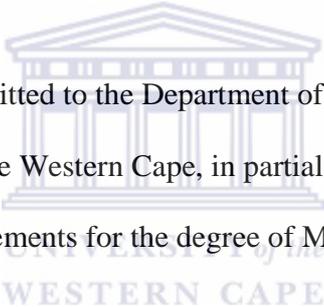


**EXPLORING THE EXPERIENCES OF CAREGIVERS WITH A CHILD  
RECEIVING HOSPITAL TREATMENT FOR A CHRONIC ILLNESS.**

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Thesis submitted to the Department of Psychology,  
University of the Western Cape, in partial fulfilment of the  
requirements for the degree of MPsych.

**SUPERVISOR: UMESH BAWA**

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**KEY WORDS**

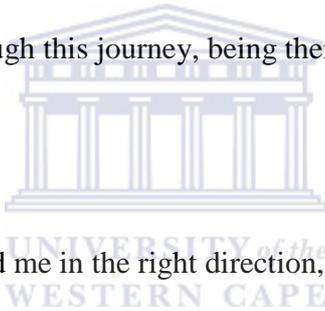
**Chronic illness, children, caregivers, parents, stress, coping, public hospital, South  
Africa, contextual stressors, psychological symptoms.**

## DEDICATION AND ACKNOWLEDGMENTS

I dedicate this thesis to my mother, Del, who made a last request to me that I please make sure I finish my thesis. Well, here it is Mum. Thank you for your always love and support. I miss you so much. Rest in peace.

Thank you to my father, Deryck, for his practical help, his love, and his fatherly pride.

There are many dear friends who have cheered me on from the sidelines, and I thank you all for being alongside me through this journey, being there to listen, and for celebrating with me at the finish line.



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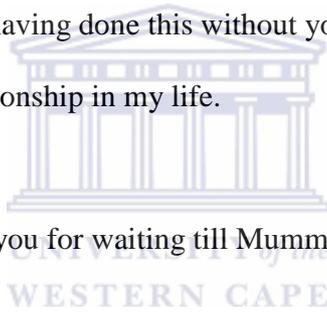
Thank you to Umesh for always being willing to help in any way he could. I have appreciated your kindness so much.

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Thank you to the mothers and the grandmother who so kindly offered to be interviewed for the study. Your stories moved me deeply. I hope I have done them justice. I have endless admiration for your resilience in the face of such enormous challenges.

Most especially I'd like to thank my husband, Brian, whose constant love, encouragement and belief in me has kept me going through the difficult times of the last few months. I cannot imagine having done this without you. I am forever grateful for the wonderful gift of your companionship in my life.

And finally to our baby, thank you for waiting till Mummy was finished before gracing us with your presence.



# DECLARATION

I hereby declare that this thesis is all my own independent work, and has not been previously submitted to any other university as part of another degree.

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RACHAEL SHERIFFS



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# CHAPTER ONE

## 1. INTRODUCTION

An extensive research literature shows that caring for a chronically ill child is often stressful for parents (Melnyk, 2000). Key stressors include finding a new role in relation to the child within a medicalised setting, dealing with the child's difficult emotions and behaviours, managing the distress of seeing a child suffer, and finding resources for the personal toll intensive caregiving requires (Ray, 2002). Besides these more direct implications, the caregiving role may also impact adversely on other areas of social and occupational functioning. Of particular concern are the psychiatric symptoms that can be found in the accounts of caregiver experiences, such as chronic sorrow and post-traumatic stress (Stallwood, 2005).

This study explores the experiences of caregivers with a child receiving treatment for a chronic illness in an urban South African children's hospital. The study is grounded in the theoretical framework of stress and coping, in which previous authors have conceptualised the various strategies used to cope with life stressors (Folkman & Lazarus, 1985; Lazarus & Folkman, 1984). Previous studies in this area have mainly taken place in developed countries, and there is thus a need for research that comes out of public hospital settings in developing contexts. Consequently, a primary focus of the present study is the investigation of the contextual issues that may contribute to the caregiving experiences of South African parents/caregivers.

The researcher conducted in-depth semi-structured interviews with the primary caregivers of children between 1 and 12 years old who had been diagnosed with a long-term chronic condition for a period of at least 3 months prior to the study. The data from these interviews were analysed using thematic analysis (Braun & Clarke, 2006). A qualitative research framework was employed in this study in order to generate richly descriptive data, which would shed light on the experiences of caregivers within the complex social conditions of an urban developing context.

The dissertation proceeds with a review of relevant literature, in order to introduce key concepts, in preparation for a description of methods, results and recommendations to follow.



## **1.1 BACKGROUND**

### **1.1.1 Defining chronic illness**

Illness is defined as “an abnormal process in which aspects of the social, physical, emotional or intellectual condition and function of a person are diminished or impaired, compared with that person’s previous condition” (Anderson, Anderson & Glanze, 1998, p. 126). Illnesses can be described as either chronic or as acute. An acute illness begins abruptly with marked intensity and then subsides after a relatively short period of time (Anderson et al., 1998). The term chronic is derived from the word ‘chronos’ which refers to time (Anderson et al., 1998). Although now three decades old, Pless and Pinkerton’s (1975) definition of chronic illness remains useful and worthy of consideration. In their view chronic illness is “a physical condition, usually non-fatal condition, which lasts longer than three months in a given year, or necessitates a period of continuous hospitalisation of more than one month in a year” (as cited in Bradford, 1996, p. 5).

Chronic illnesses are illnesses that can be managed (e.g. through pain control) but cannot be cured, and may improve, remain stable or become progressively worse (Eiser, 1990; Hobbs & Perrin, 1985; Thorne, Harris, Mahoney, Con & McGuiness, 2003; Zimmerman, 1995). Interventions are mainly limited to controlling symptoms, preventing progression and encouraging ongoing home-based self-care (Thorne et al., 2003). Despite impairment in physical or mental functioning, chronic illness may be associated with a relatively

normal life span, or alternatively may progress towards fatality (Mattsson, 1972). Lubkin and Larsen (2006) describe variations in chronic illness trajectory:

A chronic disease can appear suddenly or through an insidious process, have episodic flare-ups or exacerbations, or remain in remission with an absence of symptoms for long periods of time. Maintaining wellness or keeping symptoms in remission is a juggling act of balancing treatment regimens while focussing on quality of life.

(p.4)

### **1.1.2 Chronic illness in children**

Examples of chronic illnesses affecting children include asthma, eczema, diabetes, HIV and AIDS, cerebral palsy, sickle cell anaemia, cystic fibrosis, cancer, epilepsy, spina bifida and congenital heart problems (University of Michigan Health Systems, 2007).

Such illnesses each encompass different characteristics that may affect the child and family in differing ways. Amongst other variations, the illness may cause difficulties in mobility, may be static or dynamic, may occur at different ages, may affect cognitive or sensory functioning, and may be visible or invisible to others (Bradford, 1996).

### **1.1.3 The prevalence of chronic illnesses in South African children**

A review of the literature for the purposes of this study shows up the paucity of valid and comprehensive childhood chronic illness prevalence statistics in South Africa. This shortcoming arises from a combination of inaccurate diagnosis and recording of illness prevalence (The Child Health Policy Institute, 2001), as well as the simple fact of

substantial gaps in the research record. As will be seen the result is a picture of chronic illness prevalence which is relatively fragmented and incomplete.

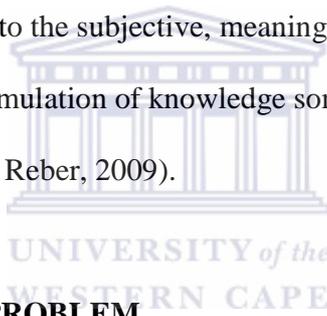
It is estimated that at least one in every ten children in South Africa is affected by a chronic condition (Berry & Guthrie, 2003). The Child Health Policy Institute, based at the University of Cape Town, published the available prevalence rates of the following four chronic illnesses in children under 18 years of age in 2001: asthma (13.3%); congenital heart disease (0.7%); acute lymphocytic leukaemia (0.025%) and cystic fibrosis (0.02%). National statistics for diabetes are not available, but trends show marked increases over the last few years (The Child Health Policy Institute, 2001). Data from more recent studies have made the following contributions to our knowledge on prevalence rates for specific illnesses. Cape Town and Polokwane have relatively high prevalence rates for asthma in children aged 13 to 14, (20.3% and 18%), in comparison to other areas within South Africa, and the African continent (Ait-Khaled et al., 2007). Allergic diseases such as asthma, allergic rhinitis and atopic eczema are increasing significantly in the adolescent population in Cape Town (Zar, Ehrlich, Workman, & Weinberg, 2007). Cerebral palsy is estimated at 1% prevalence, according to a study of children under 10 from a rural district in KwaZulu-Natal (Couper, 2002). The prevalence of epilepsy is largely unknown, but two studies from large rural communities demonstrated an active prevalence of 0.67% (Christianson et al., 2000; Eastman, 2005). It is estimated that up to 6% of children are affected by congenital disorders and birth defects (Robertson, 2006). Finally, the number of children, between 0 and 14 years of

age, estimated to be living with HIV/AIDS in 2006 was 294,000 – a prevalence rate of 1.9% (Dorrington, Johnson, Bradshaw & Daniel, 2006).

## **1.2 DEFINITION OF TERMS**

The term ‘caregiver’ has been used in this study in order to encompass both parents *and* those adults who are not parents but are the main guardian of the child and responsible for their care. However, the terms ‘caregiver’ and ‘parent’ are used interchangeably in the study as a proportion of prior studies in this area use only the term ‘parents’.

The term ‘experience’ pertains to the subjective, meaning-filled, lived experiences of caregivers, rather than the accumulation of knowledge sometimes denoted by the concept of ‘experience’ (Alan, Reber & Reber, 2009).



## **1.3 STATEMENT OF THE PROBLEM**

The focus of this study is the impact that a child’s chronic illness has on caregivers. Parental responses to a child’s chronic illness diagnosis have been found to lead to psychological symptoms such as anxiety, depression, defensive retreat, exhaustion, and chronic sorrow (Stallwood, 2005). The American Psychiatric Association (1994; as cited in Melnyk, 2000) has called attention to the fact that parents of children who experience life-threatening illnesses or medical procedures are at risk of developing Post Traumatic Stress Disorder (PTSD), due to the loss of parental role and feelings of helplessness surrounding the inability to protect their child from pain and fear (see also Colville & Gracey, 2005). By way of example, researchers have found evidence of PTSD in parents

of children recently diagnosed with type 1 diabetes, with 24% of mothers and 22% of fathers meeting full criteria for PTSD, and a further 51% of mothers and 41% of fathers meeting criteria for partial or sub-clinical PTSD (Landolt et al., 2002).

Children with chronic illnesses are likely to be hospitalised repeatedly, but they also spend much time at home where caregivers are responsible for managing their care (Katz, 2002). The management of a chronic illness in children requires parental knowledge and expertise in terms of the administering of medication, the use of technical equipment, the recognition of symptoms and the control of pain (Balling & McCubbin, 2001; Ray, 2002).

When a child undergoes hospitalisation key stressors described by parents include the uncertainty around outcomes, the inability to shield the child from painful procedures, the unfamiliarity of the hospital environment, coping with the child's new behaviour, concerns about finances, concerns about being able to support other siblings, maintaining home and work responsibilities, travelling, and separation from the child (Melnik, 2000).

Although the stress of parenting a child with a chronic condition has been found across cultures (Krulik et al., 1999), a review of the literature reveals that the majority of studies looking at parental stress factors relating to childhood illness have taken place in developed countries. Consequently, the particular issues that face parents from developing countries, such as South Africa, have not been thoroughly explored. Adverse life circumstances – such as poverty, social isolation and life stressors – have been found

to have a detrimental impact on parenting and to increase the stress between parent and child (Krulik et al., 1999).

Research studies have attempted to assess whether certain categories of chronic illness are linked to particular psychological outcomes (Rutter et al., 1970; MacLean et al., 1992; McAnarney et al., 1974; Perrin et al., 1989; Wallender et al., 1989a; all cited in Bradford, 1996). However, Pless and Perrin (1985; as cited in Bradford, 1996) in reviewing this research found that the difficulties experienced by families who have a child with a chronic disorder vary only slightly from disorder to disorder, or from family to family. They concluded that the nature of the family is more influential than the nature of the disorder in determining the frequency with which certain problems are experienced (see also Doherty et al., 2009; Gannoni & Shute, 2010). This finding points towards the feasibility and relevance of the present study in examining the experiences of caregivers of children with a range of illness presentations.

The clear evidence of the potential psychological implications of childhood illness for caregivers points to the value of further research into the experiences of this vulnerable group.

#### **1.4 AIMS OF THE STUDY**

The aim of the study is to explore the experiences of caregivers with a child receiving hospital treatment for a chronic illness in a South African public hospital setting.

## **1.5 OBJECTIVES OF THE STUDY**

The objectives of the study are to gain an understanding from caregivers' point of view of the following:

- the general experiences of caregivers to chronically ill children
- the emotional impact of having a child who needs hospital care
- the practical implications of managing the child's illness
- the impact on other areas of functioning in the caregiver's life
- any changes in parenting role
- the resources and coping skills used by the caregiver
- experiences with hospital staff
- the caregiver's perception of the future for themselves and their child.



## **1.6 RATIONALE**

Given the potentially serious psychological consequences of having a child under hospital care for chronic illness (see above), and the limited understanding of how psychosocial issues may mediate this experience, it is of importance that studies such as the present one contribute to knowledge in this area. Once some understanding is gained as to what parents face in looking after a sick child, a concept of appropriate and effective support may be developed.

This study was conducted at a children's hospital in Cape Town where, according to the director of Paediatric Rehabilitation Services, there is currently very little in the way of supportive services available to parents, psychological or otherwise. The information

about parents' experiences collected from this research may highlight particular needs this group has for future supportive interventions within the hospital setting.

