](http://nova.na/asset/5965/1/5965_1.pdf)). Enhancing the caregivers' physical and psychological well-being is important as is enhancing the well-being of the child receiving care.

### **3.12 Chapter Summary**

Most of the research on the experiences of families who have a child with a disability indicates that, although there may be commonalities in the parenting experiences, the impact differs considerably among families (Joosa & Berthelsen, n.d.). Still, caregiving can result in negative psychological states like depression. But with positive psychology interventions, which are all about treatment methods or intentional activities, positive feelings, behaviours or cognitions and the increasing of well-being in caregivers can be cultivated (Sin & Lyubomirsky, 2009). Positive psychology is a young field within psychology but psychologists, educational psychologists, and practitioners can effectively incorporate positive psychology interventions into their practices as a way of improving the well-being of not only caregivers but many others.



## **CHAPTER 4**

### **METHODOLOGY**

This chapter begins by providing a brief detail of the qualitative research method and a short history of it, followed by the reason why the researcher thought that the phenomenological approach seemed suitable by discussing a few assumptions of the qualitative paradigm within the context of the research topic. A brief discussion on phenomenology (which was the research method used for this research) in terms of its philosophical roots will follow. The chapter then stated the aims of the research (as already stated in chapter 1) as well as look at the research questions that guided this study. The chapter also discusses the methodology used within this study as well as the research design, followed by a description of the participants and the sampling technique. A description of the data collection and of the data analysis will then be provided. The chapter ends with a look at the ethical considerations that arose in the conduct of this study.

#### **4.1 Research Design**

Qualitative ontology, epistemology and the social action research are some of the approaches within the qualitative paradigm which the researcher found suitable and applicable in terms of exploring the well-being of caregivers of a family member with Down syndrome in Namibia.

Ontology is the science or study of being - the emphasis being on the theory of existence (King & Horrocks, 2009). Qualitative researchers embrace ontology because it values

participants' own interpretations of reality from their context. Reality is socially constructed by each participant; therefore, this approach allowed the researcher to reveal the well-being of the caregivers when taking care of a family member with Down syndrome from within their unique context.

The term epistemology originated from the Greek word *episteme*, which means knowledge (Kruass, 2005). In order to gain the relevant knowledge from a participant, "the qualitative research method encourages researchers to reduce the distance between themselves and the study participants" to grasp the point of view of the participant or respondent. (Creswell, 1994, as quoted in Vujovic, 2008, p. 64). It is, therefore, important that a trusting relationship is built between the researcher and the participant in order for the participant or respondent to feel comfortable and at ease when sharing their experiences in having to take care of a family member with Down syndrome. By being within a relaxed atmosphere the researcher can try to understand from the participants or respondents the phenomenon being studied and the meaning it has for them.

One of the characteristics of qualitative researchers in general is that they make use of rich data which can be related to the anti-positivists and this is sometimes referred to as interpretive or the social action approach. The anti-positivists see social reality as consciously and actively created by individuals (Hayes, 2000, p. 8). The methodology is centred on the way in which human beings make sense of their subjective reality and attach meaning to it. Knowledge is, therefore, personally experienced rather than acquired from or imposed from outside (Dash, 2005). In order to understand the social reality of others it is important to enter their world, so as to comprehend fully the meaning and values they give to their intentional

participation within their world and within their daily lives. When doing this, it becomes possible for the researcher to fully appreciate how people create meaning in their respective environments. Anti-positivism produces a rich, descriptive text that captures as accurately as possible the feelings, convictions and viewpoints of others in the context of the natural setting (Neuman, 1997, as quoted in Vujovic, 2008).

Anti-positivism, therefore, emphasizes a phenomenological approach, which is constructed around the belief that individual behaviour is determined by the experience gained out of that individual's direct interaction with the phenomena. With the phenomenological method, the well-being of the caregivers who takes care of the family member with Down syndrome can be interpreted through their actions, ideas and experiences, because with this research method it is possible to explore human experience. Therefore, it is imperative that the researcher develops an empathic understanding of the phenomenon being studied so that she can reproduce in her mind the feelings, motives and thoughts that are behind these caregivers' actions. This research method deals with the experiential and subjective component of existence; it is concerned with the life world of the individual, insisting that individuals know more about their experiences than anyone else (Keen, 1975, as quoted from Vujovic, 2008).

Within the context of this study, phenomenology will provide a way of understanding the phenomenon of the well-being of the caregiver who takes care of a family member with Down syndrome.

According to phenomenology, the knowledge and understanding of human beings are fixed in our everyday world. This means, that phenomenology does not see knowledge as

quantifiable or able to be reduced to numbers or statistics, but that truth and understanding of life can emerge from people's life experiences (Byrne, 2001). Phenomenology is a branch of philosophy, and Edmund Husserl (1859-1938), a German philosopher, is the founder of this philosophical movement. Another influential thinker was Rene Descartes (1596-1650) who was considered as the first modern philosopher.

The aim of phenomenology, according to Husserl, is to study human phenomena without considering questions of their causes, their objective reality, or even their appearances. Husserl believed that one should seek what appears to be taken as reality and should then start one's investigation with what is experienced. Phenomenology is concerned with the primary reality, the thing itself as it appears; that is, the 'phenomenon' (Smith, 2003, p 12). The aim is to study how human phenomena are experienced in consciousness, in cognitive and perceptual acts, as well as how they may be valued or appreciated aesthetically (Wilson, 2002). Phenomenology is to return to the concrete, captured by the slogan 'back to the things themselves' (Groenewald, 2004).

Husserl (1936/1970) believed that human experience in general is not a matter of lawful response to the 'variables' that are assumed to be in operation but that experience is a system of interrelated meanings – a Gestalt that is bound up in a totality termed the 'lifeworld' (Smith, 2003, p. 12). The lifeworld entails the world of objects around us as we perceive them and our experience of our self, body and relationships. This means the human realm essentially comprises embodied, conscious relatedness to a personal world of experience (Smith, 2003). The lifeworld can be defined, according to Finlay (2008), as the world that is lived and experienced – a world "that appears meaningfully to consciousness in its

qualitative, flowing givenness; not an objective world ‘out there’, but a humanly relational world”. Experience is of a meaningful lifeworld.

This study is, therefore, operationalized from a phenomenological point of view since it brings to the fore the experiences and perceptions of caregivers from their own perspectives of what it is to take care of a child with Down syndrome.

The research can be classified as qualitative research from a phenomenological approach. This means that caregivers were observed and questioned by making use of questions developed by the researcher to understand their experiences in caring for a Down syndrome child. This method was considered most appropriate, as the researcher aimed to explore the experiences and well-being of caregivers of a child with Down syndrome. Furthermore, it allowed the researcher to study the meaning caregivers give to their experiences of their world.

## **4.2 Population and Sample**

The research population consisted of the caregivers who are either the parents or the guardians responsible for raising and caretaking of the child with Down syndrome. An availability sample consisted of the parent(s) or the guardian responsible for the child.

During the research professionals such as speech therapists and occupational therapists were contacted via telephone to make an appointment in order to obtain names of possible participants. However, most of the participants which they provided were either from the

Moreson and Dagbreek Schools (these are schools for the intellectually impaired). The researcher also made an appointment beforehand to see the principal of Moreson School where she obtained the names of possible participants. The researcher contacted the Dagbreek School's principal and obtained by email the names of possible participants who could share their experiences in terms of caring for a family member with Down syndrome.

The population for this study consisted out of 16 caregivers who either had children at Dagbreek and Moreson Schools. However, some of the respondents were also identified through word of mouth. Through snowball sampling these respondents were gathered. Snowball sampling refers to a gradual accumulation of relevant cases through contacts and references (Blanche, Durrheim, & Painter, 2006). At least 4 respondents did not want to be interviewed owing to the sensitivity of the research topic as well as 5 respondents who did not attend their appointments.

No specific age group of a child was focused on as the well-being of a caregiver changes according to the development of a child's age. A study by Eisenhower, Baker, and Blacher (2005) was conducted on families of children aged 36 months and then again when the children were between 48 and 60 months. Within this study they found an increase in problem behaviour in the children, which was associated with an increase in maternal stress. Another study, done by Bourke et al. (2008) also shows that it is possible that as the child enters late childhood and middle adolescence, it becomes difficult to obtain services, and that uncertainty about the child's future may promote stress within mothers. Lastly, Gallagher, Phillips, Oliver, and Carroll (2008) found that the more challenging the behaviour of the child, the greater the parents' recourse to mental health services.

### 4.2.1 Participants

Participants were from Windhoek, coming from various neighbourhoods. Most of the participants were the mothers of children with Down syndrome as the father were either at work or elsewhere and preferred that the mother took part within the study. Despite the changing gender roles, “mothers still tend to have primary responsibility for child care and are, thus, most subject to the challenges associated with their child’s disability” (Abbeduto et al., 2004). Participants were also from various ethnic groups.

Following are the demographic details of the participants in this study.

Table 1

*Demographic Details of the Participants (n=16)*

Participant no.	Age	Gender	Caregiver relationship to member with DS
1	46	Female	Mother
2	44	Female	Mother
3	39	Female	Mother
4	40	Female	Mother
5	32	Female	Mother
6	42	Female	Mother
7	41	Female	Mother
8	54	Female	Grandmother
9	27	Female	Sister
10	55	Female	Mother
11	42	Female	Mother
12	64	Female	Mother
13	52	Female	Mother
14	46	Female	Mother
15	47	Female	Mother
16	56	Female	Mother

Participants consisted of 16 female caregivers of whom two were the grandmother and the sister related to the individual with Down syndrome. Mean age = 45.43 years, range = 27-56 years. The demographic details were summarized in Table 1 to provide an overview of caregivers and their characteristics.

### **4.3 Data Gathering**

#### **4.3.1. Interview**

Interviews based on the phenomenological paradigm were used to gather data. An interview refers to structured or unstructured verbal communication between the researcher and the participants, in which information is presented to the researcher (<http://uir.unisa.ac.za/bitstream/handle/10500/1962/04chapter3.pdf>).

The researcher studies the phenomenon without predetermined expectations or categories, and tries to understand the data from the perspective of the participant. This means penetrating the individuals' mental world and exploring the phenomena each individual experiences (Hayes, 2000). Interviewing of participants took place within the home and office environment where the participants felt most comfortable and safe.

The researcher followed these steps with each interview: made an appointment with each participant at a time which suited them and prepared a tape recorder. Before the researcher conducted the interview, she thanked the participant for their time and willingness to be part of the study, the participant were asked for permission to record the interview and were



reminded before the start of the interview that the interview is voluntary and that if they had difficulty answering the question/s or felt uneasy about the question/s that they can withdraw from the interview at any time.

#### 4.3.2 Conducting of Interview

The main technique for collecting data within this research study, as already mentioned, was by interview. The interview was non-directive and the researcher projected an attitude of unconditional positive regard. Interviews were tape recorded and notes were taken. The researcher made use of an interview guide. An interview guide includes the key or central questions that the researcher asks the interviewee during an interview (<http://uir.unisa.ac.za/bitstream/handle/10500/926/03chapter3.pdf>). The interview was informal with the central question - **“What are your experiences in taking care of a member with Down syndrome in all dimensions of your life?”** – and this question was explained to each respondent.

The phrase *dimensions of your life* refers to the spiritual, financial, physical, emotional, psychological, social needs and work of an individual. One’s social situation like the relationship with your husband or wife or the relationship with the community are also part of one’s dimensions of life. Experience was defined as “What do you think?”, “What do you feel?”, and “How do you act?” The researcher asked the question and made sure that each respondent understood the question. Although this was the central question within the research, additional questions were asked to establish a relaxed atmosphere and to make respondents feel comfortable as well as to get more information from them (Please see

Appendix A). Participants were free to raise issues or explore questions not included in the interview guide.

The researcher's attitude was one of unconditional positive regard and the respondent was allowed to do as he/she felt like. Non-directive conversation techniques, for example, minimal encouragement, attentive listening, clarification, paraphrasing, reflecting, and summarising were used to gather information. Enough time was allowed for the respondent's response and a relaxed atmosphere was created to help the participants to feel at ease. With each interview undertaken, the researcher experienced that the duration of the interviews varied from one participant to another.

#### **4.3.3 Reliability and Validity**

To ensure reliability of the interview the research approach was consistent and neutral. Consistency was obtained through a description of method of data collection, analysis and interpretation, the use of a coding-recoding process and "the use of colleagues and methodology experts to examine the research plan and its application" (Rothmann, 2000, p. 6). Neutrality of the research was obtained through conformability of the data and its interpretation.

