

**RESILIENCE FACTORS IN LOW-INCOME AFRICAN FAMILIES OF CHILDREN WITH  
DOWN'S SYNDROME**

by

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## DECLARATION

I, SHARON TSHEPISO MPHONG MADALA declare that this mini-dissertation hereby submitted to the University of Limpopo for the degree of Master of Arts in Clinical Psychology, has not been previously submitted by me for a degree at this or any other university, that it is my own work in design and in execution, and that all materials used have been indicated and acknowledged by means of complete references.

Signed at \_\_\_\_\_ on the \_\_\_\_\_

\_\_\_\_\_  
Madala STM

## **DEDICATION**

The following study is dedicated to all families with Down's syndrome children.

## **ACKNOWLEDGMENTS**

I would like to express my deepest gratitude to God, His Grace the Comforter, thank You for keeping Your promises and for all Your blessings and generosity. I also thank my family and the patience my parents have had with me. My appreciation is also extended to Prof S Mashegoane (research supervisor) for his time, effort and patience with this mini-dissertation. Most of all, for the incredible faith he seems to have in me. I would also like to thank my son (Tshepiso Wayne Zwivhuya) most of all for the tremendous inspiration; he has been a wonderful child when I was too busy trying to complete the mini-dissertation. Grateful thanks are also due to Dr. Samuel Dseagu for his wisdom, support, guidance, and mostly for him to encourage me not to give up. The cooperation received from the Pediatrics Out-Patient Department at Dr. George Mukhari Hospital, Garankuwa is also very much appreciated. Amongst those involved, in particular I would like to thank Sister S. M. Padi, Sister S. M. Shongwe and Dr. E. M. Honey. I am also honoured to extend my gratitude to three academics and professionals who expressed their unconditional material support by emailing me helpful journal articles; that is, Liezl Jonker (University of Stellenbosch), Professor Froma Walsh (School of Social Service Administration and Department of Psychiatry, University of Chicago), and Gillian Saloojee (Childhood Disability Research Project, School of Health Systems and Public Health, University of Pretoria). Last, but not least, a very special thanks must also be given to the respondents and their families for taking the time to share their adversities and triumphs with me. I am humbled by their grace, honesty, humility and resilience.

## **ABSTRACT**

The current study explored resilience factors among low-income African families in South Africa, caring for children with Down's syndrome. Two studies were conducted. In study 1, qualitative data about the family was obtained through semi-structured, one-to-one interviews from eight family members, seven females and one male, who described themselves as primary caregivers of the children. Data were thematically analyzed. Themes that emerged from the interviews included perceptions of impoverishment, blaming witchcraft for the ailment, the experience of emotional distress by the main caregiver, caregiver's lack of social support and sense of isolation, frustration pertaining to the timely reception of state grants, family conflict, fathers' rejection of Down's syndrome children, and spirituality. The sample for study 2, the quantitative study, consisted of 36 respondents who were all primary caregivers representing families of children with Down's syndrome. It first explored possible sources of social support for Down's syndrome children's families. Several sources of support were found to be helpful. Personal or children's physicians, followed by social agencies, were found to be extremely helpful. Yet neighbours, other parents and partners' relatives were considered not to be helpful at all. Social and parents' groups and professionals such as therapists, teachers and social workers were perceived not to be available sources of support. Quantitative analysis then used correlation analysis to identify independent variables that can be included in a regression model to predict family satisfaction. The results of regression analysis were complex to interpret. Reframing was negatively related to family satisfaction. Both studies revealed a number of challenges confronting low-income families caring for Down's syndrome children. Nonetheless, a replication of the findings is recommended.

## TABLE OF CONTENTS

<b>Content</b>	<b>Page</b>
Declaration.....	ii
Dedication.....	iii
Acknowledgements.....	iv
Abstract.....	v
 <b>Chapter 1: Introduction</b>	
1.1 Introduction.....	1
1.2 Statement of the Problem.....	2
1.3 Background to the Problem.....	3
1.4 Study 1 (Qualitative Research).....	4
1.5 Research Question.....	4
1.6 Study 2 (Quantitative Research).....	5
1.7 Hypotheses.....	5
 <b>Chapter 2: Theoretical Framework and Literature Review</b>	
2.1 Operational Definitions of Concepts.....	6
2.2 Theoretical Framework.....	8
2.3 Literature Review.....	9
2.3.1 South African Statics of People with Disability .....	9
2.3.2 General Resilience Factors.....	9
2.3.3 Conclusions.....	12
 <b>Chapter 3: Study 1—Research Methodology</b>	
3.1 Introduction.....	14
3.2 Locating the Research Respondents.....	14

3.3	Research Questions and Data-gathering Procedure.....	14
3.4	Explication of the Data.....	17
3.5	Unit of Analysis, Study Population and Sample Size.....	18

#### **Chapter 4: Study 1—Results and Discussion**

4.1	Introduction.....	19
4.3	Results.....	19
4.3.1	Poverty and Lack of Resources.....	22
4.3.2	Blaming Witchcraft.....	22
4.3.3	Anticipation, Symbolic Loss and Subsequent Frustration and Grief.....	25
4.3.4	Emotional Distress Experienced by Caregivers.....	27
4.3.5	Isolation and Lack of Social Support.....	28
4.3.6	Frustration Resulting from Delays by the South African Social Agency.....	30
4.3.7	Family Conflicts.....	31
4.3.8	Rejection of Down’s syndrome Children by their Fathers.....	33
4.3.9	Spirituality.....	35

#### **Chapter 5: Study 2—Research Methodology**

5.1	Respondents .....	37
5.2	Measures.....	37
5.2.1	Family Support Scale.....	37
5.2.2	Family Satisfaction Scale.....	38
5.2.3	Family Stress.....	39
5.2.4	Family Coping.....	39
5.3	Procedure.....	41

## **Chapter 6: Study 2—Results, Discussion and General Discussion**

6.1	Plan of Analysis.....	42
6.2	Demographic Details of the Sample.....	42
6.3	Sources of Social Support for the Families, according to the respondent.....	44
6.4	Correlation Analysis of Family Satisfaction, Family Stress and Dimensions of Coping.....	47
6.5	The Prediction of Family Satisfaction from Family Stress and Coping Dimensions.....	49
6.6	Discussion.....	51
6.6.1	Characteristics of respondents and their respective families.....	51
6.6.2	Sources of social support identified.....	52
6.6.3	The stress model.....	53
6.7	General Discussion.....	54

## **Chapter 7: Conclusion, Limitations and Recommendations**

7.1	Conclusion.....	56
7.2	Limitations.....	56
7.3	Recommendations.....	57

<b>REFERENCES</b> .....	59
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### **APPENDICES**

Appendix A: Demographic Questionnaire.....	77
Appendix B: Information Letter and Consent Form.....	80

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## List of Tables

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<b>Tables</b>	<b>Page</b>
Table 1: Demographic Information of Respondents (Study 1).....	21
Table 2: Demographic Details of the Sample (Study 2).....	43
Table 3: Perceived Sources of Social Support.....	45
Table 4(a): Correlations Between Major Variables of the Study (N = 36).....	48
Table 4(b): Regression Analysis for the Prediction of Family Satisfaction.....	50

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## **CHAPTER 1**

### **INTRODUCTION**

#### **1.1 Introduction**

When family functioning is interrupted by a major event of a crisis nature, the family tends to either mobilize its resources and thrive, or fail to cope and go through a period of dysfunction (Lee, Lee, Kim, Park, Song, & Park, 2004). Family crises come in many forms, such as a terminal, debilitating illness, loss of a loved one, and so on. This study focuses on families with Down's syndrome children. When a child is born with the disease, the concerned family goes through a crisis period, demanding that it mobilizes its resources. In fact, Fortier and Wanlass (1984) observed that the official diagnosis of a child as handicapped marks the occurrence of a family crisis in itself. In addition, parents of children with disabilities show significantly more stress within the family system as compared to parents of typically developing children (Smith, 2007).

Fortier and Wanlass (1984) further elaborate that the crisis following the diagnosis of a handicapped child affects the family on many levels. On a behavioral level, the family may need to provide immediate care for the handicapped child, arrange transportation to treatment, alter previous methods of scheduling time and meet new financial needs. On the affective level, the family members begin working through feelings of grief, anger, guilt, helplessness and isolation. On a physical or sensory level, somatic symptoms such as headache, pseudoseizures and so forth, may arise as a result of the crisis-related stress (Fortier, & Wanlass, 1984).

On an interpersonal level, the family may have to deal with labeling and stereotyping, a sense of isolation from others, handling "helpfulness" and advice from friends, and providing support for other family members. On a cognitive

level, the family is called upon to assimilate technical information about the disability and to deal with the impact of the diagnosis on established values and expectations (Fortier, & Wanlass, 1984). All families are faced with challenges at one time or another. Kalil (2003) added that family resilience factors are important means by which families manage to master challenges.

The study will investigate family resilience factors that could be positively associated with adaptation in low-income African families raising a child with Down's syndrome in South Africa. Dan Jansen might have said it best: "Sometimes our greatest triumphs come from what, at the time, seem like our greatest failures" (Naber, 1999, p. 4). The phenomenon of achieving positive outcomes despite misfortune has been studied by psychologists since the 1950's, and is known as resilience (Galli, 2005). When a child who has been diagnosed with Down's syndrome is added to the equation, how does this affect the family's perceived stress, coping mechanism and functioning? Therefore, understanding the experiences, including the types of social support available to the families of a Down's syndrome child is essential if successful interventions are to be developed. However, the area of understanding experiences and the availability of social support for families who have a Down's syndrome child is still limited in South Africa. The present study first investigates experiences of disadvantaged African families with a downs syndrome child using primary caregivers as informants. In the next study more informants are recruited to provide objective details concerning social support and related issues among disadvantaged African families with a Down's syndrome child.

## 1.2 **Statement of the Problem**

When a child has been diagnosed with Down's syndrome, the family's coping mechanisms, functioning and finances are affected. Parents of children with Down's syndrome need to be encouraged and supported to raise their

handicapped children at home rather than turning them to residential settings for placement and care (Ohuegbe, 1999). Nevertheless, there is little empirical evidence available in South Africa on family resilience among African families of low-income caring for a child with Down's syndrome. Failure to consider this group, who probably possess unique characteristics to require appropriate forms of intervention, may lead to neglect by professional helpers (Mariach, 2003). Therefore, this study adds an African dimension to research on experiences and social support among families caring for a Down's syndrome child.

### 1.3 **Background to the Problem**

One of the commonly used models in studies of family functioning is the Resiliency Model of Family Stress, Adjustment and Adaptation, better known with its short-form resiliency model (McCubbin, & McCubbin, 1988; McCubbin & McCubbin, 1996; McCubbin, & Thompson, 1991). The model states that severe stressors tend to disrupt the functioning of a family, such that the family is required to find ways of adjusting and eventually adapting to the stressor. According to McCubbin and McCubbin (2001), research relating to Hill's ABCX Model, the Double ABCX Model of Adjustment and Adaptation, has tended to be Eurocentric and limited to the response of two-parent families to stressful and crisis situations. However, the resiliency model has been successfully utilized with a variety of family types, including people of colour and different ethnic origins. The acknowledgment that ethnicity, culture and diversity in family structure are important to an understanding of family stress and family resilience has opened the door for employing the resiliency model in the South African context, and it has already been applied in a number of studies.