## **1.7 MOTIVATION**

The study is motivated by the need to address gaps in the literature on parental experiences of receiving hospital treatment for a child's chronic illness. More specifically, information is needed about the experiences of parents in a developing context such as South Africa, in order to ascertain whether they have particular struggles and require certain types of support. Although there has been some attempt to look at parental experiences cross-culturally (Krulik et al., 1999), there is more to be understood about the ways in which South African cultural factors and environmental stressors mediate the coping experience for parents. It may be possible that the findings of the study are able to inform future interventions within the hospital setting that will help to provide a more supportive environment for the caregivers of these children.

## **CHAPTER TWO**

### **2. THEORETICAL FRAMEWORK**

#### **2.1 STRESS AND COPING RESEARCH**

The majority of the research into the experiences of parents of children receiving hospital treatment for a chronic illness is located within the theoretical framework of individual responses to stress and coping. There seem to be large individual differences in the way that people respond to stress, and therefore on the individual level it is likely that people are processing and managing stress in different ways.

##### **2.1.1 Problem-focused and emotion-focused coping**

The theory of stress and coping developed by Lazarus and Folkman (Folkman & Lazarus, 1985; Lazarus & Folkman, 1984) focuses on an individual's cognitive appraisal of an event – the personal meaning the event is given as either a challenge, a threat or a loss/harm to the individual (Folkman, 1984). The person who copes successfully is more likely to perceive the event as a challenge, rather than a stressor with purely detrimental consequences. For example, and with reference to the present study, the way a mother appraises a child's illness has been found to moderate the relationship between the stress she feels about the illness and the psychological symptoms that she may develop as a result (Manuel, 2001). Further, individuals who cope successfully are seen as able:

to reduce harmful environmental conditions and enhance prospects of recovery; to tolerate or adjust to negative events and realities; to maintain positive self-image; to maintain emotional equilibrium; and to continue satisfying relationships with others.

(Cohen & Lazarus, 1979; as cited in Folkman, 1984, p. 843)

These markers of successful coping are both behavioural and cognitive responses to a stressful experience that bring about a sense of mastery or control over the internal and external environment (Lazarus & Folkman, 1984). To respond in this way individuals need to feel that they have the necessary resources – both internal emotional resources and external resources such as social support or financial means – to cope with the stressor. Coping efforts fall into two categories – coping that focuses on regulating stressful emotions known as ‘emotion-focused coping’, and coping that focuses on reducing harmful environmental conditions known as ‘problem-focused coping’ (Lazarus & Folkman, 1984). Emotion-focused coping includes finding relief through talking to others, spending time caring for oneself, expressing emotion, for example, through crying, and seeing the problem in a new light (Folkman, 1984). “Problem-focused coping includes strategies for gathering information, decision making, planning and resolving conflicts in order to solve or manage problems that impede or block goals and create distress” (Folkman, 1997, p.1213).

### **2.1.2 Relationship-focused coping**

More recently, other researchers have added the concept of relationship-focused coping (O’Brien, DeLongis, Pomaki, Puterman, & Zwicker, 2009). Relationship-focused coping is made up of behavioural and cognitive efforts to keep positive relationships going

amidst stressful circumstances. Empathic responding – a certain form of relationship-focused coping – is the expression of warmth and caring, usually towards a partner, which helps to soothe interpersonal stress and maintain good relations. It is likely within a family context in which stress revolves around caring for a loved one that this empathic responding reduces marital discord, leading to stronger marital bonds and increased emotional resources to weather stressful circumstances, such as caring for a chronically ill child (O’Brien et al., 2009).

### **2.1.3 Finding meaning in distress**

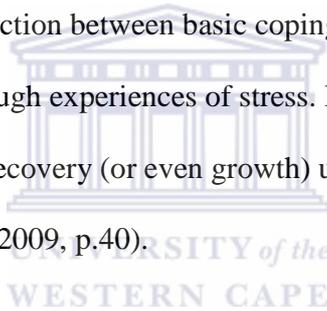
In the context of the coping theory above, positive psychological states are understood to be achievable through regulating the distressing experience of the stressful event. In other words, positive feelings are able to come in as a respite or relief from negative feelings when the person is managing to cope successfully through emotion-focused or problem-focused efforts. Folkman (1997) discovered that positive psychological states co-occur with negative psychological states in caregivers of partners dying from AIDS, and proposed a modification of her earlier theory developed with Lazarus (Lazarus & Folkman, 1984). She found that 99.5% of participants reported positive meaningful events in the midst of their distress (Folkman, 1997). Such meaning-making often occurs when there is nothing that can be done to alleviate a stressful circumstance (Park & Folkman, 1997).

Finding positive meaning, an aspect of emotion-focused coping, is most commonly associated with having an experience of feeling connected and cared about (a ‘restorer’),

feeling a sense of achievement and self-esteem (a 'sustainer'), and having an opportunity to be distracted from everyday cares (a 'breather') (Folkman, 1997; Lazarus, Kanner & Folkman, 1980, as cited in Folkman, 1997). People create meaning by "finding a redeeming value in a loss", "finding that new or closer bonds with others have been formed" or "finding that the event has clarified which goals or priorities are important and which are not" (Folkman, 1997, p. 1215). People may also find meaning in spiritual or religious beliefs, attributing responsibility for the event, perceiving personal benefits such as growth, making downward comparisons, focusing on or exaggerating other areas of their life in which they feel fortunate, and seeing the event in a longer term perspective – the 'big picture' (Folkman, 1997; Park & Folkman, 1997). In studies specific to caregiving, positive affect is associated with deriving personal satisfaction from caregiving (Haley et al., 1996). Stepfathers within families in which a child has a chronic illness are more likely to be an involved partner in family-centred care when they give the situation positive meaning (Zarelli, 2009). They may do this through focusing on an optimistic interpretation of the present within a previously developed spiritual or medical-scientific philosophy of life, which in turn leads to hope for the future (Zarelli, 2009). Finding positive meaning in stressful events and engaging in personally meaningful goals is associated with emotional and physical wellbeing for those who experience high levels of sustained stress (Folkman, 1997; Folkman, 2009; Haley et al., 1996; Park & Folkman, 1997).

#### **2.1.4 Personality traits**

The ability to find positive meaning in stressful circumstances can be argued to be dependent on beliefs that a person holds about themselves and the world, expectations derived from past experiences of stressful life events, and the influence of personality traits, such as optimism (Park & Folkman, 1997). People with high self-esteem (holding a positive attitude towards oneself) and self-mastery (a sense of control over life events) tend to perceive stressful events as less threatening to their wellbeing (Taubman-Ben-Ari, Shlomo, Sivan & Dolizki, 2009). Resilience is a personality trait that is protective in times of stress (Carver, 1998; Steinhardt & Dolbier, 2008). Leipold and Greve (2009) describe resilience as the connection between basic coping efforts, and the ability to actually grow and develop through experiences of stress. Resilience is described as “an individual’s stability or quick recovery (or even growth) under significant adverse conditions” (Leipold & Greve, 2009, p.40).

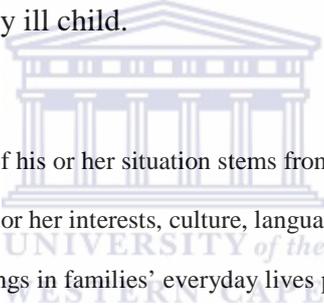


Locus of control is a theoretical concept, originally developed by Rotter (1966), understood to mediate the stress experience. Someone with an internal locus of control believes their environment to be much more amenable to their own actions than someone whose locus of control is external. The less control a person feels they have over the events that happen to them, i.e. they attribute control to “luck, chance, fate or powerful others” (Folkman, 1984, p.841), the greater their stress responses tend to be (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002).

### **2.1.5 Spiritual resources**

Some authors suggest that spiritual beliefs may regulate the emotional and physical impact that stress has on caregivers (Pargament, 1997, as cited in Banthia, Tedlie, Moskowitz & Folkman, 2007; Park, Cohen & Herb, 1990). Prayer and religiosity were associated with fewer physical symptoms and improved quality of life in caregivers of chronically ill children (Banthia, Tedlie, Moskowitz, & Folkman, 2007). It seems that people from lower income households use prayer more than those who are economically comfortable, possibly because those from higher income households may turn to prayer as a last resort, or when they are most discouraged, suggesting that reduced wellbeing leads to more prayer (Banthia et al., 2007). In a study of specific religious beliefs of 103 parents of children with disabilities, it was found that when parents held a positive view of God they were more likely to appraise their circumstances as a challenge and see what they could gain from the experience. When parents held this positive view of God and had a vertical religious focus they saw God as in control of their lives. These beliefs, in addition to the appraisals made, influenced the coping strategies chosen by the parents (Newton & McIntosh, 2010). Behaviours associated with a religious lifestyle, such as health-protective behaviours, drawing on a wide social network for support, and time spent in stress-reducing meditative quiet time possibly reduce the physical and emotional effects of stress (Idler et al., 2003). Drawing on spiritual beliefs and behaviours is seen as an emotion-focused coping response as it has a soothing function that usually offers comfort (Fokman, 1997).

Theories of coping and stress are important in understanding individual differences in coping styles and responses, but they do not provide the whole picture. These factors mentioned above refer to the way an individual processes an experience and this framework does not provide an account of the contextual issues that may impact on the experience of stress and the availability of resources to deal with stress. In addition to individual factors we should consider the broader system of family, community, health structures and economics, and the ways in which these extended systems may contribute to the mediation of stress variables. Ray (2002) points to the role of context in the creation of people's individual coping response style to stressful life circumstances, such as that of caring for a chronically ill child.



...a person's understanding of his or her situation stems from social and historical roots and cannot be separated from his or her interests, culture, language, history, or ethical standpoints. The prior meanings in families' everyday lives provide both the conditions and the limits of their understanding. Context is primary, there can be no single authoritative interpretation of the caregiving experience...Understanding families' interpretations is critical to understanding the health of families raising children with chronic conditions, as well as the range of situated options their interpretations allow.

(p.425)

The findings from this study will be looked at in the light of both individual processes of coping responses and in the context of the caregivers' wider socioeconomic world, with its contribution to both the successful management of stress, and the added burdens of circumstance to the experience of having a child with a chronic illness.

## **CHAPTER THREE**

### **3. LITERATURE REVIEW**

The review starts with a consideration of broad aspects of the impact of a child's illness upon caregivers, after which relational aspects between parent and child are presented. Thirdly, psycho-emotional effects on caregivers are examined, and finally the specific ways that such intense caregiving impacts on social and occupational areas of the caregivers' functioning are discussed.

#### **3.1 CAREGIVERS' EXPERIENCES OF HAVING A CHILD WITH A CHRONIC ILLNESS**

For parents, having a child with a chronic illness is typically a stressful experience and a time of heightened anxiety arising from a number of aspects related to a) caring for their sick child, and b) minimising the impact of the child's illness on personal, family, social and occupational life (Board & Ryan-Wenger, 2002; Kain, Mayes, Weisman & Hofstadter, 2000; Melnyk, 2000; Ray, 2002). These two areas of concern for caregivers are considered below.

The number of parents caring for a chronically ill child is increasing as advances in medical care allow for the possibility of home-based care (Hatzmann, Heymans, Carbonell, van Praag & Grootenhuis, 2008). The long-term nature of this intense caregiving often puts immense strain on families, significantly affecting quality of life

(Baker, Jacoby & Buck, 1997). Hatzmann et al. (2008), in a survey of 533 parents of a child with a chronic condition, found that 45% of these parents were at risk of impairment in their health-related quality of life – as measured by “gross and fine motor function, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive and depressive emotions, and aggressiveness” (Hatzmann et al., 2008, p. 1030). Parents who are full time caregivers of chronically ill children report a decrease in their physical health, which they attribute to “lack of time, lack of control and decreased psychosocial energy” (Murphy, Christian, Caplin & Young, 2007, p.180). It has been found that parents of chronically ill children suffer more often from physical health problems such as asthma, migraine headaches, back ache and arthritis than parents of healthy children (Lach, Kohen, Garner, Brehaut, Miller, et al. 2009). Research evidence suggests that the burden that such intensive and sustained caregiving places on the family drains physical, financial and emotional resources (Moskowitz et al., 2007; Swallow & Jacoby, 2001a).

### **3.1.1 Caring for the chronically ill child**

#### ***3.1.1.1 Navigating the parenting role***

When a child is chronically ill, families often need to undergo substantial changes in lifestyle, structure and function, including the redistribution of roles and responsibilities, particularly those of the parents (Krulik et al., 1999; Main, 1997). After the diagnosis of a child’s chronic illness a period of many months, or years, of intense caregiving usually follows for the parents (Krulik et al., 1999). Parents report feelings of inadequacy

(Hanson, Johnson, Jeppson, Thomas & Hall, 1994; as cited in Melnyk, 2000) and problems with attachment (Abidin, 1995; as cited in Krulik et al., 1999) when their child is chronically ill, potentially creating a situation in which parents are unable to provide for their child's emotional needs (Melnyk, 2000). Parents have reported that the separation from their child whilst in hospital is stressful (Seideman et al., 1997). Anxiety surrounding a child's illness may inhibit the usual parental roles of protection, nurturance and decision-making (Board & Ryan-Wenger, 2002, Krulik et al., 1999).

In a hospital setting, parents may struggle to adjust their parenting role when other professionals are responsible for their child's care (Melnyk, 2000). In these new circumstances of engagement with a child's chronic illness as well as health care systems and professionals, some parents describe feeling sidelined and helpless in their caring roles (Kratz, Uding, Trahms, Villareale & Kieckhefer, 2009; Melnyk, 2000). Parents report having a need to remain involved and in control of their child's care whilst in hospital (Balling & McCubbin, 2001). One study gave strong emphasis to the importance of retaining a central role in decisions regarding the care of their child, and being regarded by practitioners as unique individuals rather than uniform medical 'cases' (Jackson et al., 2008). If parents feel that their expertise is appreciated then they adjust to the major changes in parenting role more easily (Balling & McCubbin, 2001). Amongst other challenges, caring for an ill child necessitates the development of medical knowledge about the condition, and proficiency in a broad range of technical skills, in order to recognize symptoms and provide appropriate treatment (Melnyk, 2000; Ray, 2002; Swallow & Jacoby, 2001b).