The validity of the research was ensured through credibility and transferability. To ensure credibility of the interview the researcher made sure to spend sufficient time with the participant to establish rapport, to facilitate comfort and to increase the willingness to make known sensitive information (Rothmann, 2000, p. 7). The researcher rephrased and repeated questions to the participant so as to gain credible information. Reflexive analysis was taken

into account to prevent close relationships between the researcher and the participant which could possibly have an effect on the interpretation of findings. The researcher ensured that there were no inconsistencies between the data and the interpretation thereof.

#### **4.4 Data Analysis**

The interviews were transcribed verbatim. This ensured that the richness of the text was not lost. These verbatim transcripts were then analysed by making use of content analysis. Content analysis stands for categorizing answers into different types and the number of each type is counted. This means, identifying the general themes mentioned in the interviews and then counting the number of times they are mentioned (Hayes, 2000). The researcher did this by analysing the data, dividing it into segments and then scrutinising it for commonalities that could reflect the themes. Themes are topics or ideas which occur recurrently during the course of a qualitative analysis. The data was then categorised in terms of similar comments and grouped together. This helps in determining dominant and sub-themes. The themes that appear are used to describe and understand the phenomenon under investigation which is the experiences of the caregivers. These themes were checked and verified by an Industrial Psychologist for confirmation and/or criticism.

#### **4.5 Ethical Issues**

To ensure ethical behaviour, the researcher was at all times sensitive to ethical matters. In order to protect participants, well established ethical principles were followed which are inherent within qualitative research (Orb, Eisenhauer, & Wynaden, 2000).

Capron (1989) states that any kind of research should be guided by the principles of respect for people, beneficence and justice. According to Orb, Eisenhauer & Wynaden (2000) Capron considered that respect for people is the recognition of participants' rights, including the right to be informed about the study, the right to freely decide whether to participate in a study, and the right to withdraw at any time without penalty. In order to ensure ethical research, the researcher made use of informed consent. Informed consent is when participants exercise their rights as autonomous persons to voluntarily accept or refuse to participate in the study. Consent has been referred to as a negotiation of trust, and it requires continuous renegotiation (Orb, Eisenhauer, & Wynaden, 2000, p. 95).

Within this study, the researcher developed a specific informed consent agreement, in order to gain informed consent from participants. The researcher explained the purpose of the research to the participants in detail (without stating the central research question), procedures of the research, and the benefits of the research. Each family's experiences and feelings are unique and need to be respected; therefore, in order to ensure no harm is done to the participants, participation was voluntary; it was explained to participants that they are free to withdraw at any stage during the process. Participants were ensured of anonymity although most did not care whether their real identities were used as they felt quite relaxed about the whole research. Please see Appendix B for the consent form.

A second ethical principle which was made use of during this study was beneficence – doing good for others and preventing harm. Beneficence means that the researcher does whatever

he or she reasonably can to ensure that participants are not harmed by participating in the study and ensures the well-being of the participants.

Participants were asked for permission within the consent form to use the data they provide for research purposes. This permission was gained by means of a written document (see Appendix B for a copy of the consent form). Owing to the sensitivity of the research topic, the participants were ensured confidentiality.

#### **4.6 Chapter Summary**

The advantages of this qualitative phenomenological research study were that it was an appropriate approach to researching human experiences, in this case, the well-being of the caregiver of a family member with Down syndrome. Rich data from the caregivers were collected which ensure both a pure and thorough description of the phenomenon.

## **CHAPTER 5**

### **RESULTS**

Chapter five presents the themes which emerged during the interviews with the caregivers. This will be presented in tabular form to give an indication of the responses of caregivers to certain themes and their ranking. There were 16 respondents who took part within the interview.

There now follows a discussion on the findings of this research.

#### **5.1 Results**

The results obtained regarding the well-being of caregivers of a family member with Down syndrome are presented in Table 2. The frequencies of themes are indicated. Based on the frequencies, a ranking was assigned to each theme.

Table 2

*Well-being of Caregivers*

<b>THEMES</b>	<b>FREQUENCY</b>	<b>RANK</b>
<b><u>Knowledge of Down syndrome</u></b> Caregivers' knowledge on Down syndrome	15	1.5
<b><u>Challenges that Caregiver experiences</u></b> Caregivers' challenges with child Caregivers' ways of coping with their situation in everyday life	15 3	1.5 13
<b><u>Realization that child has Down syndrome and ways of coping</u></b> Caregivers realize for the first time that their child has Down syndrome Caregivers' feelings when realized child has Down syndrome	13 6	3 8.5
<b><u>Spiritual beliefs and lessons learned</u></b> Spiritual effects it has on the caregiver Special lessons caregivers learned by having a Down syndrome child	12 9	4 6
<b><u>Expectations</u></b> Future expectations of caregivers Caregivers' expectations before learning their child has Down syndrome	11 1	5 21.5
<b><u>Economic effects</u></b> Financial effects on the caregivers	7	7
<b><u>Emotional effects</u></b> Caregivers' fear of dying and not knowing what will happen to child Caregiver's feeling that she will always have a companion	6 2	8.5 16.2
<b><u>Spousal Relationships</u></b> Spousal relationship is/are affected	5	10
<b><u>Effects on social life: family relations</u></b> Family support is minimal	4	11.5
<b><u>Effects on social life: social reactions</u></b> Feelings of shame when out in public Caregivers' negative experiences within the community Social support from other parents	4 2 1	11.5 16.2 21.5
<b><u>Effects on work</u></b> Caregivers' work is affected	2	16.2
<b><u>Sexuality</u></b> Caregivers feel hysterectomy is/or was needed Caregivers feel child needs to be on contraceptives	2 1	16.2 21.5

The themes and sub-themes which are presented in the above mentioned table emerged during the interviews. Now follows a discussion on the meaning of each theme, with their

sub-themes. Literature will be used to support the findings. It should be noted that the researcher used numerical order (from the highest count to the lowest) to express the frequency.

### **5.1.1 Knowledge of Down Syndrome (Rank=1.5)**

This theme relates to the knowledge of the caregiver on the subject of Down syndrome. When most caregivers found out that they were expecting a Down syndrome baby they tried to find out the nature of Down syndrome as best they could. This gave most caregivers some sort of understanding of what to expect.

This theme (rank = 1.5) was mentioned by most (15) caregivers who reported that they do understand and know what Down syndrome is all about but only to a limited extent.

According to participant E, Down syndrome is: *“a spectrum of mental, developmental challenges and a spectrum of physical challenges”*. Participant D says: *“he is not mentally able like most of the people are. He is slow in learning and it has to do with the chromosomes. He has an extra one...”*

Although caregivers knew what Down syndrome is in terms of the syndrome, they did not know the physical and sensory conditions as well as the medical conditions associated with the syndrome. Not knowing everything about the nature of Down syndrome was due to a lack of information. According to Lam and McKenzie (2002, p. 234), research has shown that practitioners are at fault for disregarding parents' concerns and for withholding information.



The limited knowledge of the caregivers has helped them to provide care and to support the development of their child as best they can.

## **5.2 Challenges that Caregivers Experience**

The following section looks at the challenges different caregivers reported and the different ways each caregiver coped with his/her situation. According to Buckley (2002), parenting can be a rewarding and a challenging experience for most parents, and to be a parent of a child with a disability adds more challenges.

### **5.2.1 Caregivers' challenges with child (Rank=1.5)**

Parents of children with disabilities experience greater stress and a larger number of caregiving challenges, such as more health problems, greater feelings of restriction and higher levels of parental depression than parents of children who are not impaired (Heiman, 2002, 160).

Fifteen caregivers of the interviewed indicated that they become tired because of the challenges and responsibilities related to their child (rank=1.5). Most of those challenges which caregivers experienced took place in the early years of the child's life. Responsibilities ranged from having to carry their child around to being constantly working with the child to increase development, to helping with daily activities, e.g. bathing and washing hair.

This theme is supported by the following responses. Participant B explained it in these words:

*“... if you want them to do something you must start by doing it yourself. And that puts a big, yes actually a load on you. Because I want my child to stay healthy and to do that, I must make sure that she exercises, does exercises regularly. So what I have to do is to climb on my bicycle and ride the bicycle myself with her. I have to do exercises at the gym wherever with her. So it means a lot of physical things for me. I have to set the example”.*

Another challenge to participant B is the fact that her daughter can't read and write although she was in school for fourteen years. This is what she had to say: *“other challenges that I'm still facing are girl B can't read and write. So I would like to see her one day, I don't know when it will be. But just to do basic simple reading”.*

Participant C looks after her younger sister who has Down syndrome. For participant C looking after her sister who was 15 years of age (at the time of the interview) is frustrating in terms of her hygiene. Participant C feels that at that age her sister should have been able to take care of herself in terms of her hygiene, although she understands that her sister is Down syndrome and has certain shortcomings. She should make sure that her sister is bathed and what is most challenging to her is that when her sister menstruates then she has to clean after her, and remind her to make use of sanitary towels. This is what participant C had to say: *“when she has her menstruation and she does not understand anything of that. I forget, I forget. And I put those stuff in, pads and stuff in her school bag but she throws it away or she takes it out or she leaves it somewhere. And then they call you from school”.* When asked how she feels about this, she said the following: *“I get irritated at her. I really get irritated but then eventually it comes to compassion”.*

Participant K reports that she still has to bath her daughter and this is sometimes challenging for her. She said *“I still bath her but obviously I mean like when I don’t feel good or I have a problem with my back being sore, it’s not always the easiest”*.

Participant L’s daughter has a heart defect, and to this mother it was a challenging situation. In her own words: *“... the heart. That was the problem, and yes we were a little bit scared. We did not know how to handle her. And what would we give to her, you know, with regard to food, with regard to medical aid, all these types of things, what will happen to the heart that would give a problem and all these types of things”*.

Participant M said the following: *“When she has her periods then I have to help her, I can’t leave her to deal with it on her own. Because she is not capable to do it, which means I constantly have to be there and help”*.

For participant P carrying her son around when he was already two/three years old, was too physically challenging. She said the following: *“...he had low muscle tone. I had to carry him a lot you know. You know this was not so easy .And obviously a child with low muscle tone you have to carry them and be physically involved .This is something that of course was sometimes very demanding”*.

Each family’s physical demands are influenced by the child’s specific variables like age, sex and severity of the problem (Gupta & Singhal, 2004).

### 5.2.2 Caregivers' ways of coping with their situation in Everyday Life (Rank = 13)

During the interview with the caregivers, three caregivers stated that in order to cope with their situation at home they take time out when it becomes tiring and stressful. The following are coping strategies which they mentioned they make use of:

Participant B says when she takes time out; she leaves her daughter with someone else and does the following: *"perhaps go to a friend for a day and just go to the movie with a friend"*. Sometimes she and her husband will go. This is what she said: *"we will go for a day or two just to camp somewhere or go alone on shopping or whatever"*.

Participant E said: *"I travel for work. And then my elder daughter sometimes baby sits. And you know I think I have it pretty much well organised .I'm a manager. I manage my people at my work or the team at my work and I manage my team at home. And I think I don't feel guilty; I don't feel like I have to always be with her I, yes I create space for my own things and we combine, you know .Me time and her time"*.

Participant F said she does the following: *"I just go to boot camp Mondays, Wednesdays and Fridays I try to do creative stuff at home you know .I like to make some things..."*

This theme can be supported by the following research findings. According to Taanila, Syrjala, Kokonen, and Jarvelin (2001), in order for a family to cope they make use of their existing resources and strategies. Coping strategies are the active processes and behaviours that the caregivers/family actually tries to employ to help it to manage, adapt to or deal with a stressful situation (Taanila et al., 2001). Coping is the constant change in one's cognitive and

behavioural efforts to manage specific external and/or internal demands that are appraised as taxing the family's resources (Taanila, et al., 2001, p. 74).

Taanila et al. (2001, p. 81) found within their study that parents take time for themselves to get rest and relaxation from the everyday duties and to do something together, or would take time for themselves and go out with friends.

### **5.3 Realization that child has Down Syndrome and Ways of Coping**

The next themes are all based on when different caregivers realized that their child had Down syndrome, which was either at birth or a few months later. Also this theme covers the ways parents coped with finding out their baby is/has Down syndrome.