South African research successfully employing the resiliency model as a conceptual basis includes: studies of resilience among families where a parent has accepted a voluntary teacher's retrenchment package (Der Kinderen, &

Greeff, 2003); the prevalence of resilience in migrant families (Greeff, 2007); resilience in families in which a parent has died (Greeff, & Human, 2004); and variables associated with resilience in divorced families (Greeff, & Van der Merwe, 2004). The resilience model relates well to an African and/or indigenous context, at least theoretically. It has influenced the present study of families with children diagnosed with Down's syndrome. This study investigates elements of resilience in African families from a low-income stratum. The first study is qualitative, to allow an opportunity for family dynamics to emerge. In the second study, elements of the resilience model are investigated. This approach to the investigation is influenced by the recognition that family resilience is time- and culture-specific, and may change over time as families face different challenges and life events (Kalil, 2003). For example, Pépin and Sudom (2008) found that Caucasian military families drew upon a broader set of individual, family and community capabilities for successful adaptation, whereas ethnic minorities placed more emphasis on a smaller set of capabilities, including family time together and sense of fit with the military lifestyle. Therefore, it is not clear what aspects of resilience will emerge from African low-income families.

#### **1.4 Study 1 (Qualitative Research)**

##### **1.4.1 Aim of the Study**

The aim of the study was to investigate experiences of low-income African families in South Africa, caring for a child with Down's syndrome.

##### **1.4.2 Research Question**

The central research question was: What are the experiences of low-income African families raising a child with Down's syndrome?

## **1.5 Study 2 (Quantitative Research)**

### **1.5.1 Aim of the Study**

The aim of study 2 was to investigate the functioning of some of the central concepts (family stress, sources of social support for family members, and family satisfaction) in the resiliency model in the context of African families caring for a Down's syndrome child.

### **1.5.2 Hypotheses**

#### **1.5.1 Hypothesis 1**

Families of children with Down's syndrome will receive support within the family system itself. That is, the family's adaptation will be enhanced by support from spouses and the in-laws of the children's parents (who are also grandparents of the children).

#### **1.5.2 Hypothesis 2**

Family satisfaction will be associated with low levels of family stress among families of children with Down's syndrome.

#### **1.5.3 Hypothesis 3**

Family satisfaction will be associated with high levels of social support among families of children with Down's syndrome.

## CHAPTER 2

### THEORETICAL FRAMEWORK AND LITERATURE REVIEW

#### 2.1 Operational definitions of concepts

**Adaptation:** entails restorative action by the family during which it alters its internal functions, such as behaviors, rules and roles, and external reality, to achieve a fit family-environment and to restore stability following a family crisis; thus adaptation is affected by the family's response to a stressful event, their available resources, and presence or absence of effective coping strategies.

**Adjustment:** focuses on the strengths and capabilities of a family system which helps to explain why some families are better suited than others to adjust to minor changes such as relocations, vacations, and short-term illness. When these adjustments are inadequate to meet demands, for example when there are structural changes such as loss of a job, or when resources are depleted, the adjustment process ends, hence the family enters into a crisis phase, and the need for more permeable and possible structural changes to restore stability arises.

**Caregiving:** is a calling to individuals privileged to help relieve those who suffer physically, emotionally and spiritually.

**Down's syndrome:** is a genetic condition caused by the presence of an extra chromosome which can result in intellectual and physical delay. Sometimes there is an error in the way chromosomes

are shuffled and the baby gets an extra chromosome number 21; that's why Down's syndrome is also known as trisomy 21.

**Family Stress:** Family stress in this study is defined as family members' emotional and physical responses caused by heightened anxiety that arises from an actual or perceived demand that calls for adjustment or adaptive behavior.

**Resilience:** is a dynamic process encompassing positive adaptation within the context of significant adversity. The concept of resilience was originally developed by researchers studying the positive adaptation of children under adverse circumstances (Kalil, 2003). Although it was not clear whether the concept referred to a trait or a state, it nevertheless was used as a property of the individual. More recently, its application has been extended to the study of families (Kalil, 2003). Pépin and Sudom (2008) postulated that family resilience is conceptualized differently by researchers and practitioners. They observe that, while practitioners view family resilience as the *capacity* of a family to deal with challenges, researchers tend to view resilience as a *process* involving interactions between risks and protective factors. In addition, resilience has also been defined as a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000a, & b). This implies not only that families have been exposed to adversity, but also that they have demonstrated competence in the face of it. A key component of the concept is the notion of resilience as a



dynamic process, rather than a static characteristic, meaning that resilience is an ongoing process (Kalil, 2003).

## **2.2 Theoretical Framework**

### The Resiliency Model of Family Stress, Adjustment and Adaptation

The model selected to guide the present study is the McCubbin's (McCubbin, & McCubbin, 1988; McCubbin, & Thompson, 1991) Resiliency Model of Family Stress, Adjustment and Adaptation, better known with its short-form resiliency model. The resiliency model involves two interrelated phases of family response to stress or strain (Der Kinderen, & Greeff, 2003). The first phase is the adjustment phase and the second is the adaptation phase (McCubbin, & McCubbin, 1988). Most family transitions or changes create hardships and struggles and thus challenge the family's rules or patterns of behavior; the adjustment phase focuses on those family systems and their strengths and capabilities which explain why some families are better suited than others to adjust to minor changes such as relocations, vacations, and short-term illness (McCubbin, & McCubbin, 1988, p. 248). When these adjustments are inadequate to meet demands—for example when there are structural changes such as loss of a job, or when resources are depleted—the adjustment process ends, the family enters into a crisis phase, and the need for more permeable and possible structural changes to restore stability arises (McCubbin, 1988; McCubbin, & Thompson, 1991; Walsh, 1996). The process of adaptation is affected by the family's response to a stressful event, their available resources, and presence or absence of effective coping strategies (McCubbin, & Patterson, 1983). This aspect of the model was central in formulating the current research.

## **2.3 Literature review**

### **2.3.1 South African Statistics of People with Disability**

At one point or another it is estimated that between 5% and 12% of South Africans are moderately to severely 'disabled' (White Paper on an Integrated National Disability Strategy, 1997). This estimate includes children with motor, sensory and intellectual disabilities, and is derived from four studies, three of which were conducted among rural populations (cf. Saloojee, Phohole, Saloojee, & IJsselmuiden, 2006). After conducting a study on children with disabilities living in Orange Farm, Saloojee and colleagues (2006) also found that many of the needs of disabled children remained unmet and continued to be ignored ten years after democracy in South Africa. Although estimates of disability prevalence vary considerably, the studies completed by the United Nations Development Programme (UNDP) and the Central Statistical Service provide important information on the nature and effect of disability on individuals and families in South Africa (White Paper on Integrated National Disability Strategy, 1997).

### **2.3.2 General Resilience Factors**

General family resilience factors serve families by playing multiple roles as protective and recovery factors (McCubbin et al., 1997). These include such things as family problem-solving strategies, effective communication processes, equality, spirituality, flexibility, truthfulness, hope, social support and physical and emotional health (Kalil, 2003). The various factors that contribute to family resilience are highly interrelated and are not necessarily domain specific.

Flexibility is also a key element to family resilience and involves the system's ability to appropriately shift roles as needed (Cohen, Slonim, Finzi, & Leichtentritt, 2002; Hall, 2004; Lee et al., 2004; Walsh, 2003). Communication is the basis of many family processes (Jonker, 2006). In addition, Kalil (2003)

deduce that communication plays a particularly important role in cases of chronic illness or loss. Families adapt better to crises when there is clear, congruent, open communication and emotional expression among family members; and freedom and safety to express positive and negative emotions. This enables constructive conflict resolution, collaborative problem-solving and effective joint decision making (Cohen et al., 2002; Lee et al., 2004; Walsh, 1996). According to Patterson (2002b) many methods of communication can be protective for families, but poor communication can increase vulnerability to risk. Lam et al. (1999) specifically cite good communication between parents.

At the level of the family unit, communication and problem-solving are two key coping strategies that help families to manage stresses (Kalil, 2003). In addition, Patterson (2002a) reviewed resilience in families of children with disabilities and identified the development of communication competence as one of nine family coping processes that are identified as protective processes for families. Jonker (2006) also found that the two most significant predictor variables of family adaptation when caring for a mentally ill family member living in an underprivileged, semi-rural area of South Africa are the family's style of communication during crisis, and the family's use of passive appraisal as a coping style. In addition, she also found that the most commonly mentioned resilience factors cited by the family representative of a family member with mental disorder were: 1) Religion and spirituality; 2) Characteristics of an individual family member, excluding the patient, that is, perception, attitude, hope, acceptance, perseverance, patience and tolerance; 3) Family characteristics (emotional and practical intrafamilial support, love for one another, family as priority, and mutual respect), and 4) Social support. These results are in keeping with findings from international and South African family resilience studies (Jonker, 2006).

Research consistently supports the notion that social support is a resilience

factor in that it encourages and reinforces coping efforts (Jonker, 2006). This includes support from extended family, friends, neighbours, community groups, faith congregations and colleagues (Cohen et al., 2002; Garmezy, 1993; Hall, 2004; Lam et al., 1999; Marsh, & Lefly, 1996; Masten & Coatsworth, 1998; Walsh, 1996). However, Rutter (1985) cautions that it is not sufficient to simply have a large social support system. He added that it is not the extent or frequency of social contacts that matters, but rather individuals' satisfaction with their relationships (Rutter, 1985). For example, in Jonker's (2006) study of families caring for a mentally ill family member living in an underprivileged, semi-rural area of South Africa, she found that the family's use of friends and relatives as a source of coping (i.e., coping network) indicated a negative association with family adaptation.

Religion and spirituality have been identified by a number of researchers as a resilience factor on both individual and family levels (Beavers, & Hampson, 2003; Cohen et al., 2002; Hawley, 2000; Kiser, & Black, 2005; Marsh, & Lefly, 1996). Walsh and Pryce (2003) define religion as "an organized belief system that includes shared and usually institutionalized moral values, beliefs about God or a Higher Power, and involvement in a faith community" (p. 339). Spirituality on the other hand, is a broader term encompassing transcendent beliefs and practices which may be experienced within or outside of organized religion. Involvement in a faith community has a number of advantages, including health and social benefits, and support during difficult times (Walsh, & Pryce, 2003). In addition, Walsh (2007) postulates that recovery is a journey of the heart and spirit, bringing survivors back to the fullness of life.