Seeking information and gaining knowledge is a method used by parents to cope with the uncertainty around their child's illness and to "restore order in a chaotic existence" (Starke & Moller, 2002, p.245). The mothers in Starke and Moller's 2002 study sought information by looking up their child's diagnosis in medical reference books, borrowing medical literature from hospital staff, reading newspaper articles and speaking to other mothers whose children had the same diagnosis (Starke & Moller, 2002). The reasons they gave for information seeking were to be able to explain the condition to others, and to understand what the doctors were doing with their child in order to try to control interventions (Starke & Moller, 2002). Gathering information has also been suggested as a strategy that reduces parents' anxiety and uncertainty surrounding their child's illness (Balling & McCubbin, 2001). In a recent study, parents expressed a preference for information to be delivered verbally by a medical professional on a one-to-one basis, backed up with literature that they can take away to read, and a contact telephone number should they have further questions (Jackson et al., 2008). It has been found that when a parent has knowledge about their child's condition, daily stressors are less likely to culminate in severe psychological symptoms (Manuel, 2001).

### ***3.1.1.2 Patterns of relationship between parent and child***

The stress generated by the diagnosis and course of the child's illness has the potential to disrupt and change the relationship between parent and child in certain ways that have been outlined in the research literature.

Due to the strangeness of the hospital environment children often suppress or camouflage their feelings, resulting in submissive or compliant behaviour (May & Sparks, 1983, as cited in Boyd & Hunsberger, 1998; McCollum, 1981). This may mean that parents do not always recognize their child's anxiety, contributing to the child's needs not being met (Boyd & Hunsberger, 1998). A child's behaviour in hospital, described in the literature as possibly uncooperative, withdrawn, regressed, rebellious or whiny (Melnik, 2000), may be a particularly difficult source of stress for parents and creates extra demands on parenting skills in parents who are already stretched beyond their usual parental role (Board & Ryan-Wenger, 2002).

Aggressive behaviour has been found to be twice as high in toddlers with a chronic condition compared to healthy toddlers. Asthma is particularly associated with aggressive behaviour, followed by neurological, sensory and skin/joint disorders (Borge, Wefring, Lie & Nordhagen, 2004). Hysing, Elgen, Gillberg and Lundervold (2009) found that children with chronic illnesses, especially neurological disorders, had a higher percentage of emotional and behavioural problems – such as problems with peers and inattention hyperactivity – and an increased risk of psychiatric difficulties than children without chronic illness. Children struggle with the knowledge that their illness is permanent, and with the uncertainty about its course and whether treatment will be successful. It is important that psychological problems in children are recognised in order that they are well managed by care providers (Erdogan & Karaman, 2008). These behavioural manifestations of the child's illness experience are likely to be a challenge to parenting skills, and lead to reverberating shifts in patterns of relating between parent and child.

### **3.1.2. The impact of the child's illness on aspects of the caregiver's life**

#### ***3.1.2.1 Parents' psycho-emotional responses***

In a review of the literature, Stallwood (2005) notes that parental responses to their child's chronic illness diagnosis have included depression, stress, shock, defensive retreat, anxiety, overprotection, exhaustion, and chronic sorrow. The concept of chronic sorrow has been used to describe parents' responses to the ongoing and relentless losses associated with parenting a child with a chronic illness (George, Vickers, Wilkes & Barton, 2006; Scornaienchi, 2003; Wiedebusch, Ganser, Saenger & Muthny, 2007). George et al. (2006) found that parental grief experienced in relation to their ill children was long-term and often recurred at various phases of the illness trajectory (George et al., 2006). The experience of diagnosis was viewed as the most severe stressor during this grief process, with a majority of respondents describing feeling relatively unheard and marginal in interactions with practitioners during this time (George et al., 2006). These difficult relations worsened what was already a highly stressful experience for parents.

In addition to the phenomenon of chronic sorrow, other researchers have found emotions and behaviours that are signs of disorganisation, uncertainty and vulnerability, as well as psychosomatic symptoms, denial, guilt, depression, fatalism and sadness (Churchill, Villareale, Monaghan, Sharp & Kieckhefer, 2010; Kruger, 1992; Lach et al., 2009; Manuel, 2001; Melnyk, 2000; Moskowitz et al., 2007; Rao, Pradhan & Shah, 2004; Todres, Earle & Jellinek, 1994). Parents also suffer from feelings of helplessness and inadequacy (Hanson, Johnson, Jeppson, Thomas & Hall, 1994; as cited in Melnyk, 2000).

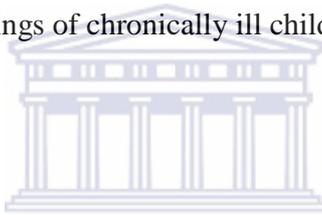
Many parents have reported a sense of guilt about their child's illness or injury (Ray, 2002; Melnyk & Alpert-Gillis, 1998; as cited in Melnyk, 2000), or about not being able to recognize their symptoms or their pain (Hauenstein, 1990; as cited in Krulik et al., 1999). Parents find it difficult to witness their child in pain, and to be unable to shield them from this pain (Melnyk, 2000; Seideman et al., 1997). Seeing changes in a child's appearance is noted as a stressful and disturbing experience for caregivers (Seideman et al., 1997). Further, parents may worry about the side effects of medications on their child (Wiedebusch et al., 2007).

Parents report feeling socially isolated and having strained relationships when a child has special health care needs, which is likely to exacerbate the emotional difficulties they face (Kratz et al., 2009). Couples caring for a chronically ill child "reported greater role frustration and higher levels of conflict over child-rearing issues, performed more child-care tasks each day, and reported fewer positive daily interactions with their partner" than couples parenting a healthy child (Quittner et al., 1998, p.123). Some gender differences have been found in the emotional responses of mothers and fathers to their caregiving roles. Mothers of sick infants reported more feelings of incompetence, problems with attachment, depression and marital problems than mothers of healthy infants (Abidin, 1995; as cited in Krulik et al., 1999). Further, it has been found that mothers of chronically ill children report lower health-related quality of life, higher psychosocial burdens and more pronounced needs than fathers do (Wiedebusch & Muthny, 2009). Two studies highlighted the key concerns of fathers as financial strain, effects on social life and partner intimacy, the demands of caring for other children, and worries about the

future (Goble, 2004; Wiedeusch et al., 2007). Parents reported that some of the behaviours that helped them to cope with a child's chronic illness were being prepared, connecting with their friends, taking on the role of advocate, investing in partnerships and caring for themselves (Kratz et al., 2009).

### **3.1.2.2 *The impact on family functioning***

Problems in family functioning are often experienced when the family includes a child suffering from a chronic illness (Lach et al, 2009). Besides the strain on marital relations as mentioned briefly above, most studies in the area of family functioning examine the difficult experiences of the siblings of chronically ill children, some of which are described below.



In a study of thirty families in which there was a child with cystic fibrosis, it was found that parents underestimated the risk of suffering amongst healthy siblings, and overestimated the physical health of non-sick offspring. In particular, they overestimated the mental health of their non-sick sons and the social health of their non-sick daughters (Demerval et al., 2009). A meta-analysis which examined fifty-one published studies of siblings of children with a chronic illness found that psychological functioning (i.e. depression and anxiety), peer activities and cognitive development scores were lower for children who had a sibling with a chronic illness than for controls (Sharpe & Rossiter, 2002; Stoneman & Berman, 1993; as cited in Lobato, Kao & Plante, 2006). In particular they found that when the sibling's chronic illness required a daily routine of care the

negative effect sizes were larger for the well sibling compared to illness that did not require this daily management and attention from parents (Sharpe & Rossiter, 2002).

Siblings are highly influential in each other's lives, often spending more time with each other than with their parents, and thus play a large role in shaping one another for adult life (Lobato et al., 2006; Lubkin & Larsen, 2006). A sibling is likely to have complex emotional reactions to having a brother or sister who is 'different'. Examples of sibling complaints include that they are not told enough about their brother or sister's condition, that they are given more household chores, that they are expected to help look after their brother or sister, and that they feel embarrassment and isolation from their peers (Lobato et al., 2006). It is thought that the effects on siblings have decreased over recent years as disability is more widely accepted in society (Sharpe & Rossiter, 2002). A sibling's adjustment to chronic illness within the family has been found to largely rest on the way that the parents perceive and cope with the illness. When families attempt to 'normalise' the child's chronic condition, siblings fare better. Normalising involves attempts to minimise the condition's impact on their family life, defining the condition as within a normal range of life experience, and showing to others through the activities that they engage in that they are a normal family (Knafl & Deatrick, 1990).

### ***3.1.2.3 The impact on occupational life***

Invariably, parents suffer from fatigue (Ray, 2002), and there is wide disruption to their normal everyday functioning, including their responsibilities in the home and the workplace (Board & Ryan-Wenger, 2002; Moskowitz, 2007). Many mothers reduce the

hours that they work, or cease working all together in order to care for their child full time (Leiter, Krauss, Anderson & Wells, 2004; Westbom, 1992).

There may be related financial concerns and there may be the stress of travel distance between the home and the hospital (Melnyk, 2000). All these factors are in addition to the uncertainty parents are carrying about their child's illness, its course and possible consequences (Melnyk, 2000). Income levels have been found to be correlated with caregiver wellbeing (Williamson, Walters & Shaffer, 2002). According to a study by Meyers, Lukemeyer and Smeeding (1998) families from low-income households in which there is a child with a chronic illness to care for experience increased daily costs and greater financial hardships than other low-income, but healthy, families. Clawson (1996) found that families were more successful in adjusting to the new roles and ways of relating that the child's chronic illness necessitated when they had both the emotional and material resources they needed (Clawson, 1996).

In summary, it has been found that caregivers are profoundly affected by the experience of parenting a child with a chronic illness. With respect to their parenting, they need to develop new parenting roles that fit alongside the medical system they now find themselves in, and they need to deal with the changes in their child's behaviour, emotions and appearance. There is often a serious impact on their psychological wellbeing, with symptoms of depression, anxiety and trauma for some caregivers. Parents may also suffer from social isolation, and their friendships and marital relationships are frequently affected by the stress of caregiving. Family life, in particular the wellbeing of siblings, is

negatively affected by having a child with a chronic illness. Finally, caregiving needs often prevent parents from working, thus increasing financial stress in families.

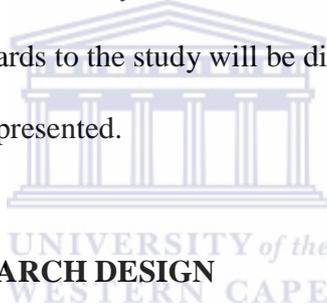


## **CHAPTER FOUR**

### **4. METHODOLOGY**

#### **4.1 INTRODUCTION**

This chapter will provide a rationale for the use of qualitative methods in the study of caregivers' experiences. The recruitment of participants and the interview procedure will be described. Thematic analysis was used as a means to make sense of the data; the method for carrying out this form of analysis will thus be explained. The question of validity and reliability with regards to the study will be discussed, and the researcher's self-reflexivity process will be presented.



#### **4.2 A QUALITATIVE RESEARCH DESIGN**

This study used a qualitative design in order to explore the experiences of parents with a child in hospital. Qualitative research aims to produce research that is derived from participants' subjective experience of reality. It is believed that these subjective accounts render an in-depth and meaning-filled quality to the data that is produced through qualitative research methods, thus informing the researcher about the lives of participants with a richness that quantitative methods are not able to access. Qualitative methods are appropriate when trying to broaden the understanding of a participant's experience into previously unexplored areas, as they do not carry pre-conceived notions of what may be found. Qualitative researchers are able to get closer to the lives of their subjects in order to gain this richness and depth of data, unlike the "remote, inferential empirical

materials” (Denzin & Lincoln, 1994, p.5) used in quantitative methods. Naturalistic verbal data, such as that gathered from interviews, stays close to the participants’ subjective account of their lives (Smith, 2008). It is such subjective material that is the focal essence of qualitative investigation. Within most qualitative paradigms a concern with language assumes a central position, as the fundamental means whereby “human communication, interpretation and understanding” takes place (Smith, 2008, p.2). The centrality of language in social meaning making requires a correspondingly close linguistic focus in the analysing of qualitative data (Smith, 2008). It is the subjective experience and worldviews of participants that are closely examined in such investigations, aiming to accumulate layered personal accounts of the social realities of relatively small numbers of respondents, rather than numerical comparisons of a large population. Although qualitative research forgoes generalisability, its contribution is to add personalised depth and thickness in describing the circumstances of a particular target population.

The qualitative researcher need not claim to be studying an objective universal truth that any investigator would find if aiming to repeat the study with the same population. Instead of attempting to be an unbiased observer, the qualitative researcher may position herself as co-creator in the knowledge that is gathered through the social interaction of the interview process (Richardson & St. Pierre, 2005). This approach, in which the researcher is seen as subjectively involved in the research process is known as constructivism. “Constructivism assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed, and aims

toward interpretive understanding of subjects' meaning" (Charmaz, 2000, p.510).

Constructivism arises from an epistemological claim that knowledge is socially constructed, and an ontological claim that social reality is constructed, and therefore knowledge and reality are mutually constitutive (Guzzini, 2000). A researcher is not free of their theoretical interests, and data is not coded in an "epistemological vacuum" (Braun & Clarke, 2006, p.84). The use of qualitative methods of analysis in this study aims to produce hypotheses or concepts about participants' subjective experiences, rather than objective generalisable facts, and this process will unavoidably reflect the interpretive process of the researcher. "Data do not provide a window on reality. Rather, the 'discovered' reality arises from the interactive process and its temporal, cultural, and structural contexts" (Charmaz, 2000, p. 524). As part of the research process the researcher has reflected on her own engagement with the research participants and what she may have brought to the interview process and to the subsequent analysis. This self-reflection will be discussed later in this section.