#### **5.3.1 Caregivers realize for the first time their child has Down Syndrome (Rank = 3)**

Thirteen caregivers reported that they only found out after their child was born that he or she had Down syndrome. This theme can be supported by the following caregiver responses:

*Participant B: "when she was four months old I realised that her growing is slower than my first child and the muscles are not that stiff that it should be actually at that stage. So then I went back to the doctor for an examination, to examine her. And yes, they were at that stage still worried about her case and they knew about her and remembered her. But they read up and investigated on her specific case. And then they took blood tests and then they could say 'yes it was Down syndrome'".*

Participant D: *"... the doctor informed me that she suspects that he has got Down syndrome and did tests and I think it was confirmed within a month that he is Down syndrome. You, as a mother, you always have got that instinct that something is not okay".*

The following caregiver/participant only realized after two months that her child was Down syndrome:

Participant H: *"He was 2 (two) months old. It was, we had a problem to feed him .He drank very little and we knew that there was a problem. And so we went back to the doctors and they sent us to the specialists and they did some tests.*

It is evident that some caregivers only realized after birth, after a month or even later that their child had Down syndrome. This delay in knowing was caused either by not having the financial means to get tests done to find out whether they were expecting a Down syndrome child or to get certainty whether it is a Down syndrome baby they will have. Having to wait for blood tests in the past took time and as a result some caregivers only heard a month or so after the birth that their child had Down syndrome. Regardless of when and how caregivers found out that their child had Down syndrome, they adapted to their situation in order to satisfy the needs for the development and education of the child after accepting their disability (Ergun & Ertem, 2012). Mothers, according to Ergun and Ertem (2012), who were able to accept and adapt to their child's lifestyle had a healthy relationship with their child and their social environment.

### 5.3.2. Caregivers' feelings when realized child has Down Syndrome (Rank = 8.5)

Under this theme, six caregivers reported that when they heard their “perfect born baby” is not that perfect but has Down syndrome, they were either shocked, grieved, in denial, disappointed or had feelings of guilt and embarrassment. This theme can be supported by the following responses:

Participant B only found out after four months that her daughter had Down syndrome. These are the feelings she expressed during the interview when the researcher asked her how she felt when she eventually found out that her daughter had Down syndrome: *“Well it was a very bad moment in my life. Very sad. It felt to me as if someone took away my normal child and gave me a sick child. That’s how I felt”*.

When participant H found out after two months that her son had Down syndrome, she said the following: *“I felt like a loser”*. When the researcher asked her why she said that, she replied: *“because when we expect the baby you expect a perfect born baby”*.

Participant O knew since birth that her daughter had Down syndrome although she only received confirmation six weeks later through blood tests. Her feelings when she realized her daughter had Down syndrome were: *“... I was really shocked at when she was born and grieved”*.

The birth of a mentally retarded child, according to Venkatesh Kumar (2008), is one of the most traumatic events experienced within a family. As a result parent’s reactions and emotions can vary from being angry, sad, and disappointed to feelings of acceptance and

content while other parents might feel their child's disability affects their entire family structure and life (Friend & Bursack, 2009).

Most parents are filled with feelings of grief about their child's disability, or they tend to experience sadness for themselves because of the changed family dynamic or they tend to mourn the loss of unfulfilled expectations. As a result of the changed family dynamic, parents, according to Venkatesh Kumar (2008), experience a variety of 'psychological stress' which is related to the child's disability.

#### **5.4 Spiritual Beliefs and Lessons Learned**

The following themes are based on how some caregivers came to grow spiritually stronger and how their spiritual beliefs have helped them to accept their situation. It also looks at the special lessons they have learned through this experience.

##### **5.4.1 Spiritual Effects it has on the Caregiver (Rank = 4)**

Twelve caregivers reported that they have grown spiritually because of their experiences; they became closer to God. Some caregivers reported that they feel they have a deeper spiritual awareness which has helped them to cope with the situation which they are currently in and others feel that they are special in a way. Caregivers felt that they are blessed in some way and with all this they came to accept their child with Down syndrome. The following responses can confirm this theme.



Participant A feels that: *“such a special child can only be given to a special family. I believed that oh I must be somehow special if God chose my family, me to have this child”*. Participant A also reported that she feels *“... really blessed. Especially with boy A being around. We really had to get in touch with reality. You know with reality and really live like with our feet on the ground you know. And I think that has grew us, that has grew us into better people you know and better parents for that matter. So yes I think we are blessed”*.

Participant H reports the following feelings: *“this probably brought me closer to the Lord. I am now on a level that I am deeper; I have a deeper relationship with the Lord. And where I trust the Lord in a lot of things for boy H etcetera. So that made me stronger spiritually ...a more mature person...”* And participant K believes that: *“it is a gift from God. Whether it’s such a child or not”*.

Having spiritual beliefs, as these caregivers have, helps them as families to adjust and adapt to having a child with a disability. This can be supported by the intensity of one’s spiritual and religious beliefs which according to Abery (2006, p. 9) has been associated with less stress in families who have children with developmental disabilities. According to Brown (2004), spiritual values and having a ‘dream’ for the family and particularly having a family member with with Down syndrome are associated with enhanced quality of life.

#### **5.4.2 Special Lessons Caregivers learned by having a Down Syndrome child (Rank = 6)**

Nine caregivers within this theme reported the positive contributions made by their child. Raising a child with a disability like Down syndrome has helped some caregivers to gain a greater understanding of themselves and through this they learned valuable lessons like patience, acceptance, tolerance, compassion, humanity and unconditional love.

This theme can be supported by the following caregiver responses. Participant A says she has learned *“to take life slowly”* and to *“listen more attentively; you give more attention to little things that might not have been so important before .So you take a step back and you just have to learn to go slower in life”*.

Participant B expressed the following: *“children with Down syndrome teach you a sense of humour in your house”*.

Participant C said she learned the following: *“... she teaches you humanity. She teaches you compassion and she teaches you forgiveness because she’s always so loving and forgiving... She teaches me to value myself”*.

Each child with Down syndrome has taught different lessons to each caregiver for which each caregiver is thankful. The child with Down syndrome not only brings negative experiences to the family but also makes positive contributions to family life. According to Cuskelly, Hauser-Cram, and Van Riper (2009), parents report increased feelings of empowerment, personal growth, and a rearrangement of priorities, as examples of the positive changes they attribute to their experience of parenting a child with a disability. Poehlman and colleagues found, as quoted from Cuskelly et al. (2009) that mothers saw their child with Down syndrome as having a number of very positive personal characteristics that acted to maintain and develop connections between family members and with others.

## 5.5 Expectations

The following themes are about the future expectations each caregiver has for his/her child. It then looks at what the expectations of the caregiver were before learning that their child had Down syndrome.

### 5.5.1 Future Expectations of Caregiver (Rank = 5)

Eleven caregiver participants reported that they would like to see a special needs class in Windhoek Government, a medical centre where parents can take their child with Down syndrome to various professionals without having to pay an exorbitant amount of money and a social network where these children can come together and interact with each other. This theme can be supported by the responses below.

Participant E feels that *“they are special and they have special needs and they have, things are slightly different. But it doesn’t mean that you must do exclusion. I would love to see Government Schools starting with a special needs class”*.

Participant P said the following: *“I would like to see that there is something coming, a little farm for handicapped adults. That is the most important. where they can work, where they can produce. You know it is not a job. There are a lot of little jobs that they can do but it has to be a positive job that they understand that they are important for life. And whether it is the cows’ milk or the garden or the woodwork or the, making up the bed or cooking or whatever, this is their life, to me, weaving or whatever. You know it is a combination of all and this can only be done on a small holding, a small*

*farm. Where they can keep a cow and maybe have a couple of goats or chickens or whatever and do something, you know bake cakes. Make a living for them”.*

Participant O would like to see the following in Windhoek: “ *I would love... a programme in place that if a child with Down syndrome or any other impediment is born, you just say from the delivery room, okay the doctor can just go and say ‘it’s okay, here’s the number, go to these people’. And you have the support”.*

As most caregivers (parents) are filled with shock, anger, stress, sadness and despair when their baby is born with Down syndrome, it would be useful for the caregiver (parents) to join a support group that would provide both information and understanding. Being a member of a support group can be of great advantage to the caregivers as it provides friendship and emotional support, practical advice, and information and advocacy when better services are needed for children (Buckley, 2002). Not only would the caregiver benefit but it would also support other family members such as brothers, sisters and grandparents.

Early intervention would benefit children with Down syndrome tremendously in terms of their development. According to research studies, appropriate education provided in inclusive settings will offer the best opportunities for children with Down syndrome (Hughes, 2006). These children can become an active part of society and they can fully integrate themselves into their communities if they learn the proper rules and techniques to do so early on. This statement can be confirmed by Brown’s (2004) work, that it is important to include individuals with Down syndrome socially and psychologically as this will provide an enriched and inclusive environment that will foster self-esteem and quality of life.

### **5.5.2 Caregivers' Expectations before learning child has Down Syndrome (Rank = 21.5)**

One caregiver explained that she had great expectations for her child before she found out that the child had Down syndrome. This theme can be supported by the following caregiver response. Participant B stated as follows: *"I saw my daughter one day growing up and becoming someone with a career like my other child. So I wished that everything or I hoped that everything would go well for her like for my other child. A normal healthy life with a family and her own children. And I dreamt about all those things. But unfortunately, yes all my dreams actually stopped that day when I heard about her disability".*

Most parents when they find out that the wife is pregnant they dream about what the new baby will look like and they dream about a wonderful future for their child. However, when they realize that it is not what they have hoped and dreamed of, they are filled with complete sadness and overwhelming loss for that perfectly normal child. These statements can be supported by Ergun and Ertem (2012, p. 776) who indicate that most parents have expectations of raising a normal child, and hold hopes and expectations for the future of that child. However, when parents have a child with some impairment, they may experience dramatic changes to their social life, expectations, plans, work life and their financial status (Ergun & Ertem, 2012).

## **5.6 Economic Effects**

This theme describes the financial situation caregivers experience in terms of having a child with a disability like Down syndrome.

### 5.6.1 Financial Effects on the Caregiver (Rank = 7)

Seven caregivers indicated that having a child with Down syndrome puts a strain on their financial income as well as the fact that they do not have a proper job. The following are some quotes by caregivers on how they are affected financially.

According to participant B although her daughter is in good health, she has to take her regularly for check-ups at the doctors as well as to different therapists who help with the development of her daughter. This is what she had to say: *“So I really put in a great effort to get her to these therapists. And that costs a lot of extra money. So it definitely has an impact”*.

Participant L’s daughter has a heart defect. She feels that the parental income is not sufficient and as a result her daughter sometimes suffers. She said: *“... I sometimes feel, you know a person looks towards the finances. Will we cope, will we not cope and then your children suffer as a result of that. And she suffers as a result of that. The medical costs are a bit much. I have to help my husband and then you look straight into that again. And so it can become quite a tough one.*

Although participant L has a Government Medical Aid, this aid does not cover all the costs, which then means that the parents have to provide the rest which to them is sometimes challenging. In February 2010, they took their daughter to Cape Town, South Africa, to a heart specialist. This is what she had to say: *“...afterwards we were covered in doctor’s accounts because the medical aid covers only a portion you know. So then the rest you must take out and give. That has pulled a bit at our pockets. But how should I say the everyday costs are not so terrible. It is*

*not so heavy. And it's now just that we have to get ourselves ready for the next big operation, you know. So we have to kill everything that is still there so that we get ready for the next one".*

Not all children with Down syndrome are difficult to take care of; some are more difficult than others and sometimes this place extra financial demands on the family, especially the parents (<http://www.down-syndrome.org/information/family/overview/?page=3>). Since children with Down syndrome have different health care needs which leads to more hospital appointments and often more illness than that experienced by typically developing children, this tend to cause more strain on the finances of the parents (<http://www.down-syndrome.org/information/family/overview/?page=3>). "It is when the healthcare needs of the child with Down syndrome are more significant and serious than they are for the majority of children with Down syndrome that they increase the family's vulnerability" (<http://www.down-syndrome.org/information/family/overview/?page=3>).

## **5.7 Emotional Effects**

The following themes are based on the caregivers' emotional feelings in terms of having a child with Down syndrome.

### **5.7.1 Caregivers' fear of dying and not knowing what will happen to child (Rank = 8.5)**

This theme indicates that six caregivers expressed their concern about what would happen to their child when they die. They are worried about who will take care of their children. The following are some of the responses.

Participant B had the following to say: *“Well I would say just for her to have, to always have somebody who cares for her because she won’t be able, although she’s quite independent, she will always need someone who loves her and who cares for her and who looks after her. And this is in the back of our mind as parents. I believe that we have these fears of falling away and leaving this child alone behind. But I’m quite sure that her brother will care for her if I’m not there and my husband is not there anymore”*.