In particular, it was found that the study of resilience in families, and the development of programs to develop family strengths should also take into account social class and ethnicity (Pépin, & Sudom, 2008). South African family resilience studies conducted on families in a variety of socio-economic, cultural

and crisis contexts found similar results to studies conducted internationally (Jonker, 2006). The following resilience factors were commonly identified: communication (Der Kinderen, & Greef, 2003; Greef, & Human, 2004; Greef, & Le Roux, 1999; Holtzkamp, 2004); social support (Der Kinderen, & Greef, 2003; Greef, & Human, 2004; Holtzkamp, 2004); intrafamilial emotional and practical supports (Greef, & Human, 2004; Holtzkamp, 2004); family time spent together (Greef, & Le Roux, 1999); religion and spiritual support (Der Kinderen, & Greef, 2003; Greef, & Le Roux, 1999; Holtzkamp, 2004); coherence and the family's internal strengths, ability to work together and to depend on each other's supports (Greef, & Human, 2004); and individual characteristics of family members (Der Kinderen, & Greef, 2003; Holtzkamp, 2004). In their qualitative study, Greef and Ritman (2005) found that the specific personality characteristics reported as contributing to family resilience were optimism, perseverance, religion and spirituality, expression of emotion and self-confidence.

Jonker (2006) found that each culture has unique norms that dictate degrees (i., e. the intensity of family members' relationships and involvements with each other) of caregiving. For instance, parents are expected to extend more sympathy to their children than they will receive in return (Kalil, 2003). Karp (2001) also added that in negotiating the boundaries of involvement, striking similarities are identified, including the experience of obligation and emotions such as frustration, responsibility, love, anger, and resentment.

### **2.3.3 Conclusion**

According to Spink (1976) when research begins during the early crisis period of high anxiety and high motivation, adaptive coping techniques could be developed before the parents used denial and rationalization to build up defenses against further vulnerability; and it may increase the parent's comfort in raising a handicapped child. While most parents who have a handicapped child suffer

chronic sorrow, some researchers have made attempts to conduct research with parents who coped by isolation, withdrawal, avoidance or defensiveness; and they found positive results. For example, research by Goodman (1967) on 140 families adjusting to the birth of infants with Down's syndrome examined the response to the offer of professional help in terms of the family's pattern of coping with crisis (cited from Fortier, & Wanlass; 1984). Examples were given of families who coped by isolation, withdrawal, avoidance or defensiveness.

It appeared that families who participated more readily in helping programs were those with an awareness of deeply conflicting feelings, with a willingness to use their increased energy in search for information and new sources of inner strength, and with the ability to focus on the problem (Fortier, & Wanlass, 1984). In an article based on counselling experiences with parents of severely retarded children, Olshansky (1962) argued that chronic mourning is a normal reaction to having a handicapped child. Evidence from the literature suggests the need for extended counselling on a long-term basis for parents to deal with periodic recurrences of grief. Walsh (2002) concluded that as the family becomes more resourceful, its ability to meet future challenges is enhanced. Thus, interventions aim to build family strengths as problems are addressed, thereby reducing risk and vulnerability (Walsh, 2002).

## 2.4 **Summary**

In this chapter, a theoretical framework was discussed based on the resiliency model which describes families as functioning within a number of subsystems. The literature review has explored research that has been undertaken on various aspects of the family resilience concept. It has explored the literature on stress in families of children with disabilities, particularly the benefits of social support for the family to be able to develop effective coping strategies.

## **CHAPTER 3**

### **STUDY 1: RESEARCH METHODOLOGY**

#### **3.1 Introduction**

This chapter explains the methods of the study. It first describes how the respondents were sampled or located. It also explains the strategies used to gather data.

#### **3.2 Locating the research respondents**

Once the University of Limpopo Research Ethics Committee granted approval of the study, permission was sought from the hospital to access families of Down's syndrome children who were associated with the Dr George Mukhari hospital in Garankuwa, Gauteng. A clinic and support group had previously been identified to be operating in that hospital by the researcher. The sister in charge of the clinic and the support group provided a total list of the members of the support group. From this group, a sample was drawn. Thus, the strategy of this study can rightly be called a within-case, purposive sampling method (Miles, Huberman & Saldaña, 2014). Within an identified group, purposive sampling was used to select individuals who had knowledge of the caregiving experience and were, according to Barbie (1992), willing and apparently able to share that knowledge. For inclusion in the study, family representatives were caregivers involved in the primary care of the child with Down's syndrome for at least a period of a year; and they gave their consent to participate in the project.

#### **3.3 Research questions and data-gathering procedure**

The study received ethics approval from the University of Limpopo Research Ethics Committee. Once this was done, the research proceeded. The researcher

used a phenomenological data-gathering method to generate and collect information. However, before proceeding with the actual question of the study, the researcher asked the respondent questions pertaining to his or her family. She first went through aspects of ethics, reminding the respondents that their participation will always be considered voluntary; that withdrawal for whatever reason would not be questioned, and that the information provided would not be linked in any way to them. The information letter which described the study and explained the ethical aspects, and also contained a consent form (see appendix B), was distributed among the prospective participants.

Furthermore, the researcher made the respondents aware that questions about their personal and family backgrounds would be used to further understand the issues, rather than to identify them or their families. Once that part was done, the respondents were asked to provide their families' perspectives regarding how they cared for their Down's syndrome child. They were asked the questions:

"What are your family's experiences of looking after your child?", and  
"Who do you consider your source of constant support, and why? Note that the source can be an individual or a group of persons"

Probes and clarifications were used to assist and/or encourage the respondent to respond and do so appropriately. For instance, for the first question, respondents were encouraged to focus on the family's experience and not on themselves. Those who seemed to be unsure how to proceed, they were made aware that family members tend to share ideas and experiences in common about an issue, such as the care of their child. Those are the ideas and experiences they were asked to share with the researcher. Respondents who said little were initially told that they can say more, if they so wished. When they said something and stopped, the researcher simply asked them to say more about whatever they were saying.



Concerning the second question of the interview, once respondents stated their sources of support, they were asked to clarify why they considered that source to be their support. Respondents who appeared to be unsure were made aware that a source of support is a person or group of persons, or even an organization or facility they felt was available for them in case they had a need. It was explained to them that the support can be anything from a talk about their problem to material things, including finance.

Social research projects are likely to be shaped by administrative, ethical, and political consideration (Barbie, 1992). In order to ensure research was ethical, the researcher made use, as already stated, of informed consent forms that explained the research procedure (Appendix B). In addition, scientists agree that participation in research should, as a general norm, be voluntary; and that research should not harm those that participate in it, unless they willingly and knowingly accept the risks of harm. Speaking about the experiences of being a family caregiver to a relative with Down's syndrome might evoke feelings and emotions in respondents. Indeed, the respondents expressed various emotions overtly during the course of recounting their experiences. This reaction might cause discomfort for researchers or render them uncertain as to how to proceed. In the event where a respondent became upset during an interview, the researcher stopped the interview to provide emotional support to her/him, and suggested psychosocial follow-up as and when necessary, at the Clinical Psychology Unit (CPU) in the hospital. This was the case with respondents 6 and 8, respectively. The respondents were given the option of stopping the interview and rescheduling for another time. Fortunately both respondents agreed to continue. Although the emotional aspect of speaking about the experience of being a family caregiver might be challenging to researchers and respondents alike, family members are also frequently appreciative of having the opportunity to share their stories with someone who is genuinely interested in what they have to say (Penner, & McClement, 2008). Anonymity and confidentiality were the two

important techniques to be employed by the researcher, especially in survey research in the protection of the subject's interest and well-being (Barbie, 1992).

### 3.4 **Explication of the Data**

The heading 'data analysis' is deliberately avoided here. Kvale explains that the "term [analysis] usually means a 'breaking into parts' and therefore often means a loss of the whole phenomenon ... [whereas 'explication' implies an] ... investigation of the constituents of a phenomenon while keeping the context of the whole" (Kvale, 1996, p. 53). Analysis of data, or "data explication", was conducted according to rules of thematic analysis whereby units of relevant meanings were extracted manually from each interview, in which main thoughts, constituents of themes, were generated from the interpretation and exploration of various statements and situations (McMillan & Schumacher, 1993); and the redundant units were eliminated. At the end, themes were formed. Colour coding method was used to analyse each interview and the field notes.

According to Liamputtong (2009), the idea of data analysis signifies transformation; therefore in order for researchers to have a better understanding of their data, it is wise to start coding whilst data are still being collected. After that, validation was conducted by returning to each respondent, to determine if the essence of the interview was correctly captured. Tentative themes emerged from the transcripts and a list of combined themes was developed. Liamputtong (2009) exhorted that researchers should try to see how these tentative concepts and linkages relate to the existing literature; indeed the researcher incorporated tentative themes with the existing literature to develop combined themes. Finally, the resiliency model was incorporated with the combined themes to show their inter-relatedness.

### **3.5 Unit of Analysis, Study Population and Sample Size**

It must be obvious at this time that the level of analysis is the family unit. Regarding sample size, there were certain considerations made. First, the issue of scope was taken into consideration. Qualitative data is labour intensive and complex to handle. In any case, a rule of thumb is that respondents are recruited for as long as they have unique information to contribute. However, when there is nothing new added to the data already collected, it is deemed that the study has reached a point of saturation and it is no longer necessary to add new respondents. Most studies reach this point around ten respondents. In this study, by the time saturation of data was reached, eight family caregivers had been interviewed.

## **CHAPTER 4**

### **Study 1: RESULTS AND DISCUSSION**

#### **4.1 Introduction**

This chapter reports the results of the qualitative part only. A description of the respondents is given, and then the themes that emerged from the interview data are discussed.

#### **4.2 Description of the respondents and their families**

Respondents were seven females and one male, and all of them came from families who had only one child with Down's syndrome. Table I shows the demographic characteristics of the respondents and their families. The average age of the respondents at the time of the interviews was 51 years. All respondents were the children's biological parents. They were Black Africans, and spoke either Setswana, IsiZulu, Sepedi or Xitsonga. However, Setswana is a predominant dialect spoken in the area in which the interview took place. Most participants were married and unemployed. The average age of the Down's syndrome children was 5 years and their average age at the time of diagnosis was about 2 years.

The majority of the participating parents had a high school qualification or a diploma, and only two had a primary school education. One of the families that participated in the study reported an annual income of under R10,000 per year; four families earned between R21,000 to R30,000 per year; one earned between R51,000 to R60,000 per year; another one earned between R21,000 and R30,000 per year. Most respondents were unemployed, and reported that their annual income was actually based on their child's social grant. It must be pointed out that the skewed demographics, particularly the low SES, unemployment

status and poverty observed in this study is likely a consequence of having recruited from a public health facility rather than a feature of a population of families caring for a Down's syndrome child in this geographic area.