#### **4.3 RESEARCH SETTING**

The study took place at an urban children's hospital in South Africa. This hospital services clients from across South Africa, and the African continent, as well as local residents. It is a government hospital and thus provides medical services to those who cannot afford medical aid or private hospital care.

## **4.4 PARTICIPANTS**

### **4.4.1 Target population**

The target population for the study were caregivers of children who were receiving hospital treatment for a chronic illness at the hospital. Participants were included if they were a) the primary caregiver of a child with a chronic illness, b) the child had been diagnosed for a minimum of 3 months before the study took place, c) the child was between 1 year and 12 years old, and d) the parent was able to speak English. Participants were excluded if a) their child was critically ill and b) the doctor in charge judged the caregiver's participation to be harmful to the caregiver or to the child.

### **4.4.2 Recruitment of participants**

Permission to conduct the study was obtained from the University of Cape Town's Research Ethics Committee, and from the Superintendent of the hospital. The researcher contacted doctors in charge of wards and clinics at the hospital via email to ask them for their help in accessing suitable parents to take part in the study. Of the five doctors contacted, three responded indicating that they were interested in helping with the study. These three doctors were from the Nephrology, and Tracheotomy and Ventilation wards, and the Asthma and Allergy clinic. A meeting was set up with each of these doctors in order to explain the purpose of the study and to discuss the method of recruitment. Doctors were asked to suggest participants they thought to be suitable for the study and the researcher approached these caregivers to invite them to take part. The caregivers were given an information sheet (See Appendix A) to take away to read, and a consent

form (See Appendix B) to sign if they were agreeable to participate in the study. The information sheet explained the purpose of the study, the questions that would be asked of participants, the rights to anonymity and confidentiality, the benefits and possible risks of taking part, the fact that their participation or non-participation would not affect their relationship with hospital staff or the quality of their child's care, and the rights of the participants to withdraw from the study at any time. Of the caregivers approached, nine indicated that they were willing to be interviewed for the study, and interview times were arranged with them at their convenience.

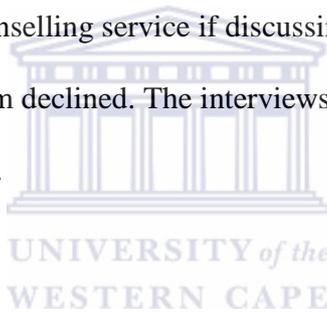
#### **4.4.3 Participant details**

Nine caregivers were interviewed, eight of who were mothers, and one of whom was a grandmother. The number of participants interviewed was limited to nine as it was found that gaining the necessary practical support and endorsement from doctors in the context of an extremely busy and stretched hospital system was a difficult challenge. However, it became clear that this number reached the data saturation point. In other words, it appeared that use of further data would primarily only add to repetitiousness, perhaps at the expense of the level of detail that the study aims to provide. (Please see Appendix C for a table of biographical details).

#### **4.5 PROCEDURE**

Participants were interviewed using a semi-structured format in a private room at the hospital. The interview questions were open-ended and used as a guide for the interview to ensure consistency across participants in the areas that were discussed (See Appendix

A). The questions were guided by key themes, or “sensitizing concepts” (Charmaz, 2006, p.16), derived from the literature pertaining to previous findings of parents’ experiences of caring for a child with a chronic condition (Melnik, 2000; Ray, 2002) and were used as “points of departure” (Charmaz, 2006, p.17). The open-ended technique aims to elicit detailed responses from participants, which although theory-driven, allows participants to fill in gaps in this knowledge base (Denzin, 1989). Kvale (1996, as cited in Pouliot, 2007) defines interviews as “attempts to understand the world from the subjects’ point of view, to unfold the meaning of peoples’ experiences, to uncover their lived world to scientific explanations” (p. 369). At the end of the interviews participants were asked if they would like the contact details of a counselling service if discussing their experiences had felt distressing for them. All of them declined. The interviews were recorded onto tape and then transcribed word for word.



#### **4.6 DATA ANALYSIS**

The data were analysed using Thematic Analysis, a qualitative analytic method that seeks to identify themes, or repeated patterns of meaning, that arise from the data by means of a coding procedure (Braun & Clarke, 2006). The process of analysis progresses from one of description, where patterns and categories are found within the semantic content, or surface meanings, of the data towards an interpretive analysis in which the deeper meanings, relevance and importance of these patterns is expounded, with theoretical knowledge from previous studies in mind (Braun & Clarke, 2006).

A theme is “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experiences into a meaningful whole” (DeSantis & Ugarriza, 2000, p. 362). Analysis involves moving constantly back and forth between the original data, the codes that are found and the themes that are generated (Braun & Clarke, 2006).

The data were analysed according to Braun and Clarke’s (2006) step-by-step guide to thematic analysis. During the first phase the researcher familiarised herself with the data by reading through the transcribed interviews repeatedly. After this thorough reading the researcher took notes of initial ideas of broad general themes and possible categories within these themes, and created a mind map diagram depicting how they may interlink.

In the second phase the researcher read through the interviews one by one, writing notes alongside each paragraph of the transcription, giving a name, or code, to each aspect of experience the participant spoke about. The coded experiences could be about an activity the participant engaged in, something that happened to them, a feeling, a meaning to an experience, a way of seeing or a social encounter and so on. After a while these codes started to repeat themselves, within, and across, the interviews, and quotes that represented these codes were collated into a document for each code.

In phase three of the analysis, the researcher looked for broader themes that these codes logically fitted into. “A theme captures something important about the data in relation to the research question, and represents some level of *patterned* response or meaning within

the data set” (Braun & Clarke, 2006, p.82). Ideally, a theme will recur a number of times across all the interviews, but more important than frequency is whether the theme encapsulates something significant in relation to the research question (Braun & Clarke, 2006). Initially, the researcher categorised the data into 10 broad themes – six major themes and four minor themes.

Through further examination of the themes for consistency and coherence in the fourth phase of analysis, it was found that there was some overlap between the themes generated and they were therefore streamlined into five major themes, with sub-themes incorporated. It became apparent that there was not enough data to support some of the smaller sub-themes, or the data was too diverse, and so these sub-themes were discarded. If there were different aspects to a sub-theme that seemed significant enough to comment on, then the researcher created mini themes within the sub-themes. The relationship between the different levels of themes became clearer as the analysis progressed, and it was possible to create a thematic map showing the interaction between the five major themes. Quotes relevant to each of the major themes were collated in separate files. As the researcher worked through the interview data, notes were made in the margins alongside the quotes of key thoughts and ideas that were seen as important to the research question.

In the fifth phase of analysis themes are defined and named in order to provide a succinct and evocative sense of what each theme is about. A narrative was created around the data

quotes, which described both their content and their relevance to the research question – why and how they are of interest (Braun & Clarke, 2006).

In the sixth and final phase of analysis the researcher undertook to write up the thematic analysis into a final report, which told the story of the data, substantiated with evidence of the themes within the data, and supported with a theoretical understanding drawn from the literature.

#### **4.7 ETHICAL CONSIDERATIONS**

This study was conducted once ethical approval was obtained from the relevant university and hospital's ethics committees, and the principles outlined in the Declaration of Helsinki 2008 were adhered to (World Medical Association, 2008). Caregivers were informed in writing as well as verbally that their participation in the study was completely voluntary, that they were free to withdraw from the study at any point, and that if they chose to do so it would not prejudice the quality of their child's care.

Participants' identities were protected in the research report. The recorded interviews and transcripts were kept in a locked filing cabinet, accessible only to the researcher, and the participants were informed that following the completion of the research report these documents would be destroyed. The caregivers were to be provided with contact details of their local FAMSA (Family and Marriage Association of South Africa) counselling service if they found discussing their experiences distressing.

#### **4.8 TRUSTWORTHINESS AND CREDIBILITY**

Qualitative research aims to uphold the ‘confirmability’ or ‘trustworthiness’ of findings (Glaser & Strauss, 1967). Following the suggestions of Glaser and Strauss (1967), the fieldwork was carried out consistently, participants were allowed the opportunity to express their experiences fully, the data was analysed systematically, the interpretation of the data was substantiated with evidence, and equal opportunity for all perspectives in the data to be found was ensured (Ritchie & Lewis, 2003).

The researcher aimed to uphold the credibility of the data by identifying, categorising and labelling phenomena to reflect the meanings the participants intended, and portraying these findings in a way that remained true to the data and allowed others to follow the process of analytic construction (Ritchie & Lewis, 2003). Internal validation was achieved through constantly comparing generated categories to the original data (Glaser & Strauss, 1967).

#### **4.9 METHODOLOGICAL LIMITATIONS TO THE STUDY**

It was not possible to make statements about the experiences of all South African parents or caregivers of children who are hospitalised for a chronic illness, as the sample size was necessarily small, and the participants drawn from a government hospital were mostly from lower income households, and therefore not reflective of all levels of society. The participants chosen were those caregivers who were available at the time of recruitment, which excluded those who were working. The doctors in charge of the wards suggested participants and thus it is possible that there may have been hidden bias in this selection

based on the quality of relationships between parents and hospital staff. Due to difficulties in recruitment as a result of low response rate from doctors in the hospital, the caregivers of both hospitalised and non-hospitalised children were used in this study. Finally, it was unfortunate that the study excluded caregivers who could not speak English.

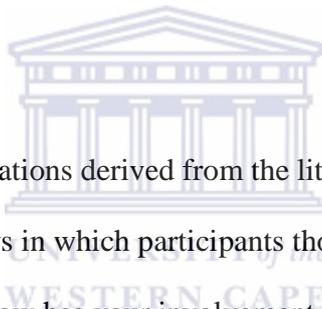
#### **4.10 SELF-REFLEXIVITY**

Constructivism requires the researcher to be transparent with regards to their personal interest in the research field as the understanding of a constructivist position is that knowledge is mutually created by the viewer and the viewed (Charmaz, 2000). The researcher has a personal interest in the field of stress and coping having been in the role of caregiver to various family members experiencing illness. Of particular interest to the researcher is the development of interventions in various settings, which support caregivers in their coping efforts. As part of her professional development as a psychologist she would like to increase her knowledge of this field, and thus was drawn to this research topic.

##### **4.10.1 Reflections on the interview process**

As part of an effort towards transparency the researcher has reflected on the process of the interviews with participants in order to throw light on the possible influence of her style as an interviewer and her subjective interpretation of the interview data. The researcher had had little experience with interviewing participants for research, and found that it was difficult to know how to respond to the participants' stories in a way that did

not influence what they did or did not share. Her previous experience in listening to people talk of difficult or painful experiences was within a therapeutic framework in personal counselling sessions, and she found it a challenge not to be drawn into giving empathic responses and reflecting on the person's experiences as one might do in a counselling setting. Her previous experience as a therapist caused the researcher to feel sometimes as though she was 'using' the participants to gather information for personal gain, rather than putting their needs first and giving something back, as she was used to doing. The researcher wondered whether this gave an apologetic impression sometimes, and as the interviews progressed concentrated on developing a more professional interview style.

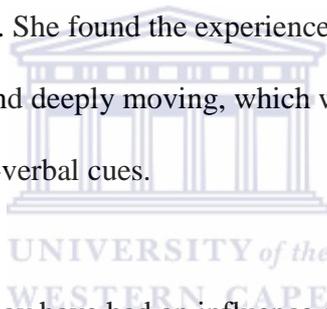


Once or twice it felt that expectations derived from the literature – which informed paths of inquiry – jarred with the ways in which participants thought about their experiences. An example is the question: “How has your involvement with hospital staff affected your role as a parent or guardian?” Often participants were confused about this question, and had no reflections to make. This question arose from previous findings, and perhaps should have been allowed to come out of the data naturally as a concept, if at all, as it had done so in these previous studies.

The researcher was aware of the fact that she was a white woman from a middle class background, and wondered whether this had an affect on how comfortable black and coloured participants felt sharing their experiences with her, due to the political history of South Africa. Participants generally seemed to be very open in talking about their

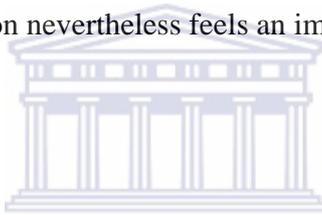
experiences, but it is possible that a researcher of the same race and class as the participants would have derived a different response.

On a more personal note, the researcher had suffered a major bereavement two weeks prior to commencing the interviews, which possibly had two effects on the research process. One was that she was struggling with feelings of sadness on some days that may have affected the confidence and professional presence with which the interviews were conducted. The other effect was possibly to cause the researcher to be more keenly aware of the participants' experience of their own pain, and, in particular, the evidence of their resilience and coping strategies. She found the experience of listening to these participants' stories inspiring and deeply moving, which was likely to have been conveyed at times through non-verbal cues.



A further personal factor that may have had an influence on both the participants' responses and the researcher's direction of interest was that the researcher was clearly pregnant. It is possible that this caused the mothers (and one grandmother) in the study to feel a kinship in this shared experience of womanhood and mothering, and helped them to feel at ease with the researcher. A pregnant woman gives a certain impression of vulnerability and softness. Secondly, the researcher in a state of pregnancy found herself particularly interested in the participants' talk of a kind of 'mother love' – a love that unbegrudgingly located their child as the centre of their lives. A personal interest such as this may cause a researcher to make more of one aspect of the data than another that does not speak to them so personally.

When looking at the research process through the lens of constructivism it is possible to allow for the fact that the eyes through which we view the world are an influence in what we see there, and in what is shared with us by others. It is the researcher's belief that participants pick up on non-verbal cues given off by the researcher about what she/he is interested in particularly, what the researcher responds to emotionally, and therefore, what to focus on in the telling of their stories. It is not possible to say whether the researcher's reflections on these possibilities are correct or not, without going back to these participants and asking them about any effects of the researcher as listener. Even then it may be impossible to have insight into this, as it may be an unconscious process. Yet the practice of self-reflection nevertheless feels an important one in the research process.