Participant D wants her son to be independent and not to rely consistently on others for help; therefore, she tries her best to teach him how to look after himself. This is what she had to say: *“normally what makes me emotional is thinking what will happen if I’m not there. So if I have to pass away now, what will happen. I think that is the only thing that really makes me emotional. And that is why I’m trying by all means to have him independent and to have him do something for himself and not to always rely on dad, mom, cousins, sister, granny or whoever is around him”*.

Two days after the birth of participant E’s daughter she had an anxiety attack because she is concerned about what will happen to her daughter when she dies. Participant E’s own words: *“...then I got this anxiety attack I think on the second day. When I am 70 (seventy) then she is going to be 30 (thirty) and then what if I die, who is going to look after her”*.

Participant K had the following to say: *“It’s just that, it makes you anxious because you don’t know; I’m not going to be there forever. You know what’s going to happen when I’m not there, when I can’t look after her. Then she’s sort of isolated. I mean she can’t go into the shop and buy something for herself”*.



Existing studies shows that parents have concerns about the child's future when they are no longer able to care for them or when they die. According to Pollack (2011), individuals with mild or moderate intellectual disabilities will outlive their parents, who are often their primary caregivers. Many of these caregivers who are sometimes already over the age of 60, will themselves experience physical and cognitive challenges, which can make it difficult to care for the person with the disability. Individuals with intellectual disabilities like Down syndrome now live a longer, fuller and richer life due to improvements within the medical field and they thrive in the family home or community-environment, which leads them to outlive the men and women who are their direct caregivers (Pollack, 2011). Pollack (2011, p. 48) also states that nearly two-thirds of all family caregivers worry that the person they care for might have to go to some place where they do not want to live.

#### **5.7.2 Caregiver feels that she will always have a Companion (Rank =16.2)**

Two caregivers within the interview said that they enjoy having their child around. Too them it is some sort of consolation knowing that they will not be alone.

Participant J for instance feels that her son is there so that she won't be alone. When her son was born, he was born a month early. When he was 6 weeks old, they noticed that he had a heart problem and when he was 3 months old, he had his first heart attack. Through all this he survived; therefore, participant J had the following to say: *"And I knew that the Lord had a plan to keep this child here. But now I know he's here to look after me again. I can't be alone so now I have got somebody to chat to"*.

Participant N mentioned within the interview that all her children are grown-up and have left the “nest” (home). However, it is only her daughter who has Down syndrome who will be staying on and that makes her happy. In her own words: *“Well I’ll always have somebody with me. I’ll never be on my own. So I’ve always got someone with me”*.

Brown (2004) states that adults with Down syndrome often live in the parental home much longer than other children. This impacts the parents as they have become used to someone being around in the house, and they are used to their child’s company. Brown (2004) found that some families adapt by viewing the person with Down syndrome as a permanent resident in the family home. “Indeed, sometimes a parent will be distressed at the prospect of the person leaving home since adaptation has formally taken place and they, the parents, would feel lonely if they left” (Brown, 2004). Parents have come to rely on the individual within the home for help and companionship, which is similar to the case of the caregivers within this study (Brown, 2004).

### **5.8 Spousal Relationship**

The theme in this section is about how the relationship between spouses is affected when they have a child with Down syndrome.

### 5.8.1 Spousal Relationship is Affected (Rank = 10)

Five caregiver respondents reported that their relationship with their spouse is affected due to the fact that they have a child with Down syndrome. This theme can be supported by the following quotes.

Participant A stated in the interview that when her son was born she was very overprotective of him. By being too overprotective of her son she pushed her husband away from her. This is what she had to say: *“You know in the beginning I tend to be very much over protective of my son. Very much over protective and in the process maybe pushing away the father for instance and so there I sense a bit he was a little bit withdrawn and all that. And I think maybe later on I started understanding that maybe he would still feel responsible or guilty or something”*.

Participant K said that she feels that her husband might feel that she does not give him enough attention. Participant K: *“I mean obviously sometimes you know, maybe he feels that I’m not giving him the time I should. You know it’s not easy. Let’s put it that way. I’m not going to say there’s nothing going on. It depends obviously yes you know, you have to be understanding in that sense. Because she needs assistance and you can’t say okay you wait now because I’ve got my husband. She’s a child and you’ve had her and you’ve got to give her the time”*.

The onset of stress and tension in participant L’s relationship came later as time went by. Participant L had the following to say: *“In the beginning we were both fired up and full of flames, taking on this big challenge together. So it was not an issue. But later it became a little bit, brought a little bit of stress. You know, the men they also want a lot of attention. So she got 24/7 (twenty four*

*seven) attention and that caused a little bit of discomfort and stress between the two of us. This brought a bit of distance between the two of us. But we worked through it again”.*

Participant N said that strain was prevalent within their marriage when their daughter was born. This is what she had to say about her relationship: *“Well in the beginning I think it was a bit of a strain because obviously one is in denial, one doesn’t want to know about this kind of thing. So that was a bit uncomfortable, but after that I mean we’ve had three (3) other kids. You know it’s difficult for someone who has always wanted to be perfect and for something to happen like this. So yes in the beginning it was a bit of a strain within our marriage”.*

Past research by Gath (1977), found that families of 30 children with Down syndrome and 30 families of same-aged typically developing children were interviewed many times and the results compared over the first two years of the child’s life (Urbano & Hodapp, 2007). Through this study researchers found that by the time the child was 24 months, 6 couples in the Down syndrome group had divorced, separated, or were showing particularly poor marital relationships whereas none of the 30 control couples showed these signs of marital distress. “Evidence suggests that marriages in the Down syndrome group may be troubled in the child’s first two years of life” (Urbano & Hodapp, 2007, p. 261).

### **5.9 Effects on Social Life: Family Relations**

Extended families like grandparents, aunts and uncles play an important role in supporting parents emotionally with their child with Down syndrome. However, if any of them have difficulty in accepting the child, this can add to the stress experienced by parents (Buckley,

2002). The following theme is based on the minimal support caregivers receive from their families.

### **5.9.1 Family Support is Minimal (Rank = 11.5)**

Four caregiver respondents confirmed that they only get minimal support from their families.

Participant C said that she is the only one of the family that takes care of her sister and that it is her problem. The rest of the family gives no help whatsoever even when she goes to family events. Participant C: *“You know she, it’s still my problem if I go to family events. They will greet her and she will be in between but I should still keep an eye on her. No one else will”*.

When participant G was asked in the interview how she perceives her social support system, she replied that it was not effective at all. She only gets financial support from her sister to look after her daughter, but not emotional support. Participant G: *“... it is just me. It’s just like that; my sister will sometimes help financially or buy something for her. But besides that it is only me”*.

Participant J’s father did not accept her son. This is what she had to say: *“my father does not like him. He was one who doesn’t accept people with any drawbacks and he couldn’t accept this little one. Although this little one was crazy about him you know. But he stays in South Africa and we only see him once a year for 3 (three) weeks. And he was too small to find out that my father doesn’t like him. He doesn’t like anybody with a problem”*.

When the researcher asked her how it makes her feel when her father does not like her son, she said the following: *“You know you feel sad and hurt but you can do nothing about it, so you just*

*accept it and you try to be there for the child. But luckily he was so small; he could not get the vibe, you know. But I know, my father even, he did it so well that we even haven't seen that he shows that he doesn't like the child. But one day there was, my aunt was there. My mother was already dead at this stage. And he told her 'I can't take this child'. That's the first time that I could see that he don't like him. He always has the pose of showing that he likes him".*

When a child with a disability like Down syndrome is born, the attitude of grandparents, uncles and aunts plays an important role in helping parents to adjust to their new baby. If the extended family has a positive attitude to this new and unknown situation then it provides great support to the parents (Buckley, 2002). Grandparents, aunts and uncles do not only provide emotional and practical support for caregivers but can also provide children with an increased range of close relationships (Buckley, 2002).

## **5.10 Effects on Social Life: Social Reactions**

This section is on how caregivers experience social reactions when they were out in public or within the community with their child who has Down syndrome. It also looks at the support caregivers received from fellow caregivers who are in the same situation as they are.

### **5.10.1 Feelings of shame when out in Public (Rank = 11.5)**

Four caregivers in the interview reported that they had feelings of shame when they were out in public with their Down syndrome child. The following respondents confirm this theme.

Participant M feels ashamed when people stare at her daughter because her daughter has big breasts and they tend to tease her about this. This is how participant M feels when they stare at her daughter: *“she shies away from people because they tend to tease her about her breasts. I sometimes feel very unhappy when they look at my child like this. Sometimes I swear at the people when they tease and make fun of her. When they say, “look at this big women”, I swear at them. I sometimes feel ashamed when people stare at her when we go into town but I have no choice”*.

When people stare at participant N’s child this is how she feels and experiences it: *“... I don’t know, it hurts when people are rude and they stare and even after 28 (twenty eight) years you still get hurt, you know it’s not a nice feeling to have as a parent”*.

In the past when participant B went with her baby daughter out to town then she would hide him from the people. This is how she went about: *“I would put her in her chair but cover her completely with blankets and things so that nobody could ask me ‘I want to see your child or whatever’*. When the researcher asked her why she did this, she answered: *“... I was ashamed and I didn’t like being looked at, I didn’t want other people really at that stage to ask me questions and to, well to look at my child. I was ashamed, definitely ashamed .Yes and I think I was not emotionally ready to give them the answers that I wanted”*.

The birth of a Down syndrome child is a huge blow to their self-esteem for most parents. They feel that having given birth to a child with a disability reflects badly on them, especially when they do not already have other children (Selikowitz, 1999, p. 6). This feeling causes embarrassment and parents then often tend to rather stay away from others.

### 5.10.2 Caregivers' Negative Experiences within the Community (Rank = 16.2)

Two caregivers in the interview mentioned that they had some negative experiences within the community when they were with their child who has Down syndrome. This theme has the same ranking as 5.7.2.

When participant A wanted to place her son within a normal kindergarten she was faced with rejection. She was told the following: *"no, some parents wouldn't like their children to be in a school with a child like that. She wasn't very eager to accept the child, that principal.... The teachers told me no, it won't be a problem; it would be lovely to have him and so on. And that teacher, the principal, she went like 'ya well, she will see, she has to talk to maybe a few parents or the board, the school board to find out if they can accept him because they don't have such a child in the school and some parents might feel you know that they don't want their children to be at school with a child like that".*

Because most people have no knowledge of Down syndrome and what such children are capable of educationally, teachers tend to ignore them. Participant K had the following to say: *"... if you hear remarks what teachers say about these children. It's ridiculous. I mean it doesn't hurt me or anything because I just think it's because they're stupid you know. But if they say 'ag, leave this child you know she can't do anything'. You can't say that, it's wrong".*

Often parents or the caregivers find that their friends, neighbours and people in the community may react negatively to them and their child with the disability by avoiding them, getting disparaging remarks or looks, or overt efforts to exclude people with disabilities and



their families (<http://family.jrank.org/pages/396/Disabilities-Impact-Disabilities-on-Families.html>).

Even though the Namibian Constitution, Article 8, states ‘human dignity needs to be respected and that no person shall be subject to torture or to cruel, inhuman or degrading treatment or punishment’ (<http://www.orusovo.com/namcon/chap3.htm>) families often still have to deal with people who have judgemental and stigmatizing attitudes and behaviours towards intellectually or physically impaired children or adults.

### **5.10.3 Social Support from Other Parents (Rank = 21.5)**

One caregiver stated that they obtained support from other families who also have a Down syndrome child, and this helped and assisted them through their devastating situation from the beginning.

Participant B: *“we contacted other people with children with Down syndrome and two (2) couples visited us over that week-end. They came to us and, well, told us how we can/should actually handle this and they offered their help and their assistance wherever and whenever we needed it. So that helped a lot also”.*

Previous research suggests that the range of emotional and practical supports outside of the family influence family well-being (Buckley, 2002). This means that the support the parent or caregiver has will impact the individual personalities and coping styles of parents. However if parents are isolated, then having more social networks will not be helpful because then the

parent or caregiver might not have the confidence to access these sources of support and may feel awkward relating to others within a group support situation. It would be good if the parent or caregivers' personal needs are first addressed before being able to benefit from other social supports available in the local community (Buckley, 2002). Research also shows that coping with stressful life events suggests that those who are socially isolated are more vulnerable and less likely to make positive adjustments (Buckley, 2002).

### **5.11 Effects on Work**

This section looks at the way in which caregivers' work is affected and their experiences in this area.

#### **5.11.1 Caregivers' work is Affected (Rank = 16.2)**

Two caregivers within the interview said that their work is affected as a result of having a child with Down syndrome.