**Table 1****Demographic Information of Respondents (Study 1)**

ID	Respondent's age	Marital status	Child's age	Child's gender	Age diagnosed	Home language	Employment status	Family size
1	25 yrs.	Married	1 yr., 8mo's.	Male	1 day.	IsiZulu	Unemployed	3
2	52 yrs.	Separated	6 yrs.	Male	3 yrs.	Setswana	Unemployed	6
3	47 yrs.	Married	3 yrs., 8 mo's.	Female	9 mo's.	Setswana	Unemployed	7
4	38 yrs.	Married	1 yr., 3 mo's.	Male	Day 1.	Sepedi	Crèche teacher	7
5	37 yrs.	Cohabiting	3 yrs., 8 mo's.	Male	6 weeks.	Xitsonga	Unemployed	5
6	39 yrs.	Single	2 yrs., 8 mo's.	Male	1 yr 6 mo's.	Setswana	Pensioner	3
7	40 yrs.	Married	1 yr., 11 mo's.	Female	1 yr 6 mo's.	Setswana	Unemployed	4
8	46 yrs.	Single	11 mo's.	Male	7 days.	Setswana	Unemployed	6

Note: All respondents were Black Africans and were biological parents of the children with Down's syndrome. Respondent 8's baby was born prematurely at 8 months, and respondent 1 was a foreign national from Zimbabwe. Respondent 6 (39 years old) was earning mental illness pension at the time of the interview.

### 4.3 RESULTS

Nine themes emerged from individual interviews with the eight respondents. The themes are as follows: 1. Poverty and lack of resources; 2. Blaming witchcraft; 3. Anticipation, symbolic loss and subsequent frustration and grief; 4. Emotional distress experienced by caregivers; 5. Isolation and lack of social support; 6. Frustration resulting from delays by the South African social agency; 7. Family conflicts; 8. Rejection of Down's syndrome children by their fathers; 9. Spirituality. Each of these will be discussed below.

#### 4.3.1 Poverty and Lack of Resources

This emerged from seven interviews (respondents 1, 2, 3, 4, 5, 6, & 8); the respondents indicated the family's lack of money to care for their Down's syndrome afflicted children. Greeff and Fillis (2009) postulated that lower-income families also tend to experience more stressful life events and social isolation. Negota and Mashegoane deduced that the quality of life of the mothers, their sick children and their families was adversely affected by the financial situation, hence they felt that they were living in poverty. In Hlabyago and Ogunbanjo (2009), respondents cited lack of money to address the HIV/AIDS orphans' basic needs such as food, clothing, shelter and education. They also found that other members in these families who were not caregivers and could be employed were unemployed (Hlabyago, & Ogunbanjo, 2009). The current study concurs with Hlabyago and Ogunbanjo's (2009) findings, in that seven respondents were unemployed; and could only survive by the disability grant of their Down's syndrome children. The findings of the study show that, the majority of participants had accepted their social status of living in poverty. For instance, some of the respondents had several children other than their Down's syndrome children; as a result, they were unable to pay for their children's education, and the majority of parents were not educated. However, the eighth respondent was

a crèche teacher, but her husband was unemployed; and she was expecting the sixth child at the time of the interview.

A survey conducted by the National Union of Metalworkers of South Africa (NUMSA) revealed that poverty from joblessness remains unusually high in South Africa compared to other middle-income developing countries (NUMSA News, 2008) The outcomes of the NUMSA survey also uncovered that, under Apartheid, black people were pushed into the least developed parts of the country, that is, the former homelands, and were deprived of assets and education. This is consistent with the experiences of seven respondents, namely, respondent 1 (aged 25), respondent 2 (aged 52), respondent 3 (aged 47), respondent 4 (aged 38), respondent 5 (aged 37), respondent 6 (aged 39) and respondent 8 (aged 46). However, results indicate that both social and financial supports are a challenge for respondents and their families, in that the majority of respondents reported it. For example, respondent 8 said:

*“I wouldn’t say that the situation has changed because we are still living under the same conditions, the only difference is that we have not seen his father for ten months since he was born. He stays in Thabazimbi .... Because we are not married, he used to come home occasionally.”*

Respondent 1 (aged 25), respondent 2 (aged 52), respondent 3 (aged 47), respondent 4 (aged 38) and respondent 6 (aged 39), were struggling to make ends meet because their spouses were unemployed. It must be noted that not all the respondents lived in poverty. For instance, respondent 7 (aged 40) did not report any problems related to poverty and lack of resources. Although she is not from a rich family, her family were supportive financially. Nevertheless, the majority of the families experienced financial hardship. Although they were able to manage with what they had, it was evident that they were living in poverty.



#### 4.3.2 Blaming Witchcraft

Three respondents, that is respondent 1 (aged 25), respondent 5 (aged 37) and respondent 6 (aged 39), believed that any type of sickness is traceable to either a natural or a supernatural cause, which must be revealed and then cured. Usually this is done by consulting a traditional healer. Many Africans believe that witchcraft exists (see Apostolides, & Dreyer 2008; Chiakwa, 1999; Encyclopædia Britannica, 2002; Manala, 2004). Additionally, it has been uncovered that in many parts of Africa and Asia, epidemics and natural disasters have been interpreted as acts of witchcraft (Chiakwa, 1999; Encyclopædia Britannica, 2002; Skota, 2007).

Negota and Mashegoane (2012) found that witchcraft and spirit possession are the familiar explanations of illness by mothers of children with schizophrenia in the rural South African context. Chiakwa (1999) also found that among the agents of sickness in African traditional belief are human, supernatural and ancestral. Chiakwa notes that “(a) rival, a wicked, or evil-intentioned person can affect the downfall of another by inflicting ill-luck, sickness or destruction on him” (Chiakwa, 1999, p. 196). According to Chiakwa (1999), this evil person manipulates the victims mischievously by means of secrecy or witchcraft often through the services of a greedy, destructive medicine man or Dibia (a Dibia is a traditional healer, fortune teller or diviner in Igbo Nigeria. In turn, the target of the infliction, such as a family or parent of a sick child, will then seek the intervention of a traditional healer or diviner). Respondent 6 expressed the issue as follows,

*“Well, in the beginning I went to a traditional healer because I did not know what was wrong with the baby. He could not sit at the age of five months and his mouth was always open, he was ill and I did not know why he was ill.”*

Onya (1999) again argued that it is also a fact of life that many people consult traditional healers, and in most cases as the first move to seeking health care regardless of the availability of any modern medical facilities or services to them. In this study, belief in witchcraft was expressed by three respondents (respondents 1, 5, & 6) of which two (respondents 5, & 6) consulted traditional healers first before taking their children to the hospital. The findings are consistent with Onya's (1999) observation.

According to Chiakwa (1999), the persistence of an illness raises doubts as to what could be the cause, and hence a supernatural cause is eventually suspected which could either be God, evil spirits, ancestors or witches. Interestingly, persistence sometimes appears to also lead to further doubts and the questioning of common wisdom. Respondents in this study also added that they paid lot of money to the traditional healers without getting healing or realising improvements to the condition of their children.

#### **4.3.3 Anticipation, Symbolic Loss and Subsequent Frustration and Grief**

Participant mothers of children with schizophrenia in Negota and Mashegoane (2012) indicated that they experienced a kind of symbolic loss following their children's illness. This also emerged in all eight respondents in this study when they specified that they felt that they have lost a perfect child, with their children's abnormality. Other parents reported that they have experienced grief characterized with feelings of anger, disappointment, and confusion (see Hillegas, 2012; Skota, 2007). According to Fortier and Wanlass (1984), the difference between grief at the death of a child and grief at the birth of a defective child seems to be the added stress of meeting the needs of the living child.

Respondent 1 (aged 25) also recalled her experiences:

*“I was twenty-four years old when I gave birth, and he is my second born; my first-born son is eight years old. I could not understand why he was abnormal; my husband too was not coping. Some people laugh at me saying that the kids who are younger than him are already walking and capable of talking.”*

Fortier and Wanlass (1984) inferred that, the beginning of the crisis may occur when the parents suspect their child is defective, and they anxiously undertake a period of observation of the child. For example, respondent 2 (aged 52) said this about the time when the child was diagnosed:

*“Well as the months went by, we continued to observe him and he took long to sit by himself, he also started walking when he was three years old; we also thought that he was never going to walk. Around that time, is then that we decided to take him to Britz hospital and it is where they told us that he will be a slow learner.”*

Respondent 3 (aged 47), remembers very well what transpired at home when her family learnt about the diagnosis:

*“My husband was shocked. However, after coming with him to the hospital for him to see other children who have Down’s syndrome he became more understanding and loving towards the child. Her siblings wish as if she was normal like them though.”*

According to Fortier and Wanlass (1984), parents of a child with a disability will need help in learning to deal with the feelings of blame and guilt because blame can prevent communication and warmth between the parents. In addition, Walsh (2002) concurs that normalizing and contextualizing members' distress as natural or understandable in their crisis situation, can soften their reactions and reduce blame, shame, and guilt. The researcher also made observation based on the respondent's experiences, that in the case of the birth of Down's syndrome baby;

the anticipated happy event becomes a tragedy. Thus the mildest empathic probing of parents' feelings will inevitably reactivate an intense but transient grief. Walsh (2002) found that, communication processes that clarify ambiguous situations, are especially important in facilitating resilience as they encourage open emotional expression; and empathetic response, and foster collaborative problem solving.

#### 4.3.4 Emotional Distress Experienced by Caregivers

Stress is defined as “a state of tension that arises from an actual or perceived demand that calls for adjustment or adaptive behaviour;” and is named “distress” when family members perceive the stress as unpleasant or undesirable (Olson et al., 1989, p. 119). Walsh (2002) also found that, family distress may result from unsuccessful attempts to cope with an overwhelming situation. Townsend and Dawes (2004) say that conditions of extreme poverty may result in endemic chronic stress and negative emotional states such as helplessness, decreasing self-esteem, depression and anxiety. All eight respondents reported feeling distressed on many levels. Respondent 2, who separated with his wife after their Down’s syndrome child was born, observed:

*“The reason for our separation is that they (child’s mother and half-sisters) do not take good care of him and that really hurts me.....”*

All eight respondents in the study reported that they have experienced emotional distress on many levels. Their situation had left them feeling vulnerable as a result of lack of knowledge about the child’s diagnosis, constant worry especially about the developmental milestones of the child. A number of aspects were perceived to be as unpleasant or undesirable by the respondents and their families: the inconsistency of the hospital appointments for follow-up which inconvenienced them due to lack of money; fear of another hospitalization for

their Down's syndrome children; unhappiness after having a Down's syndrome child; increased responsibility which was constantly giving them a fright; and some experienced anger, embarrassment and frustration. In addition to the above findings, Smith (2007) uncovered that parents of children with disabilities show significantly more stress within the family system; as compared to parents of typically developing children.

#### **4.3.5 Isolation and Lack of Social Support**

Research consistently supports the notion that social support is a resilience factor in that it encourages and reinforces coping efforts (Jonker, 2006). D'Cruz (2002) found that caregiver perceptions of informal support from extended family varied along a continuum of satisfaction to dissatisfaction. Jonker (2006) also found out that each culture has unique norms that dictate degrees (i.e., the intensity of family members' relationships and involvements with each other) of caregiving. For instance, parents are expected to extend more sympathy to their children than they will receive in return (Kalil, 2003). According to Rutter (1985), it is not the extent or frequency of social contacts that matters, but rather individuals' satisfaction with their relationships. The findings of this study are consistent with Rutter's findings; the majority of these respondents, that is, respondent 1, 2, 3, and 6 did not relate well with their significant others and this in turn, hampered support.