Having examined issues relating to research methodology for this study, the following section presents a thematic analysis of the interview data.

## **CHAPTER FIVE**

### **5. THEMATIC ANALYSIS**

In the presentation of results that follows, there will be an analysis of participants' own words without any attempt at verification of these stories by speaking to the medical professionals involved. It should be taken into account that memory and other factors may cloud their narrative. This issue will be returned to in the discussion. In order to preserve the richness of the data, extensive use of quotations will be used.

#### **5.1 ENCOUNTERING THE MEDICAL SYSTEM**

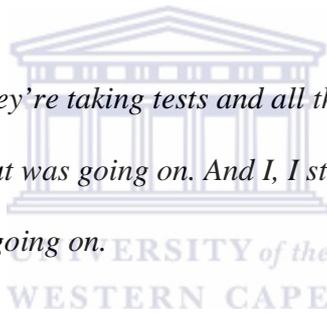
“Encountering the medical system” is a theme which describes the journey from the realisation among caregivers that there is something seriously wrong with their child's health, towards the clear identification of a diagnosis and the experience of an ongoing treatment regime. For some, part of this journey involved the experience of misdiagnosis and inappropriate treatment, and for others the experience of their concerns not being taken seriously. In addition to exploring the frustrations with the medical system, the research uncovered many participants' experience of being profoundly helped and supported by the medical system.

### 5.1.1 Something is wrong

The majority of participants spoke about a phase in which they began to suspect that there was something seriously wrong with their child, but they still did not know what this was. This stage of 'not knowing' often lasted for quite some time.

*Participant 2: ...we realised that something wasn't right...But at that stage the word cerebral palsy wasn't mentioned and as I started reading I actually discovered that I think my child has it, although no doctor had confirmed it or said the words 'cerebral palsy'. Then at 6 months when she had that fit it was confirmed.*

*Participant 1: Every day they're taking tests and all this stuff but they didn't tell me anything. I didn't know what was going on. And I, I stayed here for a month. And I still didn't know what was going on.*



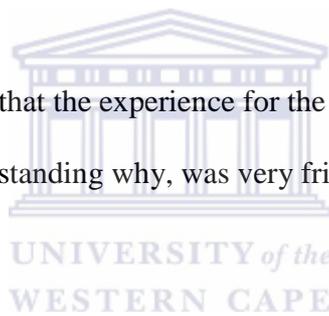
It seemed that the reason for the parent not knowing what was wrong with their child was sometimes a result of the doctors actually not knowing yet themselves. But at times caregivers felt that this was a result of doctors and nurses not communicating the information they had to the parent, as in the example above.

*Participant 6: I didn't know at that time what was happening. I was totally, totally scared...It's like somebody knocked the wind out of you.*

*Participant 7: Then one day...she just vomited blood...it was the first time that I saw her vomit blood so it was scary...there is only one doctor who knows exactly what is going on ... and she was not on night duty so ur ... we had to wait until morning.*

*Participant 9: It was a bit scary for me because I didn't know what was going on...And there was a time when her eyes was swollen, almost closed from the eczema, and I don't know what caused it. It was like someone punched her...or...in the face...you know her face was swollen and the eyes was shut. I just didn't know what went wrong.*

It is clear from these examples that the experience for the parents of seeing their child so seriously ill, and without understanding why, was very frightening.



### **5.1.2 Misdiagnosis**

Often participants described going through a phase of being misdiagnosed, misdirected and misunderstood, and being given the wrong medication for their child.

*Participant 1: ...and then four or five months gone, and um, he was throwing up and he was vomiting and he was the stools were loose, and he had this, um, this skin rash and all this. And I took him to the clinic, and they tell me, No, but there's nothing wrong with him and that. His weight was fine, everything was fine. And I tell them, No, but I can see. Everyone is telling me there's something wrong. No, they tell me, there's nothing wrong. At six months his eyes began to get yellowish. And I tell them,*

*No, man, there's definitely something wrong with this child. And they ask me, "Did he have yellow jaundice". And I tell them, Yes. So they tell me, No but it's the yellow jaundice.*

Parents suffered the difficult experience of feeling strongly that something was wrong with their child, but having this view not shared by the medical professionals concerned. At times the intuitive suspicions of caregivers seemed to be proved to be correct.

*Participant 2: The Tuesday I did take her to my paediatrician cause I could see that something was wrong. She was vomiting. And he thought it was just a bad case of constipation, and me as a mother decided it's not that, and...I was right. So, I mean, with that example it was a professional that actually made the wrong diagnosis at that stage and I took a decision I'm not giving all the things that he said I must give, but here it's totally different.*

*Participant 3: Well he was a couple of months, maybe 4 months, and it was one afternoon and I just saw his chest was...his breathing was starting to get funny and I actually went to my mother-in-law and asked her what was happening cause I never saw anything like that. And she said to me she thinks he's got asthma. So I took him to our GP, and he just said "No, it's bronchitis". I accepted that cause I didn't know at that time what asthma was or what bronchitis was because as I told you I never experienced anything like that... The fifth time we took him we took him to our other GP and he also said its bronchitis. The sixth of seventh time we took him the GP*

*wasn't on there that day and the other doctor saw him and when he saw him he said "He's got asthma".*

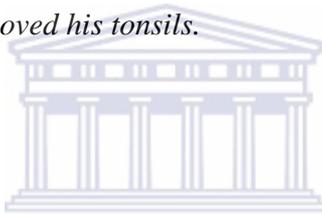
Cases of misdiagnosis often lead to the prescribing of incorrect medication, thus putting the child in danger when early treatment may have prevented further damage being done by the disease or illness in the child's body. This particularly negative – even life-threatening – scenario is described in the following three cases.

*Participant 7: I took her to...let me first say it is ur I needed to blame someone because why at the hospital when she was born it just said that she had ur...when she passed stool...her stool it was pale...and I ask why is her stool pale...and they say it is normal...and ur I was like how can it be normal because I heard that her stool has colour...it had to be green when they are born...so why they say it is normal when it pale? So I went when I went for...I took her to other hospital they said that I just have to just put her to the sun. It will just go away (laughs) and they gave her antibiotic. But when I went to [name of hospital] and they told me this that she had this condition and I was so angry with those other two hospitals...why didn't they tell me...they should have fixed that while she was still young. Yeah so I had I had to live with it.*

*Participant 1: And they tell me I must wash him in this, and I must wash him in that and whatever. I must tie some of that, what is that? um, um to tie around his neck,*

*that... What is that? that, um, garlic, ja, garlic. I must tie it around him his neck and that will take the yellow away. And nothing helped.*

*Participant 8: [name of another grandchild] had tonsillectomy, actually tonsillitis and it was removed three years ago...He was sick for six years, he was sick for six years. And they keep on postponing and saying it wasn't necessary. He developed at all times a very high fever. He would sometimes go into a fit. The clinic referred him to [name of hospital]. And [name of hospital] said, No, it must be removed, and then they referred him to [name of hospital], and then six months after the referral from [name of hospital] they removed his tonsils.*



### **5.1.3 Diagnosis**

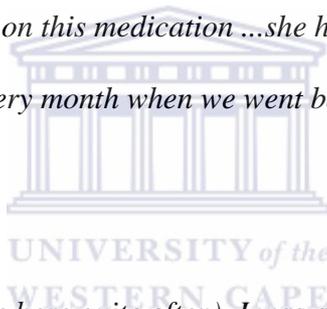
The stage of diagnosis offered a sense of relief for some parents. It was good to be able to have a reason for their child's ill health, to have a name for their condition, and thus to be able to see a way forward through treatment to managing the condition, and possible recovery. Participants spoke about how understanding what was happening was so important to them, even if it came with the realisation that their child had a long term chronic illness with all its implications for their lives, the understanding offered some comfort.

*Participant 1: And, um, they told me now this whole story from A till Z. He was just with the chronic disease, he just had this now, you see. It was just unfortunate that he had this now.*

*Participant 2: Then at 6 months when she had that fit it was confirmed (that she had cerebral palsy). And I can tell you that I think we felt relieved as well, cause she wasn't getting to her milestones, and so on and so on. And we thought now we have a name and we can find out what to do next.*

Once properly diagnosed the children are in the system and receive regular supportive contact with the hospital.

*Participant 7: After that they found that she is...she will be suitable for a liver transplant...so they put her on this medication ...she had to do regular checkups every...every month...so every month when we went back to Durban she went to [name of hospital].*



*Participant 5: Yes (we came here quite often). I was at emergency room every second or third night because the asthma attacks used to get him in the evening, when there was nothing really available for him and he needed the nebulizer. So, ja. About twice a week.*

#### **5.1.4 Positive experiences with medical personnel**

Almost all participants reported very positive experiences with the staff at the hospital, which stands in contrast to the reported experiences outlined above which they had prior to receiving services from this hospital. They spoke of how the staff often went the extra mile and provided material resources for the parents as well as medical care. They

sometimes arranged transport for the parents to the hospital if this was unaffordable to them.

*Participant 1: And then I spoke to the social worker and I tell her the situation now and whatever, and she helped me. She told that, um, even if I don't have transport, money or whatever, that I should phone [name of hospital] and they will send someone to pick me up and that.*

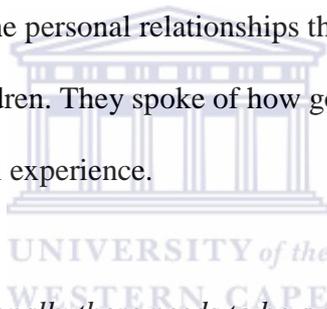
*Participant 6: "Mommy, this nurse Sister [name of Sister], she put out toiletries for me here". I was like, "What, but you have your own toiletries [name of child]. "No, she said I must take those home and use these". That's the hospitality I got here and to me it was big. The small things they did it was major. There were nurses dancing for my child, entertaining her because they know she loves music. And to see that, it's like...wow!*

*Participant 8: Ja, they (the staff) are very helpful, and they try their utmost...to help with her with her education, and the doctor always sees that she gets the right stuff which I appreciate it a lot because I can't do it, and I haven't got the money to go buy the stuff, so I appreciate what the hospital does for her.*

Participants were reassured by the expertise they encountered at the hospital.

*Participant 2: And I think we're feeling very positive and calm because of the hospital. This hospital. And the expertise that's here. It makes you feel better. It makes you feel better...we went into ICU and we felt very relaxed there because of, well it's 2 nurses on 2 children. And the expertise, we couldn't believe it, we can't believe it cause if you look at a private hospital, where we come from the nurses do their things, but here they know their job, and so that made us feel as ease. And we already started in ICU with the professors coming around and discussing you, and we felt very relaxed with it.*

Participants spoke warmly of the personal relationships that developed between nursing staff, themselves and their children. They spoke of how good relationships made such a difference to the whole hospital experience.



*Participant 3: For me personally there needs to be a relationship between a doctor and a patient. They need to develop a relationship...the service that you get at a day hospital...it's not worth it. They treat you like you come from the streets, you're not in their league, if you know what I mean. But if you come here you will always get a smile, and the sisters they know you, the doctors they know you.*

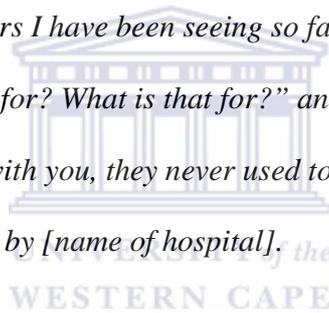
*Participant 5: It's been great (our visits to the hospital). I've never really had any hiccoughs with the staff cause they've known him since he was a little boy (laughs). He used to come in here crying. So he practically grew up in front of them. So they know him, and they try to make him feel really comfortable, cause knowing how he*

*was at first. No, they actually changed him a lot, by stealing his heart in little ways, you know, you become more relaxed as well. So, it's been a good experience. Totally.*

Many participants expressed that they felt free to ask the questions they wanted to, and that they received information that was informative and helpful.

*Participant 2: ...with the doctors they ask you questions, and they take their time with you as well, and they make you feel like you're the most important at this stage.*

*Participant 4: All the doctors I have been seeing so far have all been fantastic cause I will ask them "What is this for? What is that for?" and they've been fantastic, cause they've always been open with you, they never used to hide anything away. So, so far I've been treated quite well by [name of hospital].*



Participants reported that they received emotional support from the staff, and expressed deep gratitude for this experience of warmth and caring.

*Participant 6: Wow! They were extremely fantastic. They were fabulous. I didn't think of [name of hospital] as a place like this. I always heard people speak of [name of hospital] "No, you sit long at that place, you sit the whole day through". Being with the staff, working with them one-on-one it was like...well, it was amazing I tell you. They've been there for me...emotionally they've been there for us...But there's no*

*way I can repay them for this, for what they did for my child. They were there for us. They were really, really there.*

*Participant 7: At [name of hospital]...here they are good, friendly, and they ask you everyday if you are all right...um and they tell you that everything is going to be fine actually...and especially the doctors (laughs) they are open with everything you can ask them anything...they gave me strength because I didn't have any...I don't have any family here...so they were there for me and the nurses too so it was good.*



## 5.2 CONTEXTUAL STRESSORS

The theme “Contextual stressors” refers to the socio-economic and environmental conditions under which parents live which contribute to the stress involved in parenting a child with a chronic illness. Circumstances that are directly related to the illness include travel costs to and from the hospital, money for medication and changes to lifestyle such as the need to take care of the child full-time because their needs are special. Some circumstances arise from the struggles of a low socio-economic status and contribute to the load that a parent must carry on top of caring for a sick child. In addition to what is mentioned below, three participants spoke of how crime and the risk of child abuse affected their lives, issues that are particularly pertinent in South Africa.