Lady "L"'s daughter was born with a heart defect, and as a result her daughter was operated in South Africa which caused her to be absent from work. Not only was this a problem in the beginning but she also has to take her daughter for physiotherapy every 2<sup>nd</sup> week and this also puts strain on her work. Medical issues arise frequently and interrupt Lady "L"'s work life often. Although her employer allows her to take sick leave and time to care for her daughter, it often happens that she requires more time off from work than is allowed, thus causing her not to keep up with her work. When the researcher asked her how all this affects her work,

she replied the following: *“My boss feels I am a bit too much away from work. He’s not very happy with that .So now you have that tension at work as well .I, therefore, cut back on her physio. I now let her go every second month and not every week. Like now my boss turned my leave down in December. I am so tired, I am so tired, I thought if I can just take 2 (two) weeks from work for Christmas just to rest a bit but he felt not. He said I was away from work during the year far too much. I have already applied for leave but it was turned down. Although, you don’t know, as much as possible I tried to work it in. You know if she is sick if I am perhaps away for half a day you know. So physio is 2 (two) hours every second week. You know you don’t lie for weeks off from the work. You must now also look after your work and you also need the income. So just then I have very difficult bosses.*

During the interview, the researcher asked participant L whether her boss knows about her daughter. This is what she had to say: *“Yes, he knows. You know one day he said to me: ‘I understand your situation’ .I know this is not your fault; it’s not my fault, and it’s nature’s fault. I understand your situation but I cannot be with someone that is not at work a lot, you know. He won’t understand that I, you know, try to do it in short and as little as possible. The facts are that I am not at work now every month. And she was at a stage after the operation she was quite a bit sickly so I was then about a day in a month, there would be a sick day that I was away from the work .So that is how I basically have no more sick leave over. So he knows the situation but like I told you I have a difficult job.*

Many caregivers within the caregiving system struggle to balance work, family and provision of care to the person with the disability. This theme and statement can be confirmed by Duxbury, Higgins, and Schroeder (2009), as quoted by Murphy et al. (1997) who describe what they call “conflicted workers” as “those maintaining their work roles in the face of adverse effects due to caregiving”. Workers who are suffering from conflicts in work-life

balance are particularly stressed and overloaded (Duxbury et al., 2009). Conflicting work roles and caregiving can be viewed, according to Duxbury et al. (2009), as having repeated interruptions at work, having less energy for work, working less productively/efficiently, having to reduce hours or take unpaid leave, having to take a less responsible job, or having to resign from work entirely.

## **5.12 Sexuality**

The following themes are about the concerns caregivers had in terms of their children's sexuality as well as their concern about contraceptives. Both these themes are particularly focused on the need for contraception.

### **5.12.1 Caregivers feels Hysterectomy is and/ or were needed (Rank = 16.2)**

Within the interviews, two caregivers felt hysterectomy is important for female children. One caregiver, participant B mentioned that her Down syndrome daughter had to have a hysterectomy because she and her husband realized that their daughter would not be able to care for her own children.

This is what she had to say: *“she had to get a hysterectomy, which was quite emotional for me. Because you realise then that the chance for having grandchildren from her side is zero (0). I mean you must make this decision and you, well I made this decision not only for, yes for herself actually also because I just realised, me and my husband we realised that she won't be able to care for her own children”*

Participant M, on the other hand, felt worried that her granddaughter might be raped and, therefore, she would like her to have a hysterectomy or be sterilized. This is what participant M had to say: *“You know, sometimes we have to take a taxi and it’s not always possible as there is not always money. Then we have to travel from Katutura into town or to school and then it’s not possible. Because at times, I perhaps only have money for myself to get to work and not for her. And I do not really want to leave her at home because I am afraid my husband or my sons might rape her. I am not saying that it will happen but these are things I fear and which I am worried about. I would like to take her to the doctor so that she can be sterilised or that she gets a hysterectomy”*.

Hysterectomy, which is the removal of the womb, and a form of surgical contraceptive procedure, was used in the past according to Selikowitz, (2008), as a form of sterilization and a means of stopping menstruation in women with Down syndrome. Begun (2008, p. 15) states the following reasons why parents request sterilization of mentally retarded individuals: parents had many fears and concerns about menstrual hygiene, inappropriate sexual behaviour (like kissing and touching), fear of pregnancy, fear of sexual abuse and uncertainty about the efficacy of birth control methods.

#### **5.12.2 Caregiver feels Child need to be on Contraceptives (Rank = 21.5)**

One caregiver has mentioned that she would like her daughter to take contraceptives.

According to participant G her biggest concern is her daughter’s sexuality, because she is afraid that boys might try to sexually abuse her daughter and, therefore, she visited a doctor who suggested her daughter uses contraceptives.

This is how she feels in terms of her daughters' sexuality: *"Her sexuality is my biggest concern. I'm anxious now that she's in her adolescent stage. And she is a pretty girl. It's because of that, that I get this anxiousness. And she loves men that are also one of the things that I have noticed. And that makes me very anxious. The kids, they sometimes use the kids. I therefore went to Dr 'G'. And then he suggested that she use birth control"*.

All humans have sexual needs, whether they have a disability or not. People with Down syndrome also have sexual feelings and intimacy needs like any other normal human being. According to Dyke, McBrien, and Sherbondy (1995), parents with Down syndrome children have a great concern about contraception. It is, therefore, important that families and caregivers recognize these feelings in socially acceptable, age appropriate ways (<http://www.ndss.org/index.php>). Parents and caregivers should, therefore, ensure that they teach their child with Down syndrome that sexual intercourse is an adult act. If they are uncomfortable discussing sexual and reproductive issues, as well as the use of contraception, then they need to go to health care providers and professionals who can provide clear information tailored to patient developmental levels (Dyke, McBrien, & Sherbondy, 1995).

### **5.13 Chapter Summary**

The family caregiver within this study experiences both positive and negative aspects when providing care to a family member with Down syndrome. Some caregivers show signs of stress or distress which are due to the different challenges and responsibilities they experience. Regardless of the challenges and responsibilities they have to face, many are able to cope, adjust and adapt successfully and are able to live a 'good life'.

## **CHAPTER 6**

### **DISCUSSION, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS**

This chapter concludes the thesis with the discussion, limitations, recommendations and conclusion. The conclusion will give the key research findings.

#### **6.1 Discussion**

The results of this study are consistent with those of earlier investigations of Down syndrome children and their impact on caregivers but are also unique in several respects. Although caregivers struggle to accept and come to terms with the lost dreams they had for their child, over time they came to accept their child and the situation and their whole perspective about their child changes. While caregivers initially think of their child with Down syndrome as a catastrophe, they come to realize over time that they do have some input and measure of control over the child's development and the impact he or she have on the family. They start to realize the positive contributions their child makes to themselves, their family and to society as a whole.

Various themes within the study emerged which show how the well-being of a caregiver of a family member with Down syndrome is affected, whether positively or negatively. The findings in this study support and are consistent with other studies and demonstrate that bringing up a child with a disability can be both a rewarding and challenging experience. What the researcher has learned from this study is that although caregivers have a hard time raising a child with an intellectual impairment like Down syndrome, it is not always negative.

Caregivers experience positive benefits like the motivation to live on, increased self-awareness and spiritual growth. Having a spiritual belief system allows one to give meaning to the birth of a child with a developmental disability (Abery, 2006, p. 9). Caregivers believed their spiritual beliefs gave them a positive sense of well-being. Spirituality, which can be seen as a component of well-being, can be seen as spiritual well-being. Van Dierendonck and Mohan (2006, p. 234) view spiritual well-being as an element of eudaimonic well-being by focusing on spirituality as an inner resource. Spiritual engagement, like praying and meditating, is concerned with the process of receiving strength, support and guidance (van Dierendonck & Mohan, 2006, p. 234). Inner resources are looked at as the inner aspects of a person that produce an individualized awareness of one's inner self and a sense of being part of a deeper spiritual dimension (Van Dierendonck & Mohan, 2006). Spiritual inner resources are what gave caregivers a feeling of strength in their time of crisis, and when dealing with the uncertainties of their life. Inner spiritual resources ultimately give a sense of secondary control over the situation which leads to having greater trust that everything will turn out for the best (Van Dierendonck & Mohan, 2006).

Other findings on spirituality and well-being show that “those with a spiritual orientation tend to have higher levels of *self-esteem* and are *more optimistic in life*. People with a spiritual orientation also tend to experience higher levels of *personal growth* than do those with a secular, ‘here and now’ outlook on life. Most significantly, those with a spiritual orientation have a much greater sense of *purpose in life* than those with a secular outlook on life. Those with a spiritual orientation also tend to register slightly higher levels of *satisfaction with life*, particularly in the areas of satisfaction with *achievements in life* and *place in the community*. Finally, those with a spiritual orientation are more likely to contribute to others, whether



informally in daily life, or by giving money to charities or doing voluntary service with community groups” (Kaldor, Hughes, Castle, & Bellamy, 2004, p. 10). Given that caregivers have tremendous faith in their spiritual beliefs, it can be said that they have an enhanced positive psychological well-being.

Caregivers accepted their child and learnt special lessons like compassion, humanity, patience, kindness and forgiveness. These special lessons gave caregivers meaning in life and a positive outlook. What these caregivers have learned can be linked to Martin Seligman’s concept of ‘authentic happiness’ where he argues that there are major sets of experiences in life, namely experiencing pleasantness (the pleasant life), experiencing a high level of engagement in satisfying activities (the engaged life), and experiencing a sense of connectedness to a greater whole (the meaningful life) (Sirgy & Wu, 2007). In order for all caregivers to attain a more challenging and meaningful life, gratification can be acquired, which brings the experience of flow which is the state in which time stops and you feel completely engaged in what we are doing (Huang, 2008). Gratification is gained through one’s strengths and virtues. All these signature strengths are the lasting and natural routes to gratification, dealing with challenging life demands and thus the route to “the good life” (Olson, 2007).

Although caregivers have to face certain caregiving challenges everyday like health problems, hygiene, and the additional workload of caring for a child with special needs, it is evident that caregivers do undergo a certain amount of psychological stress in raising a retarded child. There is a huge amount of research that does suggest that parents of disabled children undergo more than the average amount of psychological stress (Venkatesh Kumar,

2008, p.227). However, at times they tend to look beyond their challenges and just enjoy the moment.

The data within this study also agrees with previous studies that caregivers are affected financially or economically. Children with disabilities require more care and this result in increased costs, leaving families as the most important source of long-term care and assistance for their impaired children (Anderson, Dumont, Jacobs, & Azzaria, 2007). According to a national U.S. study, 40% of families of children with special health care needs experience a financial burden because of their child's condition, hence, not only is the child with the disability affected, but so is the whole family (Anderson et al., 2007).

Caregivers reported that their work was affected since they have to provide care to their Down syndrome child. Smale and Dupuis (2004, p. 26) state that caregiving responsibilities may negatively affect the productivity of employed caregivers who could miss out on career moves, and thereby experience negative economic consequences or who may need to give up employment entirely to meet caregiving demands. Not only do working caregivers experience negative impacts on their work performance but these impacts may be greater than the impacts on the family (Smale & Dupuis, 2004). Smale and Dupuis (2004) argue that the need for increased time off work can cause the caregiver worker to be faced with additional tasks which can be taxing on both mind and body. The sense of feeling overloaded with work can have an impact on one's psychological well-being. Psychological well-being has to do with one's positive mental state, like being happy and satisfied in life. Diener and his colleagues did research and found that people who score high on psychological well-being go on later to earn high income and perform better at work than people who score low in well-being (Zangmo, n.d.).

The data also shows that caregivers have minimal support from their families which is also prevalent within existing studies. Also it was found that caregivers each have different experiences within the community. As already mentioned, the attitudes and reactions of the extended family have an important influence in helping the parents or caregivers of the child born with a disability to adjust. It is a great source of support when grandparents, aunts and uncles have positive attitudes, but when any of them have difficulty in accepting the child, this can add to the stress experienced by parents (Buckley, 2002).

Some caregivers still tend to receive negative reactions from other people within the community, they, therefore, restrict their social interactions or they try to be selective in order to avoid them or be less affected by them. It would, therefore, be good if the family's existing network of friends in the neighbourhood, at church, play schools, mother and toddler groups, and at clubs in the community can be a positive source of support, provided that such networks are positive about the child with Down syndrome and welcome him or her into their homes or activities (Buckley, 2002).