This theme emerged among five respondents, namely, respondent 1 (aged 25), respondent 2 (aged 52), respondent 3 (aged 47), respondent 5 (aged 37) and respondent 6 (aged 39). They perceived less support from family and friends, and were more likely to report feelings of anger, frustration and fear, corroborating the findings of Gousmett (2006). However, respondent 4 (aged 38), respondent 7 (aged 40) and respondent 8 (aged 46) did not report isolation and lack of social support during the interview; they however, gave an impression that

they were receiving enough support. In addition to the current findings, Negota and Mashegoane (2012) also found that most participant mothers in their study referred to the perceived stigma of schizophrenia, and it appeared to be the key factor underlying the social isolation experienced by some of them. Walsh (2002) also found that, family members tend to feel abnormal and deficient in comparison to "normal," "healthy" peers who are not dealing with an illness situation. Respondent 6 recapped her experience:

*“You know having a child with Down’s syndrome is very painful; I do not even go places with him because they laugh at him; so usually I visit relatives or go to places where they know his condition. When I am travelling by public transport, I talk about his condition, in order to avoid people’s stares. When there are school meetings for his elder brother, I leave him with my younger sister but the problem is that she is epileptic, so I do not leave them for too long. I have two younger sisters and an elder sister, all of them are not supportive both emotionally and financially.”*

Nduna and Jewkes (2010) found that, some respondents from large families where three generations often lived in one house, with no one working, responded at an intrapsychic level and felt themselves to be additional and unnecessary burdens. Karp (2001) also added that in negotiating the boundaries of involvement, striking similarities are identified, including the experience of obligation and emotions such as frustration, responsibility, love, anger, and resentment. Hlabyago and Ogunbanjo (2009) uncovered that caregivers in their study withdrew from requesting help because of a desire not to trouble their relatives. As a result of their findings, they concluded that the respondents experienced feelings of shame by being dependent on their extended families (Hlabyago, & Ogunbanjo, 2009). In addition, Cross, Dunst and Trivette (1986) found that satisfaction with both formal and informal sources of social support was significantly related to emotional wellbeing in parents of children with

disabilities; this was also deduced by Kirkham, Schilling and Schinke (1985). However, Rutter (1985) cautions that it is not sufficient to simply have a large social support system.

Respondent 3 perceived caregiving for a child with Down's syndrome as a burden coupled with enormous social isolation:

*"Yes, personally I could no longer attend funerals, weddings or family gatherings, I also could not go to town for a while... my husband is the one who went."*

Amongst the reasons or causes of isolation, fear of stigmatization appeared to be the most overwhelming element for all five respondents. It was observed that by not requesting help from their relatives, these families become further isolated. However, family's dissatisfaction in relationships with their relatives, resulted in feelings of shame and a desire not to trouble others.

#### **4.3.6 Frustration Resulting from Delays by the South African Social Agency**

South Africa has a large percentage of disabled people, within whom unemployment remains a fundamental problem (White Paper on Integrated National Disability Strategy, 1997). In spite of the situation, few services and opportunities exist for people with disabilities to participate equally in society (White Paper on Integrated National Disability Strategy, 1997). Hlabyago and Ogunbanjo (2009) found that all nine caregivers in their study reported frustrations in accessing social grants for the orphans due to delays, misinformation by social service workers, or lack of necessary documents required to obtain these grants. Frustrations were reported by three respondents, namely, respondent 1 (aged 25), respondent 2 (aged 52) and respondent 8 (aged 46) as a result of bureaucratic delays that took months for the social grants to be awarded or registered. Due to the delays, when the money was issued

families received a lump sum. However, respondent 1 (aged 25) was a foreign national from Zimbabwe. Her nationality prohibited her from receiving the social grant given to South Africans. Respondent 8 had been waiting for months to receive the social grant and she commented as follows:

*“It was difficult really; we barely could get by. I also applied for a disability grant five-months ago and I am still waiting. My mother had been our source of strength; she tried to help us cope.”*

Respondent 2 also reported frustrations in accessing social grants due to delays:

*“In the beginning the money was enough because we got a lump sum of more than two thousand Rands from Khuthatso’s grant, we managed but as time went by it was never enough because we paid for his crèche and the schools he is supposed to go to are expensive.”*

After conducting a study on children with disabilities living in Orange Farm, Saloojee and colleagues (2006) found that many of the needs of disabled children remain unmet and continue to be ignored ten years after democracy in South Africa.

#### **4.3.7 Family Conflicts**

Life crises and constant stressors can derail the functioning of a family, causing ripple effects for the individual family members and their respective relationships (Walsh, 2003). Gousmett (2006) found that children who have disabilities can bring much joy and happiness to a family; however, the strain of caring for them can have effects on other members of the family, not only for parents and siblings but also for extended family members. Conflicts in the family were observed in five respondents, namely, respondent 1 (aged 25), respondent 2



(aged 52), respondent 3 (aged 47), respondent 4 (aged 38) and respondent 6 (aged 39). In the study conducted by Hlabyago and Ogunbanjo (2009) conflicts were more due to financial conflicts. In a study of caregivers of patients with Alzheimer's disease, Frankel, Quill and McDaniel (2003) reported that, family variables such as negative expressed emotions strongly influence the health and well-being of both identified patients and family caregivers. Respondent 1 found it difficult and challenging to care for her Down's syndrome child with lack of emotional support from the family due to conflict:

*"Yes we had to adjust; when I fell pregnant I was expecting to have a normal child. You know African people do not understand; when it comes to this child, there is a division, some family members are supportive and some are not. They have so many questions, it is because I am the first one to have a disabled child; maybe if there were two or three of us in the family with disabled children, it would have been better."*

Respondent 2 expressed himself as follows concerning conflict in the family:

*"You know relatives will not show you how they feel, but when they are together they gossip about him. My wife told me that her family does not like him because he is a difficult child; he beats other children, so I should look for him a school in order for him to go away....."*

Their extended families also had abandoned them due to their crisis of having a child with Down's syndrome. For instance, respondent 3 observed:

*"It was very difficult, our relatives never visited nor showed us that they were concerned."*

In this study the conflicts were experienced as a pile up of the crisis situation and was as a result of misunderstanding among family members, both the nuclear and extended family members. It was also uncovered that, lack of knowledge and fear of stigmatization were the main cause of crisis situations. Walsh (2002) found that family resilience is fostered by shared beliefs that help members make meaning of crisis situations; by recasting a crisis as a shared challenge that is comprehensible, manageable and meaningful to tackle.

#### **4.3.8 Rejection of Down's syndrome Children by their Fathers**

Denis and Ntsimane (2005), in their study on men and fatherhood in South Africa, established that among the poor a very high and growing proportion of children do not live in households with their fathers. Nevertheless, Richter et al. (2012) found that in many parts of the world, a father who acknowledges and supports his children confers social value on them, enabling children to become members of a wider circle of family and kin. Three of the eight respondents reported that the Down's' syndrome children's fathers abandoned them. However, what was outstanding in these findings was that; two fathers made amends with the mothers and one father from respondent number 8, rejected the child completely as soon as he learnt about the diagnosis from the mother. Richter et al.'s (2012) study, commend what these Down's syndrome fathers did when they observed that; young fathers need interventions that will help them make and retain lifelong connections with the mother of their child and her family, regardless of the nature of their romantic relationship. The study conducted by Hlabyago and Ogunbanjo (2009) revealed that the burden of care and responsibility for children falls largely on the women. However, they established that it is likely that in many cases it is circumstances rather than choice that lead to the separation of men from their children (Hlabyago, & Ogunbanjo, 2009).

In their study, Desmond and Desmond (2006) established that, in South Africa, fathers were present in the same household as their children in only 48% of cases, compared to mothers who were resident in 80% of the cases. Single mothers raise most children and their biological fathers play a marginal role in their lives. Desmond and Desmond (2006) cautioned that their findings are only an observation, not a judgement because it is likely that in many cases it is circumstances rather than choice that lead to the separation of men from their children. Furthermore, Hlabyago and Ogunbanjo (2009) concluded that “there is no data available on the reasons for the absence of fathers” (p. 510).

In addition, Richter et al. (2012) found that South Africa has one of the highest rates of father absence in the world. These findings concur with the current research findings in that, absent fathers of Down’s syndrome children in the study did not bother to acknowledge paternity by refusing being responsible for the pregnancies. The study further reveals that the burden of care and responsibility for children falls largely on the women. Although one of the respondents in this study was a father; the involvement of fathers in the care of the children is rather sparse. Three of the eight respondents, namely, respondent 1 (aged 25), respondent 4 (aged 38) and respondent 8 (aged 46) reported that the fathers of their Down’s syndrome children abandoned them. One father, the boy-friend to respondent 8, rejected the child completely as soon as he was told the diagnosis. This is her report during the interview:

*“His father has never met him. He rejected him because of his disability. As soon as I told him that he has Down’s syndrome, he never came back. The other reason is our tradition which restricts men from seeing babies when they are less than twelve weeks; despite that he told me to make a plan because I chose to fall pregnant, ‘just like that’.”*

According to Nduna and Jewkes (2010) a socially recognized connection through paternity of a biological father, legitimizes claims of belonging and improves the status of children in their homes. In addition, Richter et al. (2012) argued that fatherhood goes beyond being just a provider, but also being a source of emotional health and wellbeing.

Seemingly, the researchers observe that fathers are expected to have a much more affective and engaged relationship with children going far beyond provision and discipline (Richter et. al., 2012). The narrative of respondent 8 clearly indicates the distress that an absent father causes for the affected families. Again Richter et al. concurs,

“We argue that the role of fathers in the lives of children and families was and remains important and, where it is well enacted and performed, fatherhood is a highly important and valuable function” Richter et al. (2012, p. 3).

#### 4.3.9 Spirituality

Walsh (1999) uncovered that, spiritual resources have been largely neglected in clinical practice, and deduced that they can be tapped as wellsprings for resilience. Respondent 7 expressed herself as a spiritual person during the interview, and this was her response:

*“They were coping because we once made a joke of it, that she could be having Down’s syndrome, so like I told you before that I compare this situation with any chronic illness because our family is spiritually grounded; my husband is a pastor, so it is easier to take one day at a time.”*

The findings on adaptation in this study indicate that, spirituality characterized by having faith in God, praying and the belief in the purpose of God are factors

which influence positive adaptation in families caring for a child with Down's syndrome. Walsh (2002) found that spiritual or religious resources, faith practices such as meditation or prayer and religious or congregational affiliation now have empirical support for their healing power.

However, perception plays a role in the adaptation of families caring for a child with Down's syndrome. Redefining the situation and giving it meaning coupled with religious beliefs, it is associated with perceptions in the resiliency model of family stress which determines how an individual or family perceive the crisis. In addition, Greeff and Fillis (2009) concur that negative evaluations of circumstances can lead, among other things, to self-recrimination and emotions like anger, sadness and anxiety. Walsh and Pryce (2003) are of the opinion that involvement in a faith community has a number of advantages, including health and social benefits, and support during difficult times. According to Brier (2008), religious participation not only can affect social support, but it also can affect the individual's belief system and potentially facilitate grieving by allowing the individual to attach a meaning as to why a loss has occurred. In addition, Walsh (2007) postulates that recovery is a journey of the heart and spirit, bringing survivors back to the fullness of life.