### 5.2.1 Financial burden of the child’s illness

For the participants whose children were inpatients the cost of travel to and from the hospital every day put a huge financial strain on their household. These were parents who wanted to spend as much time as possible at the hospital with their children, even if they could not afford to do so, and so borrowed money from friends and relatives or put themselves into serious debt, or were fortunate to receive a grant that helped.

*Participant 1: Yes. Like I say, my Ma she also doesn't work, and um, I don't work, and at first it was hard cause the travelling from home to here is R30. Well, I do get a grant for him. But first I didn't get, didn't get a grant. And we coped and so... I don't know how we got through it.*

*Participant 6: And to get here every day as well. It took a lot out of me but I wanted to be here so. The thing is this...I had to close down my business. There were days when I thought I wasn't going to be here, but I was here every single day. I made a way. I actually put myself in a huge debt to be here every day.*

*Participant 7: Yes lots of travelling and ur...every it has been stressful been um because I'm not working my mum is working and her father so they have to contribute and that is and the other thing that helped us is that she gets that support grant...yes so I had to keep that grant that money to come here...just to save it just to come here (travels by plane from Durban to Cape Town).*

For parents who lived far from the hospital it was necessary to move to be closer to their hospitalised child. This presented financial difficulties, for which solutions needed to be found.

*Participant 7: Here, yes it is stressful (finding a place to stay)...it is stressful because...ur I rent a room here at the nurses home...which is expensive...it is expensive because we have to have your own meals so it is expensive if you can't afford it...oh God I don't know...(laughs). I am just lucky now that I can afford that room because sleeping here at the chair (laughs) no, it is not good (laughs) I know because I have...I went through that just sleeping on the benches so it is better...(laughs) it is better here that I have a room just so that I can lay down...lie down.*

The medication involved in treating their children is also an added financial burden to households that may already be struggling to stay afloat.

*Participant 9: I think she will grow out of it. I don't know when but she will grow out of it. I am confident about that. But if she doesn't then I just hope they find a solution for eczema, a cure for eczema, you know. Because you can't try all the products on the market. It's money wasted and it puts a lot of strain on a person.*

### **5.2.2 Stressors associated with low socio-economic status**

Some stressors were associated with the environmental conditions that participants lived with. Tuberculosis is a disease that is most common in areas in which there is overcrowding, poor sanitation and poor diet, and is also more likely to affect people with lowered immune systems due to other illnesses such as HIV and AIDS (British Medical Association, 2005).

*Participant 1: Anyway, they... the social worker came to try to talk to me about all this. And, um, she asked me some questions, "Where do I live?", the environment and all this. And in that time my mother got sick. While I was in the hospital she had TB. And I told her this and told her the environment where I live and that. My mother she lives in a squatter camp...She tell me now, the environment where I live in is not going to help me to get on the list of the transplant and my mother's sickness is not going to help me. So I will have a choice either to move or let my child die if I'm going to keep on living there.*

*Participant 7: ...and then when ur I think when we came in 2007 she was diagnosed with TB...she had so she had to have a 9 month treatment...not a 6 month treatment a 9 month treatment where she had she had to be monitored to check whether the treatment doesn't destroy the liver because it goes to the liver...so they had to be careful that they had...it destroys the liver if they had to bring the dose down. Ja, so she had it for 9 months...we came back the following year...and again they found that that she had a TB so she was diagnosed with TB two times... she was taken out of the transplant list until she finished her treatment.*

A few participants mentioned having to share living spaces with other family members, and the added strain that this would sometimes bring.

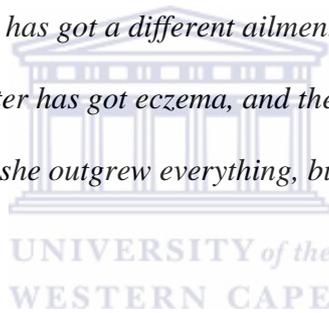
*Participant 2: So, anyway, we came to Cape Town and I worked and my husband was still in Joburg, and when he came down...ugh I was living with my in-laws as well which was (laughs) very stressful at that stage. You know it's just stressful, it doesn't matter if it's your own parents, sisters or brothers, but when you live that close to each other, you know, situations do come up and emotions fly, but we knew we had to do it for then.*

*Participant 6: ...cause I live by my Mom there...I live in the garage actually, cause we just sorted it off because the house it too full for all of us. Because it's my Mom, it's my Dad, it's my sister, it's my brother...came back there now also. And it's my*

*three kids. So, I'm in the garage. The hairdressers also there, and I have a room separated. And she used to sleep by me there.*

One participant was a grandmother who cared for her grown up children's children so that they could go and work, and four out of five of these grandchildren have serious health problems. Her own children also suffered from health problems. Eczema and asthma runs in families and for some this is a particularly large burden.

*Participant 8: I've got four grandchildren, well actually I've got five, but four I am looking after, and each one has got a different ailment...Because my son has got emphysema, and my daughter has got eczema, and the youngest, her mother, she's also got eczema, but hers...she outgrew everything, but the two eldest ones was here every month.*



Some participants spoke of just not having enough money to put food on the table for all the children. For the first mother mentioned below this meant that she took care of the children alone as her husband needed to work every single day. The second mother's partner had left her and there was no one else to help provide for her children, yet she was not able to work due to her daughter's health needs.

*Participant 4: My husband used to have to work 7 days a week...for us to...put food on the table he used to have to work an extra job...work weekends and it was worse*

*for him also...cause he never used to rest...he used to come in the evenings...spend half an hour with the children and then go sleep cause he's too tired.*

*Participant 6: Leaving them at home and me being here, or at [name of hospital], was difficult because I had to provide food. You see. And I must worry at the hospital. I must worry what they're going to eat tonight. I must rush home. I must make a way...for them to eat. Some nights, not all of it, but most of the time, they had their lunch only. There's no dinner. There's no supper. I used to go to neighbours and friends and call them up and ask them, and cook that time of the night. That was hard, but I went through it. That was the financial side. It was very, very bad.*

One participant did not have any accommodation for her and her children for a while due to her father's alcoholism and the arguments he started when he was drunk.

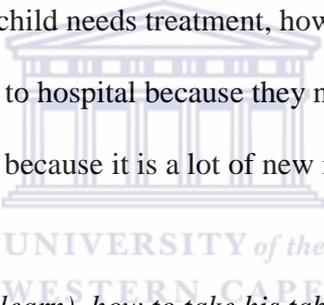
*Participant 6: I was thrown out of the house thrice since she's been at [name of hospital], since she came home weekends, in the winter. And my Dad actually is a drinker. I think he's an alcoholic and he doesn't want to get help...So, I've been suffering abuse from their side too. And, actually I am looking for a place to go, just me and my kids. Because I can't have them chuck me out. They chucked me and a sick child out of the house. She was still very weak at that time. I didn't have anywhere else to go.*

### 5.3 SPECIALISED PARENTING

Specialised parenting is a term chosen in the present research to denote the specialised nature of parenting a child with a chronic illness that goes above and beyond the scope of normal parenting, which is itself a challenge. It is about the ‘work’ of parenting a sick child, the practical and emotional skills that these parents needed to care for and protect the wellbeing of this specialised group of children.

#### 5.3.1 Developing medical expertise

Parents reported needing to learn quickly about their child’s medical condition – how to recognize symptoms, when the child needs treatment, how to administer treatment and medications, when to take them to hospital because they need emergency care. At first it is often overwhelming for them because it is a lot of new information.



*Participant 4: Yes (I had to learn), how to take his tablets and that. Cause before...I never used to know...he wasn't on the asthma vent before, it's only been a couple of years on it now. But they taught me how to give it to him...how you must blow in it...but it's difficult because you must teach everything...even the tablets he must take...you must know...now you must take a half a one...then at night a whole one. So you must learn everything. You've got to learn step by step what to do.*

*Participant 7: Yes, yes, yes, yes, yes (I have had to learn a lot of medical knowledge), it is just that with this condition you just have to learn fast...you just have to know everything...and sometimes when something has happened...I think you must know*

*before hand what is going to happen...when that things happens you already know that...it is what happens with their conditions.*

*Participant 9: It started in her folds, and when she scratches it becomes wet, and then it gets dry and then sticky, and she doesn't want you to touch it or anything. Then I came to [name of hospital] and they wet wrapped her, and they gave me medication to put on at home. I had to bath her and put a wet wrap on and then a dry wrap on again. So that made her skin better. The cracks were gone on the skin. And then I treated her at home.*

Parents often felt better when they were allowed to help with their child's care in hospital. To learn about their child's illness and how to manage it seemed to be an empowering experience for parents and this appeared to help them to cope with some of the anxiety that began in the 'not knowing' stage.

*Participant 2: They let you help too obviously, cause I was sitting there at one stage, it's just the vitamins and stuff, and I asked can I give it. So they let you in as well. Otherwise you just sit there (laughs) and you do nothing. And you're still the mother of this child, and you still feel like you want to do something. And you know it helps them (the nurses) as well.*

*Participant 6: And they let me (do some things for her). I just draw the curtains, and I call them when I need them for help, and I just did what I had to do. Irrespective of*

*what they said that I must not touch her with all the plugs on her and stuff. I just went ahead and did it...It was like taking care of my baby all over again. Like she was at birth...a baby. It really took nothing from me. It was instinct I can say.*

Parents have to learn to recognize emergency situations and respond appropriately.

*Participant 7: So sometimes it is just that with these patients when then they bleed...it means that their veins inside has grown bigger then they burst that's why they vomit blood...so they had to do this other thing...where they have to inject those veins so it doesn't burst...that's what they did just to inject those veins so that it doesn't burst. Sometimes when they didn't...when she didn't vomit blood she passed black stools...which means that she was bleeding from the inside...so I have to rush her back to [name of hospital] just to inject those veins again.*

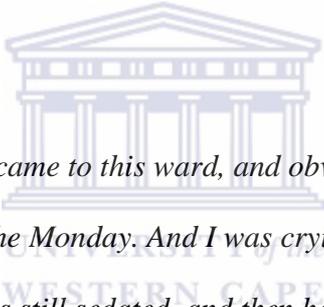
Sometimes parents spoke of needing to find creative ways to help their child, an aspect of specialised parenting.

*Participant 6: ...and emotionally...she was in a very, very, very emotional state. Every single day it was tears, tears, tears, and she couldn't express herself. So what I did was...I just made out an alphabet and asked the nurses to print it there and I did my own thing...communicated with her via the alphabet. That is the only way I could find out what was bothering her.*

*Participant 6: I actually put an album together for her...a scrapbook album...since she has been here (at the hospital) the nurses took photos. I was going to bring it here today, but I didn't think you needed to see it (laughs). And, ja, so that's basically proof of what she went through, and it's hers to keep. She has a story to tell to the world, and I want her to tell it.*

### **5.3.2 Containment: Being aware of the child's pain**

Many parents reported finding it very difficult to witness their child in pain. They found that they needed to contain both their child's emotional responses to their illness as well as their own.



*Participant 2: And then we came to this ward, and obviously it's very different from ICU and we came here on the Monday. And I was crying a lot...the Monday and the Tuesday. But in ICU she was still sedated, and then here she started to wake up...and you could actually feel the emotions, you know, you could hear the emotions, and it was just too much for me.*

*Participant 5: He hated hospitals. We had a very hard time with him at first... Yes. I was at emergency room every second or third night because the asthma attacks used to get him in the evening, when there was nothing really available for him and he needed the nebulizer... So at that time it was very stressful seeing what he is having to go through.*

*Participant 6: Most of the time I could tell that she was sad...and I was finding it a very hard time...speaking to her I didn't know what to say. It was constant prayer that was all I could do. I would pray. I didn't want to cry in front of her. I would have to walk out to cry, cause I don't want to hurt her, I just want to see her get better. Cause she was like...she was really in an emotional state. It was very, very hard for me (to see her emotions).*

*Participant 7: ur no...I just no, no not really (I don't cry often) it is when she is sick you...um...sometimes ur when she is sick and when she asks you am I going to be better again it just makes me cry.*

*Participant 8: He had many a high fever. And, I mean, being small and being dumped into a bath of cold water really wasn't nice. He used to cry, and then when he comes to you, you just see this hot fumes coming out of his mouth, this hot air, and I feel sorry for him.*

*Participant 9: It was difficult yes. To look at her, to look at her going through something like that was very heart sore. Because you don't know what to do. You don't know what to give this child to eat. So it was a bit difficult for me.*

Sometimes the pain for the parent is about seeing their child's struggles in the world outside.

*Participant 4: And...um...I'm so struggling to put him in a special school for children with special needs and in that line cause with his asthma he doesn't want to go to school cause "at school they make fun of me cause my chest pull tight Mama". Now he stays at home. And that is also difficult for me cause I want to put him in a public school so he can have more friends, cause he hasn't got friends or things at home. He will sit in front of the TV for hours and not play outside with the other children...because of his illness. Its very heart sore (watching him struggling) cause my other children wasn't like that... Especially in school now...all his friends is going over and he's staying behind...you see.*

*Participant 6: She left this hospital with a buggy. She is still in the buggy. She was scared to go outside even. When we took her out for a day it's like, "No, people are going to stare". She was very conscious of herself. Very conscious. "No, people are going to stare". I had to beg her most of the time, "No come, let's go outside", every time I had to beg her. It's like a drama playing off. "Now come ..... (name of child), I need to take you outside. You can't just lie there...like that".*

#### **5.3.4 "A sacrifice a day"**

An aspect to the special kind of care that these parents give their children is the sacrifices they make for them.

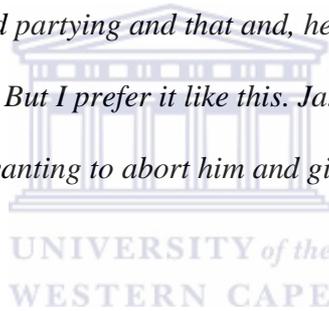
*Participant 5: I mean, he needs 100% of my attention, and if it's hospital then he has to come. I would rather bring him here than not have him having his medication and*

*being ill. So, I mean, it's a sacrifice a day, but at least I know he'll be fine. He has his medication, he has his back up.*

#### **5.3.4.1 Putting self aside**

Parenting a child with a chronic illness necessitates giving up time for oneself, which can often mean giving up a social life.