What the researcher has also learned in this study is that caregivers have some knowledge on Down syndrome. Although caregivers know what Down syndrome is, they were not aware of the other possible physical and sensory conditions as well as medical conditions associated with it. Caregivers only understood Down syndrome to a certain extent owing to a lack of information. This is because practitioners are not straightforward with their patients. Lam and Mackenzie (2002) state that practitioners are at fault for disregarding parents' concerns and for withholding information. Singer and Irvin (1989, as quoted in Lam & Mackenzie, 2002,

p234) argued that it is vital to provide as much information in as clear a fashion as possible since some mothers have a knowledge deficit regarding the syndrome. However, it is evident that having sufficient knowledge on the matter helps the caregiver to understand their situation at hand better and through this competence and resilience are fostered.

Some caregivers reported that they experienced distance within their relationships with their husbands when their baby with Down syndrome was born. However, they worked through their struggles and helped each other in the end. According to research, the support that mothers get from their husbands like encouragement, assistance, feedback and help in the completion of tasks in daily life demonstrates a high level of marital satisfaction (Venkatesh Kumar, 2008).

For some caregivers their child's sexuality, especially with regard to sexual abuse, was a concern. There are many studies that have shown that people with disabilities experience a higher rate of sexual abuse than people without disabilities (Fitzmaurice, 2002). Caregivers either made sure their daughters had a hysterectomy or want them to use contraceptives owing to parental concern about menstrual hygiene, inappropriate sexual behaviour (like kissing and touching), fear of pregnancy, and fear of sexual abuse. Davis (2008, p.273) states that the cognitive and language deficits with which individuals with Down syndrome present predispose them to unwanted pregnancies, sexually transmitted diseases, and sexual exploitation and abuse. What makes it more complex is that pregnant women with Down syndrome have a 50% chance of having a child who also has the disorder (Davis, 2008). Another concern to caregivers was the child's future when they are no longer able to care for their children or when they (the caregivers) die.

Although caregivers go through all these experiences, some of them try to make time to do other things for themselves like shopping; art work (like painting), take exercise or are involved with the church. This is done as a way of coping with the situation at home and to maintain a sense of well-being.

As Namibia, especially Windhoek, has no schools which specifically cater for Down syndrome children, many caregivers felt that this is a necessity. They would like to see schools where their children feel at ease with other children and an educational system which equips their children to lead independent adult lives in the community. Education will make a significant difference to the level of independence achieved in work, social and leisure life. Although Dagbreek and Mōreson Schools are schools for the intellectually impaired but which also take in children with various disabilities, research indicates that appropriate education provided in inclusive settings offers the best opportunities for children with Down syndrome (Hughes, 2006). Down syndrome children will benefit greatly if they are integrated socially and accepted by non-disabled pupils within an educational system. This will help them to benefit from age appropriate role models and from the benefits of feeling that they are part of the ordinary community (Hughes, 2006).

According to Ross and Van Willigen (1997), education improves the subjective quality of life, measured as psychological well-being. Schooling encompasses the accumulated knowledge, skills, values and behaviours learned at school, and in addition give qualifications that can lead to employment opportunities (Ross & Van Willigen, 1997, p. 276). Income indicates economic well-being – this will foster confidence and self-esteem in individuals

with Down syndrome. With inclusive education families will feel less isolated from the rest of the community and this will also help families to develop relationships with other families who can provide them with support.

This study also indicates that caregivers would like a centre which specifically caters for Down syndrome children where they will be able to reach their full potential and function as independently as possible. Not only should this centre provide the necessary resources for their children but also help them, the caregivers and their families to maintain their well-being.

This study has advanced our knowledge and understanding of how, despite the challenges and difficulties that caregivers have in raising a child with Down syndrome, with the financial, emotional and social problems it entails, and the concerns about the child's future, employment and spousal differences, caregivers respond with determination, strength, courage and resilience.

## **6.2 Conclusion**

There has been no scientific studies' regarding the experiences and well-being of families as caregivers of Down syndrome children residing in Namibia. Since all studies on this subject were conducted in foreign countries, the objective of this study was to explore this topic in the Namibian context.

The birth of an intellectually disabled child with Down syndrome can be an upsetting event for a family. This study found that when caregivers heard for the first time that they were expecting a child with Down syndrome they were filled with a variety of emotions. Their emotions ranged from shock, guilt, and disbelief to fear and a feeling of being overwhelmed. With time caregivers came to accept their child and their whole perspective changed about their child. Most caregivers explained that while they understood the nature of Down syndrome, they were not aware of its full impact which included physical, sensory and medical aspects. However having some knowledge enabled them to understand their child better and this fostered competence and resilience.

Caregivers within this research study consisted mainly of women, as the men were either at work or somewhere else and preferred that the mother took part. This is because mothers are seen as the primary caregiver, despite the change in gender roles; it is the mothers who are subject to the challenges associated with their child's disability (Abbeduto et al., 2004). Caregivers from different ethnic groups took part, but there was no reported difference in terms of their experiences in caring for a family member with Down syndrome.

The first research question is based on how families are faced with challenges when caring for a family member with Down syndrome. The study shows as many other such studies have done, that caregivers are faced with different caregiving challenges such as having to dress, feed, bath and carry around their child because of its delayed motor development.

Caregivers reported within the study that they experience heavy financial expenses which are related to health care and professional treatments such as physiotherapy, occupational therapy

and psychologists. Since they have to work for a living caregivers are less available to care for their child which in turn causes the caregiver physical and emotional exhaustion.

The second research question was based on how caregivers experience having a family member with Down syndrome in Namibia. The study revealed that when a child with an intellectual disability like Down syndrome is born into a family, it creates a certain amount of strain between spouses. Yet caregivers in this study reported that they have overcome their differences and now encourage and support each other to adjust better as a family. What striking was during the course of the study was how unknown and unreported the situation of children with Down syndrome in Namibia is. There is a kind of silence about Namibian families who have a member with Down syndrome, which means it is not out in the open and many people lack the knowledge of the nature of Down syndrome. Caregivers still have friends, neighbours and community members who react negatively to them and become critical and pass unfavourable remarks and looks.

The third research question in the study was on those factors which affected the stress level and well-being of caregivers. A major factor was the financial concerns of caregivers with regard to their child's health, especially when income was low. The well-being of caregivers was extremely bad when it came to their work situation. Since caregivers constantly have to take leave of absence to take their child to a doctor, they are faced with additional workload which causes depression, anxiety, feelings of frustration, anger, loss of energy, tiredness, and even burnout. Other physical symptoms which impact the health of caregivers were ulcers, digestion problems and high blood pressure. Concerns that caregivers also had in this study were their child's sexuality, especially regarding sexual abuse. Although some caregivers



made sure that their daughters had a hysterectomy or wanted them to use contraceptives their fears and concerns for their daughters were related to menstrual hygiene, inappropriate sexual behaviour (like kissing and touching), fear of pregnancy and fear of sexual abuse. Other concerns of parents were about the child's future when they are no longer able to care for them or when they (the caregivers) die.

The fourth research question has found that support for families was lacking to a great extent. No support groups are found within Windhoek (at the time of the research) and there was no support from extended family or community. The limited support caregivers did get was from the same family members who also live with the Down syndrome individual. In order to sustain their well-being caregivers rely on their faith - spiritual and religious beliefs. These beliefs are used as a coping mechanism by caregivers to get through whatever troubles them. Caregivers try to maintain a sense of well-being by going shopping, doing painting, going away for weekends or vacation or through their involvement with the church.

Caregivers had various future expectations. Some would like to see a centre where their children with Down syndrome can develop independently and feel at home as well as a place that educates parents so that they can become strong advocates for their children and which would assist the parents with advice in terms of understanding and managing their children's developmental demands. Others would like to see their children in schools which specifically cater for Down syndrome children; many caregivers felt that this is a necessity. Regardless of the challenges and difficulties, caregivers accepted their child and learnt through all this compassion, humanity, patience, kindness and forgiveness.

This study shows that despite the challenges and responsibilities that family caregivers with a member who has Down syndrome have to face, they will be able to learn and grow as a family and that adaptation is within the grasp of most families.

### **6.3 Limitations**

The following limitations have been identified in this research:

A specific limitation of this study was that it only took place within the vicinity of Windhoek which means that it was not possible to generalise the findings to the entire Namibian society. The sample for this research consisted of the parent(s) or the guardian responsible for the child. Professionals such as speech therapists, occupational therapists and school principals of the Dagbreek and Môreson Schools were approached to obtain names of possible participants who could share their experiences with the researcher. However, the participants whose names the researcher obtained from the various school principals was usually a client of these different professionals. This unfortunately had the effect of reducing the number of participants for the research to 16. It was initially intended that there would be about 32 participants.

Although the researcher would have like to hear the experiences of both male and female caregivers, the final composition of this study consisted mainly of females. This may be due to the fact that more females than males take on the caring role (Chambers, Ryan, Connor, 2000).

Participants from different ethnic backgrounds were difficult to engage with because of language and cultural barriers.

There were four participants/caregivers who did not want to be interviewed because of the sensitive nature of the topic. Five participants/caregivers said they were willing to do the interview, however, when it was time to meet with the researcher they did not come to the appointment. When trying to contact them to find out where they were, they either did not answer the phone, they answered but hung up or totally ignored the researcher.

Most of the interviews took place at the homes of the participants/caregivers; this made participants feel comfortable and at ease. The rest of the interviews were done at the participant/caregivers' workplace, which made it difficult as there were constant interruptions and the participants/caregivers could not focus completely on the interview.

#### **6.4 Recommendations**

The following recommendations can be made on the basis of the results of this study:

- Campaigns need to be held to inform the Namibian community of the nature of Down syndrome, the causes, diagnoses, how Down syndrome affects development and what to expect, etc. This will give people a better understanding of Down syndrome as well as giving the community a better understanding and compassion for families with a Down syndrome child.

- Parental support networks need to be established in order for parents who have a child with Down syndrome to go for support and to get knowledge on how to maintain their well-being.
- The Government, in particular the Ministry of Health and Social Services (policy and planning division) needs to develop programmes which assist parents financially and emotionally. It is especially necessary that Government sets up or develops a centre which can take in Down syndrome children whose parents have died. Such a centre should be a place where children with Down syndrome can develop independently and feel at home as well as a place that educates parents so that they can become strong advocates for their children, where they would receive advice on understanding and managing their children's developmental demands.
- Healthcare professionals like paediatricians, clinical geneticists, genetic counsellors, child development specialists, social workers, physical therapists as well as clinical and occupational therapists need to be updated on Down syndrome. They should try to educate parents on what to expect when the mother is pregnant with a Down syndrome baby but also should provide continued assistance after the birth if parents need help and support. Healthcare professionals are a very important resource and can help the family and child to adapt flexibly to their challenging situation.
- Counselling for caregivers should be offered for free. With counselling parents/caregivers of children with Down syndrome can be helped to function better and to extend help to their children.
- Children with Down syndrome should be allowed to go to mainstream schools as this will help families to feel less isolated from the rest of the community.

The following recommendations for **future research** can be made on the basis of the results of this research:

- Quantitative research can be conducted with questionnaires to find out the number of families in Namibia with a child with Down syndrome.
- A longitudinal study can be done within Namibia, to find out and determine the relationship between parents, siblings and the child with Down syndrome to understand the social, emotional and behavioural adjustment of each member of the family.

## **6.5 Chapter Summary**

The research begins with a discussion on my results and concludes by looking at the findings in terms of the research question. The limitations to the study were discussed. Recommendations were made in the light of the research finding together with future recommendations.

## REFERENCES

- Abbeduto, L., Seltzer, M.M., Shattuck, P., Wyngaarden Krauss, M., Orsmond, G., & Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation*, 109(3), 237-254
- Abery, B. H. (2006). Family adjustment and adaptation with children with Down syndrome. *Focus on Exceptional Children*, 38(6), 1-18.
- Anderson, D., Dumont, S., Jacobs, P., & Azzaria, L. (2007). The personal costs of caring for a child with a disability: A review of the literature. *Public Health Reports*: 122(1), 3-16.  
Retrieved on 27/08/2012 from  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1802121/>.
- American Association on Intellectual and Developmental Disabilities. (2008). *Frequently asked questions on intellectual disability and the AAIDD*. Retrieved on 12/03/2010 from  
[http://www.siswebsite.org/galleries/default-file/AAIDDFQAonID\\_template.pdf](http://www.siswebsite.org/galleries/default-file/AAIDDFQAonID_template.pdf).
- American College of Nurse-Midwives. (2005). Prenatal tests for Down syndrome: Share with women. *Journal of Midwifery and Womens Health* 50(3), 255-256.
- Begun, H. (2008). Empirical analysis of sterilization of mentally handicapped individuals in the United States. *Journal of Nursing Student Research* 1(2), 12-19.
- Blanche, M. T., Durrheim, K., & Painter, D. (2006). *Research in practice: Applied methods for the social sciences* (2nd ed.). Cape Town: University of Cape Town.
- Brannan, A. M., Heflinger, A. C., & Bickman, L. (1997). The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional and Behavioural Disorders* 5, 212-222.