## **CHAPTER 5**

### **STUDY 2: QUANTITATIVE RESEARCH METHODOLOGY**

#### **5.1 Sampling**

The target population for this study was African families with low incomes caring for a child with Down's syndrome. Once more, the primary caregiver was identified as the respondent whose articulations would be used to determine the family situation. Respondents were recruited through the Pediatrics' Out-Patient Department at Dr. George Mukhari Hospital. Purposive sampling was used to select respondents. This method of sampling is used to select individuals who have knowledge of a care giving experience and are willing and able to share that knowledge (Barbie, 1992). For inclusion in the study, family representatives were caregivers involved in the care of the child with Down's syndrome for at least a period of a year. Quantitative data has certain requirements for it to be useful. It was difficult to recruit special families such as the ones targeted in this study. Nonetheless, thirty-six participating families were obtained. Their demographic details, together with those of the actual respondents, are shown in Table 2.

#### **5.2 Measures**

Data were gathered through a variety of measures, including: a demographic questionnaire, which was used to collect background information about the respondents. The remaining scales of the study are each discussed below.

##### **5.2.1 Family Support**

The Family Support Scale consists of 19 items rated on a five-point scale ranging from not at all helpful (1) to extremely helpful (5) (Dunst, Jenkins, & Trivette,

1984). The scale measures the helpfulness of sources of support to families with a young child. Sources of support are measured across five factors. Firstly, Informal Kinship includes spouse/partner's friends, own friends, other parents, own children and church. Spouse/Partner support includes spouse/partner, parents, spouse/partner's parents, relatives/kin. The Social Organization factor includes social groups/clubs, parent's groups, school/day care centers, co-workers. Formal kinship includes own relatives/kin and own parents. The final factor is Professional Services, which includes early intervention programs, professional helpers, and the family/child's physician. The different factors ensure that the scale is measuring different, independently available sources of social support (Dunst et al., 1984). Although the factors are logical, they were not used in this study and the scale was adapted and considered a general scale. Also, an additional item of 'neighbours' was added. In this study the reliability of the family support scale was not calculable because there were many instances of the category "not available". However, previous studies found that the scale is reliable. For instance, the reliability of the total scale was  $\alpha = .85$  (Dunst et al., 1984; Hanley, Tasse, Aman, & Pace, 1998), and the test-retest reliability, measured two years apart, was found to be  $r = .50$  (Dunst et al., 1984), and over a two-week period it was  $r = .73$  (Hanley et al., 1998).

### 5.2.2 Family Satisfaction

Family satisfaction was measured with a shortened 5-item version of Brayfield and Rothe's (1951) job satisfaction scale. For the purpose of this study, we used a modified version in which the word "work" was replaced with the term "family life". Existing work-family interaction research has used a similar approach of modifying measures (Aryee, Luk, Leung, & Lo, 1999; Hennessy, 2005; Kopelman et al., 1983). Using a 5-point Likert scale, respondents were asked to indicate the extent to which they were satisfied with the five family satisfaction items. Responses range from 1 (strongly disagree) to 5 (strongly agree). High scores

indicate a high level of family satisfaction, while low scores indicate a low level of family satisfaction. Item #5 was reverse scored. An example of a family satisfaction item is, "I find real enjoyment in my family life." Aryee et al. (1999) found a reliability coefficient of  $\alpha = 0.84$  for the modified measure of family satisfaction that was used in this study. This measure of family satisfaction was positively related to life satisfaction ( $r = 0.38, p < 0.01$ ) and spousal support ( $r = 0.33, p < 0.01$ ). In the present study, the coefficient alpha ( $\alpha$ ) for the Family satisfaction scale was 0.764.

### 5.2.3 Family Stress

Family stress was assessed using a modified version of the Reeder stress inventory (RSI; Reeder et al., 1968). The RSI is a self-report measure of overall life stress. However, for the purposes of this study the words "at home" or "your family responsibilities" were added to the items (see, Hennessy, 2005). Current work-family research has used measure modifications of this nature (Aryee et al., 1999; Kopelman et al., 1983). The original form of the RSI was constructed to assess four areas of stress, including: (a) tension or nervousness, (b) nervous strain, (c) fatigue, and (d) level of challenge. Each area of stress was measured with one item. The RSI asks respondents to indicate the extent to which the statement in each item describes their experience. Response choices include: exactly, to some extent, not very accurate, and not at all. Each response is assigned a numerical value according to the Coulson scoring system described in detail by the authors of the instrument. High scores indicate a high level of family stress, while low scores indicate a low level of family stress. An example of a modified family stress item is, "My daily activities at home are extremely trying and stressful." The family stress scale achieved a reliability of 0.902 in this study.



#### 5.2.4 Family coping

The F-COPES is a 30-item, self-report questionnaire used to assess ways that families cope with stress (F-COPES; McCubbin, Olson, & Larsen, 1987). This measure was used in this study to determine which social supports were available, as seen by the primary caregivers. The measure uses a 5-point Likert scale with responses ranging from “strongly disagree” to “strongly agree.” There are five subscales: Acquiring Social Support, Reframing, Seeking Spiritual Support, Mobilizing Family to Acquire and Seek Help, and Passive Appraisal. Higher scores indicate more positive coping and problem solving strategies during times of crisis. Although the scale is known to have achieved high reliability and validity in other studies, the results are different in this study. The total scale of the F-COPES achieved a Chronbach’s alpha reliability of 0.612. Analysis was then conducted at a subscale level. Only two subscales of the F-COPES achieved acceptable reliability levels. The Seeking spiritual support and the Mobilising family to acquire and accept help subscales reached  $\alpha$  of 0.886 and 0.554, respectively.

The remaining scales were subjected to item-to-total correlation analysis. First assessment of the reliability of the Acquiring social support subscale obtained a Chronbach’s alpha of 0.393. However, item-to-total correlation analysis showed that items 1 and 25 were negatively correlated with the total score of the scale (corrected item-total  $r = -0.057$  and  $-0.062$ ). Their removal increased reliability to  $\alpha = 0.477$ . Further analysis found that the contribution of items 5 and 20 to scale reliability was poor (0.072 and 0.094), and their removal would improve the scale reliability to a value above 0.50. The removal of the two items increased reliability to  $\alpha = 0.579$ . Finally, item 8 was removed since its correlation coefficient depreciated to a value of corrected item-to-total  $r$  of 0.029. The final reliability of the Acquiring social support subscale, based on the remaining 4 items (namely, items 2, 10, 16, 29), stood at  $\alpha = 0.653$ . The reliability of the

Reframing subscale was also poor at  $\alpha = 0.311$ . Item 11 contributed negatively to the subscale (corrected item-to-total  $r = -0.266$ ), and its removal improved reliability to  $\alpha = 0.597$ . The removal of items 7 and 15 (corrected item-to-total  $r$ s = 0.107 and 0.079) improved the reliability level to  $\alpha = 0.724$ , with 5 items (items 3, 13, 19, 22, 24) remaining. The Passive appraisal subscale achieved a lowly  $\alpha = 0.136$ . None of the items would improve the scale to an acceptable, usable level if they were removed. So the scale was considered useless for use in any analysis. Important to note is that the items of the Passive appraisal subscale were all reverse scored. Other researchers (cf. Abdel-Khalek, 1998) have noted that it is not advisable to use items that are reverse keyed in non-Western samples. It appears that a similar phenomenon contributed to the poor performance of reverse keyed items of the Passive appraisal subscale in this sample.

### 5.3 Procedure

The interview process took about an hour to an hour and a half, in the Pediatrics' Out-Patient Department at Dr. George Mukhari Hospital, Garankuwa. The township is located 30 kilometers north of Pretoria. Ethical approval and permission to conduct the study were granted by the University of Limpopo Research Ethics Committee and the Pediatrics' Out-Patient Department at Dr. George Mukhari Hospital. With regard to respondent consent, respondent rights were fully explained to them, including the right to withdraw from the study at any time without giving an explanation to the researcher. It was only after indicating that they understand their rights that they signed a consent form, and then proceeded to take part in the interviews.

The questionnaires, which consisted of all the primary scales of the study, were administered on a one-to-one basis by the researcher. The interviews were

conducted in a private room at the Dr. George Mukhari Hospital. The entire interview process took about forty-five minutes to an hour.

## **CHAPTER 6**

### **STUDY 2: RESULTS, DISCUSSION AND GENERAL DISCUSSION**

#### **6.1 Plan of Analysis**

All analyses were conducted using the statistical software, the IBM Statistical Package for Social Sciences, version 21 (IBM SPSS 21.0) (IBM Corporation, 2012). Analysis began with the generation of frequency distributions to describe the sample. Then the social support scale was used to determine the types and frequency of social support that each family had, using primary caregivers, who were respondents in this study, as sources of information. Thereafter, correlation analysis was conducted between the major variables of the study. The results of correlation analysis were used to determine which variables would be included in the regression analysis, predicting family satisfaction.

#### **6.2 Demographic Details of the Sample**

The sample used to collect the quantitative data for the study consisted of 36 respondents, who were all primary caregivers representing families of children with Down's syndrome. Most of them (51.4%) were not married. Also, many were either not educated or only studied up to high school (65.7%).

**Table 2:  
Demographic Details of the Sample (Study 2)**

	N	%
<b>Primary caregivers' Marital Status</b>		
Married	14	38.9
Living with someone	2	5.6
Separated	2	5.6
Never married and not living with someone	18	50.0
<b>Primary caregivers' Occupation</b>		
Employed	9	25.0
Unemployed	24	66.7
Temporary Employment	3	8.3
<b>Primary caregivers' Highest Educational Level</b>		
No high school	7	19.4
Some high school	17	47.2
High school certificate	7	19.4
Some post-secondary, but no diploma or degree	1	2.8
Post-secondary education	4	11.1
<b>Primary caregiver's family type</b>		
Biological parents	16	44.4
Blended	1	2.8
Mother-led	18	50.0

### 6.3 Sources of Social Support for the Families, according to the Primary Caregiver

The sources of social support for the families of children with Down's syndrome were investigated, using the primary caregivers as providers of information. Data generated through the social support scale was used for this purpose. The primary caregivers of children affected by Down's syndrome perceived social groups or clubs (33/92% caregivers), followed by parents' groups and professional helpers such as therapists, teachers and social workers (30/83% of caregivers each) as the least available sources of social support for their families. Only 1 primary caregiver thought that her partner's parents were extremely helpful. The primary caregivers responded that neighbours (28/77% of caregivers), followed by other parents (26/72% of caregivers) and then relatives of their partners (21/58% of caregivers), were not at all helpful.

About (33/92% of caregivers) primary caregivers in the study rated their own or their child's physician and professional agencies (such as: public health, social services, mental health) as very helpful, followed by the other children (30/83% of caregivers) and then to a large extent their parents (18/50% of caregivers). There were many (16/44% of caregivers) who also considered their spouses or partners to be extremely helpful. The primary caregivers were of the view that the early childhood intervention program was generally helpful (32/89% caregivers). Some of the primary caregivers considered fellow church members or their ministers of religion to be sometimes helpful (16/44% caregivers). None of the respondents responded to item number 20 which inquired about their additional support system apart from the ones listed.