*Participant 1: Friends! When I, I don't know. The friends, ooh. Ja, I had a lot of friends, but now. I don't know what went wrong. When last I talked to them and this. Like they are going out, and partying and that and, here I'm sitting here, and you know what I mean. And ja. But I prefer it like this. Ja. And I don't regret having him. Yes, I had my reasons for wanting to abort him and giving him up for adoption, but I'm glad I didn't.*



*Participant 8: I've got no friends...because of looking after them, so basically I'm at home all the time. I don't go out, I don't have a social life...I don't have anything. Well, my mother is still alive, but I can't ask her for help. She's in a home. She is 81 years old. So, I can't run to her, she is frail already, and I can't burden her with my problems. I just talk to the Lord that is all.*

*Participant 9: Yes. I hardly go out. I hardly go out. It's because of her eczema. She is much better at home. Calmer at home and more at ease at home.*

Putting oneself aside also meant giving up a job when most parents would have chosen to work if they could.

*Participant 2: I think that something that would be nice but we can't really afford it...what they do with cerebral palsy children is get a caretaker, but a caretaker is like a salary, so that's the thing, we can't do that now, but I would like to go back to work, or start working. I'm a graphic designer so I can work from home. At this stage it just didn't work out that way because she's taking so much time.*

*Participant 4: At the time I had a job but I had to give up my work to look after him because he was a kangaroo baby (premature; born at 29 weeks)...and he was the youngest of four children, and I had to stay at home and look after him because there was nobody else to look after a sick child. He can't go to a crèche because he was a sick child.*

*Participant 6: And to get here every day as well. It took a lot out of me but I wanted to be here so. The thing is this...I had to close down my business.*

*Participant 7: It affected me a lot because ur...I couldn't do anything...I couldn't go back, do whatever I wanted to do...just complete my diploma or find a er...or go look for a job, because I had to be there for her 24/7...I find it hard.*

Sometimes parents said that they sacrificed their own needs for sleep.

*Participant 3: No, actually I don't go sleep early, just to make sure they're okay. I'm just too scared, okay, if I go sleep now, I'm not going to be awake to go check on them...maybe I'm too tired and I'm going to sleep right through. So, rather try and stay awake, and then okay, I know I'm up and I can peek in their room anytime I like... Then I will go to bed about 1 o' clock. Sometimes 2 o'clock in the morning. (Pause). Because I know there's only 4 hours or so for them to sleep and then I must get up and they go to school.*

*Participant 8: Most of the time (I am stressed) (laughs). 24 hours a day. And the only time I relax is when I sleep, and that is not even a long sleep...because when I tell their parents take them to bed so that I can relax then it's already 8 o' clock. And now I relax closely to 2 hours just so that my body can cool off, I can be at ease, and then I must now go and clean the house, do the dishes and all that. And when I get to bed it's 12. Half past 6 I must be up again cause then the same routine starts the following morning, God willing, every morning the same thing happens.*

#### **5.3.4.2 Responsibility**

The parents in the study spoke of a sense of deep and committed responsibility to their children, doing whatever was in their power to do to make their child well and to avoid anything further going wrong with their child's health, trying to do things "perfectly" and doing their "duty". The consequence of not taking special care of their children may be to lose them, as most of the illnesses that the children suffered from threatened their lives if not managed correctly. This seemed to be strong motivation for the parents to accept the

deep sense of responsibility of which they spoke, and something that was not possible to switch off from or to take a break from.

*Participant 1: All my concern is now just [name of child] and getting him better, and getting on my own two feet because my granny she's not going to be there for ever... I must be able to take care of me and [name of child]... I want to take care more nicely after [name of child]. I want to just do everything just right. I want to be this perfect mom that does everything by the book. Because I don't know what I'd do if (my son died)... I don't think I could go through something like that.*

*Participant 3: But I know that as a parent I have to be there for them, because they can't help themselves, they are still young, and when they are older and they can do things like tablets, see to it that they get their medication, and go to hospital themselves...that is only when they are adults. But for now I am prepared to be the parent for them, you know, to care for them. So, I think it's my duty to do it, even though how stressful it will get sometimes, but I have to do it. That is just how I feel.*

Some parents reported that they were not comfortable with the thought of anyone else caring for their children.

*Participant 2: But anyway, then what happened was that I went to look for a crèche or school or something for her, and I didn't feel comfortable with anything that I saw, and it was the end of the month, and I phoned my husband and I said, "I'm going to*

*resign. I don't know how we are going to do it. But I am going to look after her cause I feel it's the best decision we are going to do now". And he said it was fine and he respects it.*

*Participant 8: As I said I am most of the time at home, even if I must get an offer to go out or to go away for the weekend I don't think I'll be able to manage because my mind will be at home instead of being out at the vacation. "What are they doing? Are they treating the children right? Are they giving them their medication? Which they normally forget. And so it goes on. And my priority is that they must stay on their medication if they do have medication so that they can get better.*



#### **5.3.4.3 Protectiveness**

Sometimes the parents saw their parenting style as verging on over-protectiveness of the child.

*Participant 4: Me also...I sometimes think it's a problem with me also...I treat him too much like a baby...keep him away from...that's the way he was brought up...I raised him...so I kept him away from children...protecting him all the time. It's also (me).*

#### **5.3.4.4 Frustration and boredom**

The other side of the experience of sacrifice for the parents was the frustration and boredom that this sometimes brought, which two participants felt free to talk about. It is

inevitable that a parent's own needs would surface from time to time, and the losses that they had suffered would be felt and grieved for. The boredom of doing the same job every day is also keenly felt at times, a "wheel turning all the time".

*Participant 7: ...it is stressful because sometimes I just want to go and work or do something because it is frustrating just sitting at home...and the four walls...and those four walls it is...(pauses) yeah, yes I do get bored, I do get bored.*

*Participant 8: It is something I can't explain (what life has been like for me these past ten years) because...I'll say it's like a (pauses)... a wheel turning all the time. The same...the same...job I'll say I do everyday. There's no other difference in it.*

*Although sometimes I'll wish I could go on holiday, or just go away for a weekend, but when one is free the other one is not free. So, basically I am just at home 24/7 every day, there are no other days. Unless they decide to go out on a weekend, then I can say that I am free. Also, the day they come back it is back to normal. So, there is no other way.*

Sometimes the frustrated feelings were related to the child's condition, or to the child's emotional response to their condition. This may be born of a sense of helplessness, and the possible guilt that accompanies this inability to help their child. One mother talks about being frustrated with her child for looking the way she does – her face is sometimes covered in eczema – which she sees as a kind of disfigurement, and worries that it will spoil her beauty through scratching and scarring.

*Participant 7: Not to pick her up when she was crying...my husband was there...fortunately, and then she would go to my husband cause I was more of a...impatient with her...with her eczema. And then my husband was...he's very easy...got all the patience in the world...and then she goes to him. And then she calms down. But if she comes to me then I'm going to fiddle with her skin, things like that, so my husband just carries her and let's her...let's her...subside it a bit...I thought that someone was cursing my child, or something like that man. I even went to a spiritual healer to ask if there's someone that's jealous on me or on my child, but he said nothing, it's just a medical condition. But I just got frustrated (with her) for being...for looking like that and for being like that.*

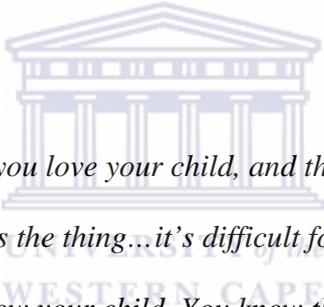
*Participant 8: See I get upset because I can't help her in any way, and the more I try to help her the more she gets upset, and at the end of the day I get annoyed cause I can't help her and it feels like I want to ring her neck.*

### **5.3.5 Devotion**

Devotion refers to the love that seems to motivate these parents to care for their children. It is a step beyond the idea of the responsibility and duty of parenting towards caring for the child out of a sense of free choice, finding meaning and fulfilment in their role as caretakers. Parents spoke of a quality in their care that is born of the special attachment that develops between a parent and their child – a parental love for a child, which would not exist in the same way within another type of caregiver relationship. Some parents spoke of the dedication they felt towards their child, and described their willingness to

care for them as stemming from their love for the child. They reported that they also gained much from the relationship themselves and enjoyed the closeness they shared with their children. These parents said that what made their intensive caregiving worthwhile were the happy moments and love they shared with their child.

*Participant 1: It's just whenever I'm sad or whatever and then when he smiles then all that sadness just disappears. So I'll pick him up and I will just, there will be a joy in my life, and I don't know what I'd do without him. Because he has brought so many things out of me, man, you see. So many happiness and so on. And ja, I just love him to bits.*



*Participant 2: Well, ja, but you love your child, and the energy they have, you know, she has a personality. That's the thing...it's difficult for other people cause they don't know your child like you know your child. You know there's a personality in what she does and doesn't like, so it's fine...Yes definitely (my love for her drives me). I can't have enough of her. You know, I was one of those people...I was Standard 5 and I already wanted children (laughs).*

*Participant 4: But actually I don't mind doing that. As I explain to my sons...my children always comes first...that is how I feel. Well in all the cases, in every case like, whether they're sick or they have needs or so I will always help with them first before I put myself. And even if I want to make time for myself I will wait till they're all asleep before I will do something for myself.*

*Participant 6: It was like taking care of my baby all over again. Like she was at birth...a baby. It really took nothing from me. It was instinct I can say.*

### **5.3.6 Meeting the needs of siblings**

When there is a sick child in a family there are often consequences for other children who share the same parents. These children seemed to get less attention from the parents than their sick sibling. Mothers in this study said that it was hard for them to go against their instinct to give more attention to the sick child, and they felt as though they had to “leave the other children behind” to care for themselves. This brought out different reactions in the siblings of the sick child, which in turn made things either easier or more difficult for the parents. Some children reportedly responded to the situation by also taking on a parental role towards their sick sibling and doing whatever they could to help their parents to care for the sick child. These children modelled their parents’ caregiving behaviour and became very protective over their siblings. This was the easier sibling response for the parent to deal with.

In other cases parents reported that siblings reacted with anger towards them when they didn’t have time to spend with them. This anger sometimes came out in “withdrawn” moods in which the child stopped communicating with the parent, or “naughty” acting out behaviour, which made life more difficult for the parent concerned.

It is likely that the siblings of the children who were sick had their own worries and concerns about their sick sibling, but it seems from what the parents spoke of that they

were not able to think about siblings reactions because they were trying to deal with their own anxieties about the sick child, and manage the caretaking as well. One parent said that she made the choice not to have more children since she could see that her first child needed 100% of her attention.

*Participant 4: Sometimes I used to...um...even leave the other children behind just to worry about him. To sit with my other child who is 16...to help her with her homework...I would rather sit with him...with the baby...than to help her...so it is difficult...for the other children also. (Pauses).. Well I didn't actually speak to them about it (how it affected them having a sick little brother). But you could see when he came home...they all helped me a lot...cause you could see he was a kangaroo baby...he was so small...they all used to help. "Mommy must I do this? Must I help you with that?" They were all there helping.*

*Participant 6: And the two boys on the other hand, they suffered. My eldest was a quiet person but he became even more quieter. He's the 16 year old. He went more into himself, where he doesn't want to be with his friends anymore. He just wants to sit at home...He was so into himself. You could talk about it to him, but it's like, I'm listening, but I'm not really. I don't think he wasn't interested but it's like, you could see it hurts him... The baby, ugh, he's just a naughty child, a very naughty child, but he actually also started to develop anger because I'm not there. He's the 9 year old. I wasn't there at home, and whenever I get there he doesn't want to speak to me. He doesn't want to speak to me. He's like ignoring me.*

*Participant 9: Maybe the little one yes (finds it difficult not having as much of my time), my boy, my ten year old. He feels a bit stressed out. I explain to him that [name of child] is small, and she doesn't know what she is going through so I have to be there for her. So that he must just understand. He is a big boy now.*



## 5.4 IMPACT ON EMOTIONAL AND SOCIAL WELLBEING

### 5.4.1 Evidence of depressed mood

#### 5.4.1.1 *Sadness*

Many parents spoke of the emotional struggles of parenting a sick child. They described a feeling of being overwhelmed and lost in the experience, not knowing what to do or how to manage the situation they were in. The tone of the parents' stories often reflected a sense of depletion, in which emotional resources and hope were low. At times they felt out of their depth and in sore need of comfort themselves, although in the role of comforter to their children. They try to describe the pain of this experience – a kind of unbearable, intolerable pain – but some are not able to put it into words. Often a parent would start to describe this feeling and not be able to finish their sentence, leaving the unspoken words hanging in the air as though too painful to name and seeming to hope the listener would know what they were speaking about. When speaking about this material in the interview the participants often had tears in their eyes, or strong emotion in their voices. Many parents mentioned that they cried from time to time about what was happening to them and to their child.

*Participant 2: That was the first time I was actually told something like that (told that her baby was going to die when 3 days old), and it's my first child, so you're not very sure about...life...at that stage anyway. So that was really bad, and I remember that*

*there are obviously all these things going through your head, and um, crying a lot, and so forth...*

*Participant 6: You know sometimes it's difficult even to get out of bed...in the morning. Because thinking about all of this, looking at her clothes that's around the place, looking at her shoes even. I actually put them in a box. Really, I didn't want to (get out of bed)...because...I want my child at home, you see.*

#### **5.4.1.2 Helplessness**

Feeling helpless was a common response from the participants. There is only so much a parent can do for their child to help manage the illness they are suffering from, and then it is usually a case of standing by and watching the struggles they are having.