- Brill, M. T. (2006). *Down syndrome*. New York, NY: Marshall Cavendish.
- Brown, R. (2004). Life for adults with Down syndrome – An overview. *Down Syndrome Issues and Information*. Retrieved on 12/08/2012 from <http://www.down-syndrome.org/information/development/adults>.
- Boerner, K., Horowitz, A., & Schulz, R. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging* 19, 668-675.
- Bouer, J.J., McAdams, D.P., & Pals, J.L. (2008). Narrative identity and eudaimonic well-being. *Journal of Happiness Studies*, 9:81-104.
- Bourke, J., Ricciardo, B., Bebbington, A., Aiberti, K., Jacoby, P., Dyke, P., Msall, M., Bower, C., & Leonard, H. (2008). Maternal physical and mental health in children with Down syndrome. *Journal of Paediatrics*, 153, 320-326.
- Buckley, S. (2002). *Issues for families with children with Down syndrome*. Portsmouth, UK: The Down Syndrome Educational Trust.
- Byrne, M.M. (2001). Understanding life experiences through a phenomenological approach to research. *Association of PeriOperative Registered Nurses Journal*, 73(4): 830-832  
Retrieved on 21/07/2012 from: [http://findarticles.com/p/articles/mi\\_mOFSL/is\\_4\\_73](http://findarticles.com/p/articles/mi_mOFSL/is_4_73).
- Chambers, M., Ryan, A.A., & Connor, S.L. (2001). Exploring the emotional support needs and coping strategies of family carers. *Journal of Psychiatric and Mental Health Nursing* 8, 99-106.
- Chen, Y., Hedrick, S. C., & Young, H. M. (2010). A pilot evaluation of the family caregiver support program. *Evaluation and Program Planning* 33, 113-119.
- Cicchetti, D., & Beeghly, M. (1990). *Children with Down syndrome: A developmental perspective*. Cambridge: Cambridge University Press.

- Christianson, A. L. (1996). Down syndrome in sub-Saharan Africa. *Journal of Medical Genetics* 33, 89-92.
- Cohen, W.I. (n.d.). Down syndrome: Care of the child and the family. Retrieved on 10/10/2012 from <http://www.us.elsevierhealth.com/media/us/samplechapters/9781416033707/Chapter%2025.pdf>.
- Colman, A.M. (2006). *Oxford Dictionary of Psychology*. Oxford, United Kingdom: Oxford University Press.
- Cunningham, C. C. (1996). Families of children with Down syndrome. *Down Syndrome Research and Practice* 4(3), 87-95.
- Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2008). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome Research and Practice* 12(3), 202-210.
- Dash, N. K. (2005). Module: Selection of the research paradigm and methodology. *Online Research Methods Resource for Teachers and Trainers*. Retrieved on 22/06/2011 from [http://www.celt.mmu.ac.uk/researchmethods/Modules/Selection\\_of\\_methodology/index.php](http://www.celt.mmu.ac.uk/researchmethods/Modules/Selection_of_methodology/index.php).
- Davis, A.S. (2008). Children with Down Syndrome: Implications for assessment and intervention in the school. *School Psychology Quarterly* 23, 271-281.
- Deci, E. L., & Ryan, R. M. (2008). Hedonia, eudaimonia, and well-being: An introduction. *Journal of Happiness Studies* 9, 1-11.
- Disabilities-Impact of Disabilities on Families. (n.d). Retrieved on 21/08/2012 from: <http://family.jrank.org/pages/396/Disabilities-Impact-Disabilities-on-Families.html>



- Dulin, P., & Hill, R. D. (2008). The caregiver experience associated mental health problems, and counselling interventions. In F. T. L. Leong (Ed.), *The Encyclopedia of Counselling: Changes and challenges for counselling in the 21st Century*. Thousand Oaks, CA: Sage
- Dykens, E. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *American Association on Mental Retardation* 43, 360-364.
- Dyke, D.V., McBrien, D., & Sherbondy, A. (1995). Issues of sexuality in Down syndrome. *Down Syndrome Research and Practice* 3(2); 65-69.
- Duxbury, L., Higgins, C., & Schroeder, B. (2009). Balancing paid work and caregiving responsibilities: A closer look at family caregivers in Canada. Retrieved on 23/08/2012 from: [http://cprn.org/documents/51061\\_EN.pdf](http://cprn.org/documents/51061_EN.pdf).
- Eaves, L.C., Ho, H., Laird, B., & Dickson, S. (1996). Raising a child with Down syndrome: Parents evaluations of health information and support. *Down syndrome Research and Practice* 4(2), 65-69.
- 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, 657-671.
- Elkins, T.E., & Brown, D. (1995). Ethical concerns and future directions in maternal screening for Down syndrome. *The Jacobs Institute of Women's Health* 5(1), 15-20.
- Ergun, S. & Ertem, G. (2002). Difficulties of mothers living with mentally disabled children. *Journal of Pakistan Medical Association* 62, 776-780.
- Finlay, L. (2008). Introducing phenomenological research. Retrieved on 03/09/2012 from [www.lindafinlay.co.uk/An%20introduction%20to%20phenomenology%202008doc](http://www.lindafinlay.co.uk/An%20introduction%20to%20phenomenology%202008doc)

- Fitzmaurice, S. (2002). Adventures in child-rearing: The sexual life of a child growing up with Down syndrome. *Disability Studies Quarterly* 22(4), 28-40. Retrieved on 03/09/2012 from: <http://dsq-sds.org/article/view/370/487>.
- Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work* 25(1), 59-68.
- Friend, M., & Bursack, W.D. (2009). Parents Reactions to Their Child's Disability. Retrieved on 12/07/2012 from <http://www.education.com/reference/article/parents-reactions-their-child-disability>.
- Fundamental Human Rights and Freedom. Retrieved on 12/07/2012 from <http://www.orusovo.com/namcon/chap3.htm>.
- Gallagher, S., Phillips, A., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology* 33, 1129-1136.
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science and Medicine* 64, 150-163.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1). Article 4. Retrieved on 9/03/2011 from [http://www.ualberta.ca/~iiqm/backissues/3\\_1/pdf/groenewald.pdf](http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/groenewald.pdf).
- Glossary: Caregiving Definition(s). *Sloan Work and Family Research Network*. Boston College. Retrieved from on 10/03/2012 from <http://wfnetwork.bc.edu/glossary>.
- Grech, V. (2001). An overview and update regarding medical problems in Down syndrome. *Indian Journal of Pediatrics* 68(9), 863-866.

- Greaves, D. (1997). The effects of rational-emotive parent education on the stress of mothers of young children with Down syndrome. *Journal of Rational-Emotive Behaviour Therapy* 15, 249-267.
- Gordon, P. A., Feldman, D., Tantillo, J. C., & Perrone, K. (2004). Attitudes regarding interpersonal relationships with persons with mental illness and mental retardation. *Journal of Rehabilitation* 70, 50-56.
- Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal* 15(1), 22-35.
- Harvey, B. (2004). Down's syndrome: A biopsychosocial perspective. *Nursing Standard* 18(30), 43-45.
- Hayes, N. (2000). *Doing psychological research: Gathering and analyzing data*. Buckingham, UK: Open University Press.
- Hedov, G., Anneren, G., & Wikblad, K. (2002). Swedish parents of children with Down syndrome: Parental stress and sense of coherence in relation to employment rate and time spent in child care. *Scandinavian Journal of Caring Science* 16, 424-430.
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Development and Physical Disabilities* 14(2), 159-171.
- Hilgemen, M.M., Allen, R.S., DeCoster, J. & Burgio, L.D. (2007). Positive aspects of caregiving as a moderator of treatment outcome over 12 months. *Psychology and Aging* 22(2), 361-371.
- Hodapp, R. M. (2007). Families of persons with Down syndrome: New perspectives, findings and research and service needs. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 279-287.

- Hodapp, R. M., Ly, T. M., Fidler, D. J., & Ricci, L. A. (2001). Less stress, more rewarding: Parenting children with Down syndrome. *Parenting: Science & Practice* 1, 317-337.
- Hughes, J. (2006). Inclusive education for individuals with Down syndrome. *Down Syndrome News and Update* 6(1), 1-3. Retrieved on 15/04/2012 from: <http://www.down-syndrome.org/practice/370>.
- Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing*. Wiley Blackwell.
- Huang, P. H. (2008). Authentic happiness, self-knowledge and legal policy. *Minn.J.L. Science and Technology*, 9, 755-784.
- How to get help if you are looking after someone: Information for carers. Retrieved on 28/01/2011 from: [http://www.merton.gov.uk/health-social-care/adult-social-care/caresupport/how\\_to\\_get\\_help\\_as\\_pdf](http://www.merton.gov.uk/health-social-care/adult-social-care/caresupport/how_to_get_help_as_pdf)
- Huta, V., & Ryan, R. M. (2010). Pursuing pleasure or virtue: The differential and overlapping well-being benefits of hedonic and eudaimonic motives. *Journal of Happiness Studies*, 11, 735-762.
- Issues for families of children with Down syndrome. Retrieved on 10/10/2012 from <http://www.down-syndrome.org/information/family/overview/?page=3>.
- Joniak, L. (n.d). The qualitative paradigm: An overview of some basic concepts, assumptions, and theories of qualitative research. Retrieved on 23/08/2012 from: [http://www.slis.indiana.edu/faculty/hrosenba/www/Research/methods/joniak\\_qual\\_par.pdf](http://www.slis.indiana.edu/faculty/hrosenba/www/Research/methods/joniak_qual_par.pdf).
- Joosa, E. & Berthelsen, D. (n.d.). Parenting a child with Down syndrome. Retrieved on 23/08/2012 from: [http://www.oadd.org/publications/journal/issues/vol12no1supp2/download/joosa\\_berthelsen.pdf](http://www.oadd.org/publications/journal/issues/vol12no1supp2/download/joosa_berthelsen.pdf).

- Kaldor, P., Hughes, P., Castle, K., & Bellamy, J. (2004). Spirituality and well-being in Australia. NCLS Research. Retrieved on 29/10/2012 from <http://www.NCLSOccasionalPaper6-SpiritualityandWellbeing.pdf>.
- Kashdan, T. B., Biswas-Diener, R., & King, L. A. (2008). Reconsidering happiness: The costs of distinguishing between hedonics and eudaimonia. *Journal of Positive Psychology*, 3, 219–233.
- Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 47, 313-327.
- King, L. A., & Patterson, C. (2000). Reconstructing life goals after the birth of a child with Down syndrome: Finding happiness and growing. *International Journal of Rehabilitation and Health*, 5(1), 17-30.
- King, N., & Horrocks, C. (2009). *Interviews in qualitative research*. London: Sage.
- King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health and Development*, 32, 353-369.
- Krauss, S. E. (2005). Research paradigms and meaning making: A primer. *The Qualitative Report*, 10(4), 758-770. Retrieved on 22/08/2011 from <http://www.nova.edu/ssw/QR/QR10-4/krauss.pdf>.
- Lam, L. & 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. *Scientific Letter*, 97(7):515-6.

Learning Disability Today, 8(9). Retrieved on 23/02/2011 from:

<http://mhtodayexhibition.co.uk/pavpub/magazines/showMagazines.asp?Title=Learning+Disability+Today>.

Leshin, L. (2007). Prenatal screening for Down syndrome. Retrieved from on 15/01/2011

<http://www.ds-health.com/prenatal.htm>.

Leshin, L. (2000). Plastic surgery in children with Down syndrome. Retrieved on 15/01/2011:

<http://www.ds-health.com/psurg.htm>.

Lui, M., Lambert, C. E., & Lambert, V.A. (2007). Caregiver burden and coping patterns of Chinese parents of a child with mental illness. *International Journal of Mental Health Nursing*, 16, 86-95.

McMahan, E.A. & Estes, D. (2011). Hedonic versus eudaimonic conceptions of well-being: Evidence of Differential Associations with self-reported well-being. *Social Indicators Research*, 103(1), 93-108.

Mahoney, G., Perales, F., Wiggers, B., & Herman, B. (2006). Responsive teaching: Early intervention for children with Down syndrome and other disabilities. *Down Syndrome Research and Practice*, 11(1), 18-28.