**Table 3:**  
**Perceived Sources of Social Support**

FSS item		Not at all helpful	sometimes helpful	Generally helpful	Very helpful	Extremely helpful	Total	Not Available	Mean (SD)
1.	My parents	3 (8.3)	3 (8.3)	6 (16.7)	18 (50.0)	0 (0.0)	30 (83.3)	6 (16.7)	3.30 (1.022)
2.	Spouse's parents	14 (38.9)	8 (22.2)	3 (8.3)	1 (2.8)	1 (2.8)	27 (75.0)	9 (25.0)	1.78 (1.050)
3.	My next-of-kin	4 (11.1)	12 (33.3)	15 (41.7)	3 (8.3)	0 (0.0)	34 (94.4)	2 (5.6)	2.50 (0.826)
4.	Spouse's next-of-kin	21 (58.3)	7 (19.4)	4 (11.1)	2 (5.6)	0 (0.0)	34 (94.4)	2 (5.6)	1.62 (0.922)
5.	Partner <sup>1</sup>	5 (13.9)	5 (13.9)	8 (22.2)	16 (44.4)	2 (5.6)	36 (100)	0 (0.0)	3.14 (1.175)
6.	My friends	14 (38.9)	7 (19.4)	3 (8.3)	0 (0.0)	0 (0.0)	24 (66.7)	12 (33.3)	1.54 (0.721)
7.	Partner's friends <sup>1</sup>	16 (44.4)	1 (2.8)	1 (2.8)	0 (0.0)	0 (0.0)	18 (50.0)	18 (50.0)	1.17 (0.514)
8.	My children	1 (2.8)	1 (2.8)	1 (2.8)	30 (83.3)	1 (2.8)	34 (94.4)	2 (5.6)	3.85 (0.657)
9.	Neighbours	28 (77.8)	2 (5.6)	3 (8.3)	1 (2.8)	0 (0.0)	34 (94.4)	2 (5.6)	1.32 (0.768)
10.	Other parents	26 (72.2)	4 (11.1)	2 (5.6)	0 (0.0)	0 (0.0)	32 (88.9)	4 (11.1)	1.25 (0.568)
11.	Co-workers	8 (22.2)	2 (5.6)	1 (2.8)	0 (0.0)	0 (0.0)	11 (30.6)	25 (69.4)	1.36 (0.674)
12.	Parents' groups	2 (5.6)	1 (2.8)	1 (2.8)	2 (5.6)	0 (0.0)	6 (16.7)	30 (83.3)	2.50 (1.378)
13.	Social groups/clubs	3 (8.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	3 (8.3)	33 (91.7)	1.00 (0.000)
14.	Church members/minister	14 (38.9)	16 (44.4)	1 (2.8)	0 (0.0)	0 (0.0)	31 (86.1)	5 (13.9)	3.58 (0.564)
15.	My family/child's physician	3 (8.3)	0 (0.0)	0 (0.0)	33 (91.7)	0 (0.0)	3 (8.3)	0 (0.0)	3.92 (0.280)

<b>FSS item</b>	<b>Not at all helpful</b>	<b>sometimes helpful</b>	<b>Generally helpful</b>	<b>Very helpful</b>	<b>Extremely helpful</b>	<b>Total</b>	<b>Not Available</b>	<b>Mean (SD)</b>
16. Early childhood intervention program	1 (2.8)	2 (5.6)	32 (88.9)	0 (0.0)	0 (0.0)	35 (97.2)	1 (2.8)	3.89 (0.404)
17. School/day-care center	1 (2.8)	4 (11.1)	9 (25.0)	0 (0.0)	0 (0.0)	14 (38.9)	22 (61.1)	3.50 (0.855)
18. Professional helpers (therapists, teachers, social workers, etc.)	1 (2.8)	2 (5.6)	1 (2.8)	2 (5.6)	0 (0.0)	6 (16.7)	30 (83.3)	2.67 (1.211)
19. Professional agencies (public health, social services, mental health)	1 (2.8)	0 (0.0)	2 (5.6)	33 (91.7)	0 (0.0)	36 (100)	0 (0.0)	3.86 (0.543)
20. Other	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	36 (100)	0 (0.0)	N/A

Note: Values are primary caregivers endorsing the item, and values in brackets are percentages.

1 = partner was understood to mean the current spouse or partner, and partners who are no longer with the primary caregiver.



#### 6.4 **Correlation Analysis of Family Satisfaction, Family Stress and Dimensions of Coping**

All the major variables of the study were subjected to correlation analysis with each other. Family satisfaction is negatively associated to family stress ( $p < 0.05$ ; see table 4a). Furthermore, family satisfaction is negatively related to reframing ( $p < 0.05$ ). Seeking spiritual support is positively related to reframing ( $p < 0.05$ ). The seeking spiritual support subscale of the F-COPES was positively related to the Reframing subscale, and the relationship was statistically significant ( $p < 0.01$ ). The remaining significant correlations were the positive correlations between the full scale F-COPES and its subscales of Acquiring social support, Seeking spiritual support and Mobilising family to acquire and accept help ( $p < 0.001$ ).

**Table 4a:**  
**Correlations between Major Variables of the Study (N = 36)**

		1	2	3	4	5	6	7	8
1. Family Satisfaction	<i>r</i>	1							
	<i>p</i>								
2. Family Stress	<i>r</i>	-0.533	1						
	<i>p</i>	0.001							
3. Family Support Scale	<i>r</i>	0.026	-0.010	1					
	<i>p</i>	0.879	0.954						
4. Acquiring social support	<i>r</i>	-0.162	0.200	.049	1				
	<i>p</i>	0.345	0.242	.774					
5. Reframing	<i>r</i>	-0.342	0.090	-.171	.017	1			
	<i>p</i>	0.041	0.603	.319	.922				
6. Seeking spiritual support	<i>r</i>	-0.231	0.119	.148	.016	.457	1		
	<i>p</i>	0.176	0.489	.391	.926	.005			
7. Mobilising family to acquire and accept help	<i>r</i>	0.148	0.022	.202	.058	-.053	.289	1	
	<i>p</i>	0.389	0.897	.236	.739	.757	.087		
8. F-COPES total	<i>r</i>	-0.038	0.026	.224	.571	.246	.570	.645	1
	<i>p</i>	0.826	0.880	.190	.000	.147	.000	.000	

Note: F-COPES = Family Crisis Oriented Personal Evaluation Scales.

## 6.5 **The Prediction of Family Satisfaction from Family Stress and Coping Dimensions**

Regression analysis was conducted to predict family satisfaction. Reframing was the only independent variable included in the analysis, based on the outcomes of the correlation analysis and the hypothesis to be investigated, which is to determine which sources of social support would predict family satisfaction. The results of regression analysis suggest that both family stress and Reframing are important in predicting family satisfaction among families of children who have Down's syndrome (see table 4b). The *t*-values in table 4b are statistically significant, and both being negative, well above the -1.96 cut-off point. In fact, the results show that regressing family satisfaction on family stress and Reframing produced an R-square value of 0.371 (adjusted  $R^2 = 0.333$ ), suggesting that about 37% (33% when adjusted) of the variation in family satisfaction was explained by differences or variability in family stress and Reframing. Interestingly, the betas or standardized coefficients are negative even when the family stress beta is the larger of the two. In effect, the direction of the sign of the betas means that as family stress and Reframing increases, values of family satisfaction will decline; the opposite will be true in cases where family stress and Reframing is lower.

**Table 4(b):  
Regression Analysis for the Prediction of Family Satisfaction**

<i>Predictors</i>	B <sup>1</sup>	Se.B <sup>2</sup>	$\beta$ <sup>3</sup>	<i>t</i>	<i>p</i>
Family stress	-0.621	0.170	-0.506	-3.651	0.001
Reframing	-0.802	0.375	-0.297	-2.142	0.040

Note: <sup>1</sup>B = non-standardized regression coefficient; <sup>2</sup>Se.B = standard error of B; <sup>3</sup> $\beta$  = standardized regression coefficient

## 6.6 Discussion

### 6.6.1 Characteristics of respondents and their respective families

The results of study 2 show that just over half of the respondents interviewed, who in fact were the primary caregivers of the Down's syndrome children, never married and were not living with a partner. Thus, the family structure of their families is that of a single-mother type. When fathers live elsewhere, there is no guarantee that they will be consistent with their financial and emotional support of the child (Lloyd, 1993). In their findings, Richter et al. (2012) found that, in many cases, children are being supported by fathers who were not only living elsewhere but are outside the household in the sense of not being considered to be members of the same household. They further wrote that, not only has the rate of marriage declined in recent decades but there have been substantial changes in the types of marriages registered (Richter et. al., 2012).

It has been argued that marriage rates are stabilising and that the low and declining rates of marriage are associated with poverty and the impact of *Apartheid* policies, rather than being the effect of female empowerment (Richter et. al., 2012). Just over 66% of the respondents had an education that is at the level of high school or less, and almost 70% were unemployed. This places most of the families in the low socio-economic status category, since these variables, together with marital status for women, can serve as proxy for socioeconomic status. In their study of identifying resilience factors in poor single-parent families, Greeff and Fillis (2009) found that lower-income families also tend to experience more stressful life events and social isolation.

The situation of low-income families has to be studied carefully. The families in this study possess many of the characteristics that make them vulnerable. Take for instance low socioeconomic status. This variable is known to influence

cognitive functions such as language development in children, independent of family structure and the educational level of parents (Brooks-Gunn et al., 1999).

### 6.6.2 Sources of social support identified

The next level of analysis focused on the sources of social support for the families. Discussion proceeds from Stanley's (2010) observation that family resilience has repeatedly been shown to be associated with a core of individual, family, and extrafamilial influences, usually caring, prosocial adults (Stanley, 2010). The balance of the family system depends on it for restoration (Patterson, 1988; Seligman & Darling, 1997). Ultimately, social and community supports are significant mediators of family stress (Perry, Harris, & Minnes, 1999). In other words, at the bottom of how social support promotes health is that, it works as a moderating or buffering factor in the relationship between stress and related strains (House, 2001; Thoits, 2011).

The primary caregivers interviewed listed the sources of social support according to whether they were available or not for the family. The primary caregivers thought that social groups or clubs, parents' groups and professional helpers (therapists, teachers and social workers) were the least available sources of social support for their families. This was rather surprising, given that groups are usually thought to be supportive. Professionals in particular, are expected to be the ones who foster family resilience (Marsh, 2003). However, it could be that it depends on the type of professional, especially the type of service offered by the professional. Most respondents thought that the physicians and professional agencies offering social services and mental and public health were very helpful. Down's syndrome has an element of a "physiological" (as opposed to "psychological") condition to it, at least as far as a lay observer is concerned. Thus, families may find that physicians who can provide medicines and agencies that can provide material support are more helpful as sources of support.