Marks, N.F. (1997). *Does it hurt to care? Caregiving, work and family conflict, and midlife well-being*. Center for Demography and Ecology. University of Wisconsin-Madison.

Martin, S. J., & Prieto, C. V. (2008). Trade-off between formal and informal care in Spain. *Social Science Research Network*. Retrieved on 27/01/2011 from: <http://papers.ssrn.com/sol3/papers.cfm?abstract>.

Margulies, P. (2007). *Down syndrome*. New York: Rosen Publishing Group.

Mintz, S. (2008). The common bonds of caregiving. *National Family Caregivers Association*. Retrieved on 27/01/2011 from <http://216.185.112.5/presenter:jhtml>.

- Molteno, C., Smart, R., Viljoen, D., Sayed, R., & Roux, A. (1997). Twenty-year birth prevalence of Down syndrome in Cape Town, South Africa. *Pediatric and Perinatal Epidemiology* 11, 428-435.
- National Alliance for Caregiving in Collaboration with AARP. (2009). Caregiving in the U.S. (2009). *MetLife Foundation*. Retrieved on 28/02/2011 from: [http://www.caregiving.org/data/caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/caregiving_in_the_US_2009_full_report.pdf).
- National Down Syndrome Society. Retrieved from on 09/08/2012: <http://www.ndss.org/index.php>
- Nespoli, L. (1996). Down syndrome: 130 years after its identification. *European Journal of Paediatrics*, 155:625-626
- Orb, A., Eisenhauer, L., & Wynaden, D. (2000). Ethics in qualitative research. *Journal of Nursing Scholarship* 33, (1), 93-96.
- Olson, R. (2007). Positive psychology: Authentic happiness. Retrieved on 16/10/2012 from <http://www.peakeffectiveness.com/Positive%20Psychology/Authentic%20Happiness%20Summary.pdf>.
- Olsson, M. B., & Hwang, C. P. (2006). Well-being, involvement in paid work and division of child-care in parents of children with intellectual disabilities in Sweden. *Journal of Intellectual Disability Research*, 50, 963-969.
- Ozmete, E. (2011). Subjective well-being: A research on life satisfaction as cognitive component of subjective well-being. *International Journal of Academic Research*, 3(4), 55-61.
- Peterson, C., & Seligman, M. E. P. (2004). *Character strengths and virtues: A handbook and classifications*. Washington, DC: American Psychological Association.

- Pollack, H.A. (2011). Health policy and the community safety net for individuals with intellectual disability. *Developmental Disabilities Research Reviews*, 17, 44-51.
- Positive Psychology: Fact Sheet. Black Dog Institute, 1-4. Retrieved on 20/03/2011 from: <http://www.blackdoginstitute.org.au/docs/PositivePsychology.pdf>.
- Redinbaugh, E.M., Baum, A., Tarbell, S., & Arnold, R. (2003). End-of-life caregiving: What helps family caregivers cope? *Journal of Palliative Medicine*, 6, 901-909
- Research methodology and research design. Chapter 3. Retrieved on: 24/09/2012 from: <http://uir.unisa.ac.za/bitstream/handle/10500/926/03chapter3.pdf>.
- Roberts, J.E., Price, J., & Malkin, C. (2007). Language and communication development in Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 26-35.
- Rothmann, S. (2000). *The phenomenological interview*. Potchefstroom: North-West University.
- Rothmann, S. & Ekkerd, J. (2007). The validation of the perceived wellness survey in the South African Police Service. *South Africa Journal of Industrial Psychology* 33(3), 35-42.
- Roizen, N. J. & Patterson, D. (2003). Down syndrome. *The Lancet*, 361, 1281-1289.
- Ryan, R.M. & Deci, E.L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual Reviews Psychology*, 52:141-166.
- Ryff, C. D., & Singer, H. S. (2008). Know thyself and become what you are: A eudaimonic approach to psychological well-being. *Journal of Happiness Studies*, 9, 13-39
- Ryff, C. D., & Singer, B. (1998). The contours of positive human health. *Psychological Inquiry*, 9, 1-28.



- Ryff, C.D. (1989). Happiness is everything, or is it? Exploration on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069-1081.
- Sari, R. N., Baser, G., & Turan, J. M. (2006). Experiences of mothers of children with Down syndrome. *Paediatric Nursing*, 18(4), 29-32.
- Schoeder, C. E., & Remer, R. (2007). Perceived social support and caregiver strain in caregivers of children with Tourette's Disorder. *Journal of Child and Family Studies*, 16, 888-901.
- Seifert, T.A. (2005). *The Ryff scales of psychological well-being*. Retrieved on 2/09/2012 from: <http://www.liberalarts.wabash.edu/ryff-scales>.
- Semiatin, A.M. & O'Connor, M.K. (2012). The relationship between self-efficacy and positive aspects of caregiving in Alzheimer's disease caregivers. *Journal of Aging and Mental Health*, 1-6. Routledge: Taylor & Francis Group.
- Seligman, M. E. P. (2003). *Authentic happiness*. London: Nicholas Brealey Publishing.
- Seligman, M. E. P. (2008). Positive health. *Applied Psychology: An International Review*, 57, 3-18.
- Seligman, M. E. P., & Csikszentimihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55, 5-14.
- Selikowitz, M. (1999). *Down syndrome: the facts*. 2<sup>nd</sup> Edition. Great Britain: Oxford University Press.
- Shaw, S. B. (1997). A modern psychoanalytic approach to caregiver support groups. *Eastern Group Psychotherapy Society*, 21(2), 159-174.

- Siklos, S., & Kerns, K.A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*, 36, 921-933.
- Sin, N.L. & Lyubomirsky, S. (2009). Enhancing well-being and alleviating depressive symptoms with positive psychology interventions: A practice-friendly meta-analysis. *Journal of Clinical Psychology: In Session*, 65(5), 467-487.
- Sirgy, M.J. & Wu, J. (2009). The pleasant life, the engaged life and the meaningful life: What about the balanced life? *Journal of Happiness Studies*, 10, 2, 183-196.
- Slade, M. (2010). Mental illness and well-being: the central importance of positive psychology and recovery approaches. *BMC Health Services Research*, 10, 26.
- Smale, B., & Dupuis, S.L. (2004). Caregivers of persons with Dementia: roles, experiences, supports and coping. *Murray Alzheimer Research and Education Program*. University of Waterloo.
- Smith, J. A. (2003). *Qualitative psychology: A practical guide to research methods*. London: Sage.
- Springer, K.W. & Hauser, R.M. (2003). An assessment of the construct validity of Ryff's scales of psychological well-being: method, mode and measurement effects. *Institutional Affiliation: University of Wisconsin-Madison Department of Sociology and Center for Demography of Health and Aging*.
- Taanila, A., Syrjala, L., Kokkonen, J., & Jarvelin, M.R. (2001). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health and Development*, 28(1), 73-86.

The strains and gains of caregiving: an examination of the effects of providing personal care to a parent on a range of psychological outcomes. (n.d.). Retrieved on 24/10/2012 from [http://www.nova.no/asset/5965/1/5965\\_1.pdf](http://www.nova.no/asset/5965/1/5965_1.pdf).

Understanding the roles of formal and informal caregivers. (2009). Retrieved on 27/01/2011 from: <http://www.articlesbase.com/disabilities-articles/understanding-the-roles-of-formal-and-informal-caregivers/html>.

Urbano, R.C., & Hodapp, R.M. (2007). Divorce in Families of Children with Down Syndrome: A Population-Based Study. *American Journal on Mental Retardation*, 112(4); 261-274.

Van Dierendonck, D., & Mohan, K. (2006). Some thoughts on spirituality and eudaimonic well-being. *Mental Health, Religion and Culture*, 9(3), 227-238.

Van Dyk, A. (2005). *HIV/AIDS care and counselling: A multidisciplinary approach*. Cape Town: Maskew Miller Longman.

Vujovic, M. (2008). *Experiencing violence: A phenomenological study of adolescent girls*. Unpublished doctoral dissertation, University of Johannesburg, Johannesburg, South Africa.

Van Riper, M. (1999). Maternal perceptions of family-provider relationships and well-being in families of children with Down syndrome. *Research in Nursing and Health*, 22, 357-368.

Zangmo, T. (n.d.). Psychological Well-being. Gross National Happy Survey Findings. The Centre for Bhutan Studies. Retrieved on 29/10/2012 from <http://www.grossnationalhappiness.com/wp-content/uploads/2012/05/Psychological-Well-being.pdf>.

- Venkatesh Kumar, G. (2008). Psychological Stress and Coping Strategies of the Parents of Mentally Challenged Children. *Journal of the Indian Academy of Applied Psychology*, 34(2), 227-231.
- Vazquez, C., Hervás, G., Rahona, J.J., & Gomez, D. (2009). Psychological well-being and health: Contributions of positive psychology. *Annuary of Clinical and Health Psychology*, 5: 15-27.
- Waterman, A. S. (2008). Reconsidering happiness: A eudaemonist's perspective. *The Journal of Positive Psychology*, 3, 234-252.
- Weijerman, M. E., & de Winter, J. P. (2010). Clinical practice: The care of children with Down syndrome. *European Journal of Paediatrics*, 169, 1445-1452
- Wilson, T.D. (2002). *Alfred Schutz, phenomenology and research methodology for information behaviour research*. Retrieved from: <http://informationr.net/tdw/puli/papers/schutz02.htm>.
- Winefield, H.R., Gill, T.K., Taylor, A.W., & Pilkington, R.M. (2012). Psychological well-being and psychological distress: is it necessary to measure both? *Psychology of Well-being: Theory, research and practice*, 2:3. Retrieved from: <http://www.psywb.com/content/2/1/3>.

**APPENDIX A****Interview guide****Demographic Questions****Section A: Information about the respondent**

1. Age of caretaker.....
2. Sex: Male..... Female.....
3. Race:
4. What is your home language?
5. Marital Status: Married, Divorced, Single, or Living together?
6. Occupation: .....
7. What is your social economic status? Low income, middle income, or high income.....
8. How many people are you in your household?
9. In which neighbourhood do you live?

**Section B: Information about the person with Down syndrome**

1. What is your relationship to the family member that has Down syndrome?
2. How old is he or she?
3. Sex: Male..... Female.....
4. Indicate what your child's position is in the family? (first born, second, third or fourth).

Question only relevant to the biological caregiver of the individual and not to the caregiver whom may be a sister or cousin of the individual.

5. What level of education does the individual with Down syndrome have and what school?
6. If not attending school, what does the individual do during the day (e.g. work)?
7. Are you aware of any medical condition that might have an impact on his her current life?
8. What do you as the caregiver understand about Down syndrome? / Or what is your understanding of Down syndrome?
9. When was the first time that you learned that you're going to have to raise a loved one with Down syndrome and how did this make you feel?

OR:

- 9.1. How did it come about that you take care of your sister, brother, cousin that has Down syndrome?

Note: this question will be asked if the caregiver is only a sister, etc and not the biological caregiver!

**CENTRAL QUESTION FOR THIS RESEARCH STUDY:**

**What are your experiences in taking care of a family member with Down syndrome in all dimensions of your life?**

**APPENDIX B****INFORMED CONSENT FORM**

My name is Tanya Byleveldt and I am a student at the University of Namibia studying towards a Master's Degree in Clinical Psychology. I am conducting a study on the "well-being of caregivers of a member with Down syndrome in Windhoek".

The purpose of this study is to explore what the well-being of caregivers of a member with Down syndrome is regarding their experiences and challenges. The reason for the study is because there are no scientific information available regarding the experiences and well-being of families of caregivers of Down syndrome children residing in Namibia.

The study's findings will be able to assist the Ministry of Health and Social services (planning and policy division) to use the obtained information to plan and implement interventions which can assist caregivers. The study will be a valuable contribution to families and societies that provide care to a member with Down syndrome. Families within the Namibian society with a Down syndrome child will benefit greatly from this study.

To accomplish this study effectively, I would like to have an interview with you lasting approximately one hour.

The interview will be tape recorded, unless otherwise requested by the participant. Please note that your name will not be recorded on the tape. You will not be identified by name in the final product. Privacy will be ensured through confidentiality. The tapes will only be heard by me for the purpose of this study. The researcher will not share your individual responses with anyone other than the research supervisor. Participation is voluntary and you the interviewee have the right to terminate the interview at any time.

**By signing below you agree that you have read and understood the above information,  
and would be interested in participating in this study.**

_____	_____	_____
<b>Name</b>	<b>Date</b>	<b>Signature</b>