Most caregivers considered their spouses or partners to be helpful, but the partner's parents were both unhelpful and unavailable according to the results. The finding supports Failla and Jones (1999), as far as spousal support is concerned. But also support Altiere (2006), who also found that extended family members may reject a child with a developmental disorder or distance themselves from the family. It will be interesting to know the reasons why this is so in the case of the families of the respondents. This study did not ask about the physical state of the child, but the finding can be interpreted on the basis of this variable, using inference.

The respondents also said that neighbours, other parents and partners' relatives were not helpful either. According to Gousmett (2006), the benefits of effective social support networks may be limited to families who have a less physically disabled, more socially acceptable child. Those who are related to the child or have some association with him or her, may have developed expectations and romantic fantasies of a "normal child". The birth of a Down's syndrome one would have disappointed them. Nevertheless, the finding of lack of social support from these individuals is not unique to Africans and to low-income factors for that matter. Orthner, Jones-Sanpei and Williamson (2004) also found that low income families can lack some of the social support required for their resilience as families.

### **6.6.3 The stress model**

The main hypothesis of study 2, the quantitative part of the study, was to investigate whether family stress and different types of social support would predict family satisfaction. First, the role of family stress. The findings indicate that family satisfaction is negatively associated with family stress. This is a negative correlation which demonstrates that as levels of family stress decrease, levels of family satisfaction increase. In addition, family satisfaction was found to

be negatively related to reframing. However, this is very surprising. First, it was expected that family satisfaction would be related to all or most types of family satisfaction, and the relationships would be positive (Thoits, 2011). This was not the case in this study.

Also, an inspection of the correlation matrix shows that Reframing was not related to F-COPES, the full scale version of social support. Yet reframing was positively related to the Seeking spiritual support subscale. As an example, religion and spirituality have been identified by a number of researchers as a resilience factor on both individual and family levels (Beavers, & Hampson, 2003; Cohen et al., 2002; Hawley, 2000; Kiser, & Black, 2005; Marsh, & Lefly, 1996). Their lack of relationship with both family stress and family satisfaction is puzzling. When entering family stress and Reframing into a regression model to predict family satisfaction, once more the performance of family stress is according to theory, but Reframing is negatively related to family satisfaction. The results are unclear, and offer very little assistance in describing the stress model in this sample. For that reason, it is best not to interpret them.

## 6.7 **General Discussion**

The results of the qualitative part of the study were clear about factors associated with caring for a child with Down's syndrome in the context of a low-income African family. The families were living in poverty and it was likely that in the instances where the fathers were not at home, their behaviour may have worsened the situation of mothers who were left to fend and care for the families as single mothers. In those families where there were two biological parents present, the situation was not better because the primary caregivers to the children were unemployed.



Nonetheless, in the second study respondents listed spouses as helpful, although a large proportion did complain about family conflict involving extended family members. This is considered an indicator that at least the spouse is perceived as an important source of social support. Listing the spouse as helpful is important because it suggests that dyadic conflict is perceived as minimal in the family. Marital conflict has been found to be an important contributor in the experience of parental stress in families of a child with a disability (Van Lieshout, Meyer, Curfs, & Fryns, 1998). However, this did not apply to some of the parents since they were of the view that the fathers of their Down's syndrome children were unavailable for their children.

Lack of material or instrumental support in poor families is usually alleviated by social grants paid by the South African government (Schatz, Madhavan, & Williams, 2011). In instances where there are delays and rejections, the family is left without a safety net. Whereas the first study could identify factors that are potential stressors to family members, particularly primary caregivers of children with Down's syndrome, and identified possible moderators, this was not the case with the second study. Family satisfaction, the dependent variable, was only related to stress. But most of the social support scales were not related to it.

The only social scale that was related to it, Reframing, the family's capacity to redefine stressors with a view to make them more manageable, was related to it in an unexpected way. For instance, religion and spirituality are known resilience factors on both individual and family levels (Beavers, & Hampson, 2003; Cohen et al., 2002; Hawley, 2000; Kiser, & Black, 2005; Marsh, & Lefly, 1996). The Reframing subscale was related to Seeking spiritual support subscale, and spirituality was found to be a resilience factor in the first study, yet Seeking spiritual support subscale was not associated with family satisfaction. The family support scale used was largely unreliable, and items had to be statistically

removed for most of the subscales to be usable. That could be one of the possible explanations for the results.

## **CHAPTER 7**

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

#### **7.1 Conclusion**

Low-income African families of children with Down's syndrome were found to have some of the problems that may undermine their capacity to cope. Some of them were living in poverty and lacked social support from important sources such as extended family and professionals such as social workers and therapists. Nevertheless, support from physicians, spouses and the church tended to compensate for it. Some of the family members, such as the primary caregivers, experienced emotional distress and were frustrated by the unexpected condition of their Down's syndrome child. There were families who were affected by lack of timely intervention by the state, in terms of providing them with much needed financial support.

It was difficult to test the stress model using objective scales. Some of the findings were difficult to interpret. The lack of reliability of one of the main scales could be the reason for this. The results that were obtained were difficult to explain because the scale results were contrary to what is expected of the scale, and given the lack of reliability, it was risky to interpret them.

#### **7.2 Limitations**

The first study represents an initial contribution to the investigation of resiliency factors in low-income African families in the Garankuwa, North of Pretoria. However, the interview schedule did not directly measure the different levels of the resiliency model. It only identified various aspects related to resiliency, but did not clearly specify at which point a factor was important. For instance, developing adaptive coping mechanisms at the initial phases of a family crisis, when the levels of anxiety are high may circumvent the development of non-

adaptive forms (Spink, 1976). Another limitation of the study is that the sample is inherently “biased” since participants were recruited in a clinical setting, a unique setting, as opposed to the community. People recruited in clinical settings are self-selected. If asked to rate support systems, as this study did, they will most likely perceive medical staff such as physicians as supportive because they use the hospital services already. Therefore, in interpreting results such as those found in table 3, the aspect of the sample’s bias must be borne in mind. There was also only one male family representative in the sample of the study. The family perceptions of males need to be explored. A single male was not enough to represent that view.

### 7.3 Recommendations

It is recommended that future qualitative studies should discriminate well the phase of the family crisis being studied. The interview schedule should be clear on whether interest is in the beginning phases when the crisis is just beginning, or whether interest is in the post-crisis period.

Quantitative studies of resilience should bear in mind that scales that are used in the West may not function well among low-income African participants. Attempts must be made to establish the psychometric properties of the scales in this group before applying them. Investigating reliability only may not be enough. Assessing reliability usually takes place when the scale has been applied. At that point it may be too late to take drastic action such as replacing the scale.

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## APPENDICES

### Appendix A: Demographic Questionnaire

Please answer the following questions about your family.

1. What is your nationality and /or ethnic background?

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2. Please supply the following information about members of your household.

		Date of Birth
Father		
Mother		
	<b>Gender</b>	
Child		
Child		
Child		
Child		

3. Has any child in your family been diagnosed with Down's syndrome?  
(The interviewer checks a box based on the response.)

 Yes No

4. If yes, specify which child is affected? Is it the youngest or the oldest of your children?

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5. Are any of your children adopted?

(The interviewer checks a box based on the response.)

 Yes No

6. If yes, specify which child was adopted? Is it the youngest or the oldest of your children?

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7. What is your annual family income? Select from the following values.

(The researcher reads out a few of the values below to give an indicator of what type of response is expected.)

- |  |  |
|--|--|
| <input type="checkbox"/> Below 10,000    | <input type="checkbox"/> R51,000—R60,000 |
| <input type="checkbox"/> R10,000—R20,000 | <input type="checkbox"/> R61,000—R70,000 |
| <input type="checkbox"/> R21,000—R30,000 | <input type="checkbox"/> R71,000—R80,000 |
| <input type="checkbox"/> R31,000—R40,000 | <input type="checkbox"/> R81,000—R90,000 |
| <input type="checkbox"/> R41,000—R50,000 | <input type="checkbox"/> Over R90,000    |

8. “What is your present marital status? Are you single or are you with someone?” If applicable, the interviewer continues: “Are you married with your current partner, or simply living together?”

(The researcher checks the option that applies)

- |  |  |
|--|--|
| <input type="checkbox"/> Married             | <input type="checkbox"/> Separated                                 |
| <input type="checkbox"/> Living with someone | <input type="checkbox"/> Never married and not living with someone |
| <input type="checkbox"/> Divorced            | <input type="checkbox"/> Widowed                                   |

8. Please indicate the highest level of education that you completed. Did you

---



finish high school, did you study after matric?

(The interviewer selects from the options below, based on the response.)

No high school	
Some high school	
High School Diploma	
Some post-secondary, but no diploma or degree	
Post-secondary diploma	
University Degree	
What is your occupation?	

## **Appendix B: Information letter and consent form**

Dear \_\_\_\_\_ (Respondent's name)

I am writing to ask for your participation in a research project. The aim of this project is to develop an understanding of your family's experiences of caring for a child with special challenges.

If you choose to take part, the following information explains the nature of the research project:

**Description of the Procedures:** You will be interviewed by the researcher. The interview will focus on the experiences of raising a child with Down's syndrome. In your next meeting or appointment with the researcher, you will be asked to complete four questionnaires in a language of your choice, either English or Setswana. The questionnaires will inquire about various aspects of your family. The entire process will take about an hour to an hour and a half in the Pediatrics' Out-Patient Department at Dr. George Mukhari Hospital. You will be assisted with completing the questionnaires.

**Participation, Withdrawal or Refusal to Participate:** Taking part in this study is voluntary. You may refuse to participate or withdraw from the research at any time without any penalty.

**Anonymity:** Please do not put your name anywhere on the questionnaires, so your answers remain anonymous. This will allow the results of the questionnaire to be kept confidential because there will be no identifying information attached to the questionnaires.

**Expected Risks of the Study:** There are no known risks for participating in the study. Some of the questions may be troubling to you, but not more so than normal discussion of these issues. If you would like to talk to anyone about uncomfortable reactions you have from the research, please contact the CPU Psychology Clinic at Dr George Mukhari Hospital.

**Expected Benefits of the Study:** Your participation in the research may provide key information about the functioning of families with a child with Down's syndrome. This information could be used in workshops for doctors, psychologists, and parents in order to teach ways to improve family functioning by implementing appropriate coping

strategies. You may become aware of some additional coping strategies as a result of reading the findings of the study. In addition, although we cannot pay you for time, you will receive a small token of appreciation for participating.

**If You Have Questions, Concerns or Comments about the research:** Please contact the researcher, Sharon Madala, on 082 XXX XXXX.<sup>1</sup>

I understand my rights as a research participant and I voluntarily consent to participate in this study. I have received a copy of this informed consent form, and I understand what the study is about and how and why it is being conducted.

\_\_\_\_\_  
Name:

Your role in the family: (Please circle one option below):

Mother	
Stepmother	
Sister	

Father	
Stepfather	
Brother	

Other: (Please specific your relationship with the child): \_\_\_\_\_

Are you the main person in the family taking care of the child with Down's syndrome?

Please select you or no in the boxes below

 Yes No

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher's Signature

\_\_\_\_\_  
Date

<sup>1</sup> The actual telephone number is hidden in this publication.