*Participant 3: Well I feel a bit spaced out (when child is really sick) because why I don't know...for me it feels like I can't do nothing for him to make it better. And even now I let him use his medication and I give it to him, but when I see him just lying there trying to breathe, and the medication is not kicking in immediately, and its like...what can I do to make it better for him...because...(pauses) I can't actually explain how...the feeling (gets tearful).*

#### **5.4.1.3 Fatigue**

Sometimes the work of caring for their child felt relentless, and parents were aware that there was no escaping the constant demands that their child had for their attention and

care. The needs of the child often interrupted sleep, and the perpetual vigilance that was sometimes needed to monitor symptoms left many parents chronically fatigued.

*Participant 4: You know, for him, and for me, there are sleepless nights when his chest is tight and waking up.*

*Participant 6: It was just that emotional part that drained me practically. There was no eating, there was no sleeping. I lost about 10k's from all this not eating, not sleeping, not wanting to leave her alone.*

*Participant 7: ur in Durban the weather it is terrible, it is hot, and when it is that hot we didn't sleep and sometimes we sleep about two o clock in the morning we have to sit outside just for her to get the fresh air. Ooh it was one of the miserable days ... if I look back thinking that I had to spend the whole night outside and come back about two o clock to sleep. So it was terrible, yeah.*

*Participant 9: You know, it was stressful for me and my husband also because at night...I'm me...I like my sleep and then my husband has to take her, but then I can't fall asleep cause I feel guilty cause my husband is up and down with her. Then I just stay awake also, and we just take turns.*

#### **5.4.1.4 Guilt**

A few of the participants spoke about guilt as an emotional response, and they wondered if they were somehow responsible for their child contracting a chronic illness.

*Participant 1: And, and I was like thinking, Now what did I do? So I asked them, Is it something that I did? And they tell me, No, it's nothing you did. And I told them about this kidney infection that I had, um, when I gave birth to him, but it wasn't labour cramps, it was the kidneys that was.... So I had pain and then they tell me, No, it's nothing to do with that.*

*Participant 2: We were obviously very shocked, and you know, you don't feel well about it, you think "why is this happening to me" you know, and in her case I had a viral infection when I was pregnant, and everything else I did was right. You know, I ate the right foods, and it's something that happened, and I couldn't do anything about it, and I didn't even know that I had it, so also there is also lots of questions, maybe faith questions as well, but that didn't last long.*

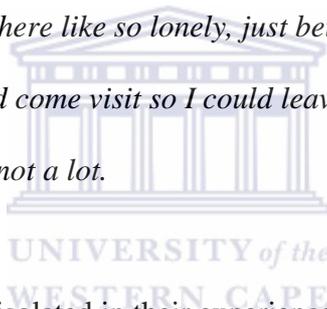
In some parents the feelings of guilt brought out a need to make up for this by being "this perfect mom that does everything by the book". The pain of seeing their child suffering (as discussed in "Specialised parenting"), layered with the pain of feeling as though they could have done something to prevent the illness, caused some parents to try to avoid any further sources of guilt by doing everything they were able to do absolutely perfectly.

#### **5.4.1.5 Loneliness**

Loneliness was a common emotional experience for these parents, especially the parents who did not have the support of a partner.

*Participant 1: And, um, but while I was at the hospital I felt so alone, because, I mean, she, my granny, she's got grandchildren to look after, she couldn't come every day, you see. And I had no one to talk to, and I mean, I'm still young... Cause I don't know the people here, and I don't talk to them, you see, and they don't talk to me.*

*Participant 6: I was sitting here like so lonely, just being here with her, just hoping that at night someone would come visit so I could leave and not be so late at the house, so, it happened, but not a lot.*



These parents spoke of feeling isolated in their experience. There were some parents, however, who connected with other parents at the hospital and found this helpful.

#### **5.4.2 Evidence of anxiety and trauma**

In all but one case, the chronic conditions that the children of these parents lived with were potentially life threatening. These parents had to live with the real risk that they might lose their child. In a few cases the parents came very close to losing their child and believed that it was imminent. Parents reported this as an immense strain to live under, and it appeared to cause them much anxiety.

*Participant 2: And I must say that was actually the third time that she was that close to death. Sorry I have to interrupt myself. The second time was when she got the fit and they also told us that she was on her way out. It was so bad that they couldn't get her out of it. But I can tell you that the feeling we had that night was indescribable. And you sit there, and you can't comfort each other because you don't know what to say, you know, you don't know what to do.*

*Participant 6: I didn't know at that time what was happening. I was totally, totally scared. That much I can tell you...I was confused for one...for once...I was scared...mostly scared that this child is not going to make it.*

*Participant 7: After she was diagnosed...it was terrible and ur...I was scared because the doctors told me that ur...that she wouldn't last ur ur they said she wouldn't ur she would not reach one year. So it was frightening and at the same time but I had to stay positive...yeah. Yeah and she was 4 months...and the thing was that I was scared because um...I first noticed that she was yellow jaundiced when she was about...2 weeks. So it was frightening and at the same time but I had to stay positive...yeah...It has been a long road (laughter), yeah it has been a long road and scary, stressed.*

These parents described this experience as “terrifying” and that it “knocked the wind out of you”. One mother said she only dealt with the reality of what she had been through once her daughter was out of danger.

*Participant 3: Well, to tell you the truth sometimes I think what if he's...so sick that...I might lose him. If his chest feel tight and maybe during the night when he go sleep and we all asleep, and I might just wake up the next morning and he's not alive anymore. Because he's complaining "I can't breathe, I can't breathe". Now on certain nights when he is sick I go peek in his room or see if he's still breathing...and I see to it that his blanket is not over his face, it's by his chest, and I can see, no okay, he's still breathing, he's okay. And it goes on like that. So till I see that he's better now. He's sleeping better, he's not breathing so heavily, he doesn't have to use his asthma vent so often, I feel, okay, he's better now. But at the time when he's sick...that is my worst nightmare...just to see him lying there...and I don't know what is going to happen...and especially if it keeps on for three or four days. Because I've heard stories of children getting asthma attacks and then sometimes they die, because they can't breathe...their lungs close up. That is actually how I feel.*

Living with the anticipation of bereavement appeared to be extremely stressful for parents. It seems to create in the parent a constant vigilance, the inability to ever fully relax, and the threat of culpability if something were to go wrong while the child is in their care.

*Participant 1: She tells me there's this transplant, this, um, [name of child] needs a transplant, a liver transplant. If he doesn't get it, he's not going to make it because I brought him in too late, and if he doesn't get the transplant he will die...Because I don't know what I'd do if... I don't think I could go through something like that*

*(losing a child). And she's so strong, the mother (a friend in hospital who lost her child). It's unbelievable how strong she can be. I don't think I'm...I will be able to do that. (Pauses).*

This mother is apparently struggling with the anxiety that her child may not survive, and that she might be responsible for this by bringing him in to the hospital too late. The anticipated loss of her child is so traumatic that she cannot even contemplate it, or know how she will survive it herself.

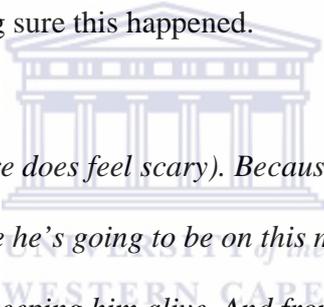
#### **5.4.3 Living with the unknown**

Part of these parents' experiences is living with an unknown future. One aspect of the unknown is the course of the child's illness. The illness is happening in their child's body, not their own, so the parent cannot always know what the child is experiencing, especially if the child is too young to tell them. After experiencing the shock of the initial illness and diagnosis, and learning that serious things can go wrong in their lives without warning or any sense of personal control, parents seem to feel the need to prepare themselves for the possibility that their child's condition may worsen or just not get better. For many, they have to live with not knowing what the road ahead contains, with the unpredictability of illness and with the fear of further pain and loss. This is conceivably very stressful.

*Participant 1: So now I'm so afraid to go home and just to... I mean here the doctors and the nurses is still here, you know, but at home it's only going to be me. I know I*

*do everything, um, by the book, but still I don't know what is going on in his body. I don't know if he's going get something, or if he's going to wake up in the morning, or if he's not going to wake up...So (pauses) just when you think everything is going so well then something happened. That's why I'm so scared to go home. Because if it could happen to her.*

Some parents think ahead to the time when their child is a teenager and what concerns this may bring along with puberty or the influence of peers. Others spoke of their worries about their child continuing to take their medication throughout their lives, once they were not responsible for making sure this happened.

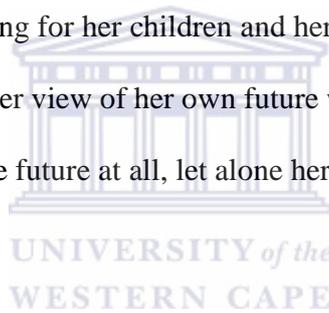


*Participant 1: Yes (the future does feel scary). Because they told me that's, as you say, a lifelong thing because he's going to be on this medication for the rest of his life now. He has to take it. It's keeping him alive. And from what I've seen here, like when they get teenagers and when then they think they're big now and they're healthy now, so they think it's unnecessary to take their medication. Or they feel shy, or so, or they're thinking, Now why must I take all this medication? And so, and here's, there's been a few teenagers here that died. Fourteen, um, eleven, thirteen. Because they didn't take their medication. Now this is also making me more scared. Because I know what I went through, you know.*

Another concern for a parent in the time ahead was how to explain to her daughter why she is different from other children.

*Participant 2: But as I say I think the worst nightmare will be when she realises “I’m different”, and how we are going to handle it because...and...obviously going through puberty...being a teenager. I can tell you...I don’t know if you’re going to put that in, but to me she’s a little girl. Puberty with everything that comes along with it, the situation, how do you handle that? Say she gets worse and not better...what do you do about that?*

Some parents were not able to contemplate the future because it felt as though they would not have any more choices than they had currently. For one participant in particular, who had spent the past 30 years caring for her children and her grandchildren who had all suffered from chronic illness, her view of her own future was especially bleak. She had difficulties in contemplating the future at all, let alone her own hopes and desires for the future.

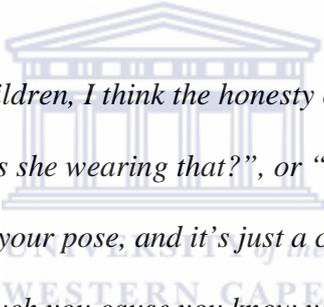


*Participant 8: I’ll be honest with you. I know it’s a dark future, but for myself and my family...I normally tell them...I don’t know how they see the future, but I take it one day at a time. Because, for me, the way the life is now, you can’t think “Oh well in so many years I’m going to do this and that and that”. When the time comes and I can do something I’ll just say “thank you” (gestures as though to God). I don’t look forward for many years...I’m going to save my money to do this, or I’m going to save my money to do that, or I would like to do this in my house, or that. I just take one day at a time.*

#### 5.4.4 Negotiating the gaze

Negotiating the gaze refers to the realisation that the child is the focus of people's stares, judgments or comments because they appear or behave differently from other children.

For some parents this brought up painful feelings at the realisation that their child will not be able to fit comfortably into the broader social system and may be ostracised from their peers. This is apparently painful for the parent to witness, and they speak of trying to "keep your pose", to be brave and not let this affect them, although it does. There is the worry that their child will not have a normal social circle, which in turn is likely to cause the parent to feel isolated too.



*Participant 2: And other children, I think the honesty of other children...they will ask very loudly, "Mommy why is she wearing that?", or "Mommy why this...?", and I think then you have to keep your pose, and it's just a child, but still, it gets to you. Words get to you. It does touch you cause you know your child is different...So what then happens is that you will see people looking at you when you do certain things with her, or maybe feed her, or when she's lying in her pram with her bottle. You know, I've got questions like, "Why is that child lying with a bottle?" She's four. You can see that she is four. And we have to explain to her, but she's disabled. So that's sometimes difficult...she wears ankle foot orthoses, and people will stare, and it's a normal thing...you don't...its not like if someone is in a wheelchair as well. She's not in a wheelchair because she is still fitting in her stroller and she likes to lie down. But...people will stare and look. It still gets to me, even after four years it gets to me. You know, I can't do that...I totally hate that...you know that people...you know...you*

*can see it in their faces, and you know, that bothers me, I don't like it, that I don't like.*

Even with friends and family, who may be expected to know more than strangers about this mother's child, she has the experience of her child being labelled as something that she is not – a baby.

*Participant 2: Um, and then another thing is with friends, cause their children can walk and play and my child can't. My daughter is older than all the other kids here that we know and then they will talk about her as the baby. And things like that...I don't say anything cause they don't mean it...they don't mean it in a nasty way, it's just something that happens. And, you know, her one cousin will play with her as though she is a doll...will do things with her...Oh, she enjoys it, but still you see it...and you don't feel that...I don't know...it bothers me, it still bothers me, there are certain things that bother me.*

Two parents spoke of an awareness of how their child may be treated in the outside world, and how they felt torn between encouraging them to socialise and protecting them from experiences of ostracisation. The first parent speaks about the tension she feels between wanting to send her child to school so that he can make friends yet wanting to protect him from the negative experiences he has had with peers because of his illness. The second parent is aware of her daughter's acute self-consciousness but tries to encourage her not to let this stop her from making contact with the outside world.

*Participant 4: And I thought when he went to school he'd be much better. But that was when the trouble started...when he went to school because he's backward...he's more slow than other children. You know, he's like a child who needs special care. He's ten years old but he's only now in Grade 3 whereas he should have been in Grade 4/5 already...And...um...I'm so struggling to put him in a special school for children with special needs and in that line cause with his asthma he doesn't want to go to school cause "at school they make fun of me cause my chest pull tight Mama". Now he stays at home. And that is also difficult for me cause I want to put him in a public school so he can have more friends, cause he hasn't got friends or things at home. He will sit in front of the TV for hours and not play outside with the other children...because of his illness.*

*Participant 6: She left this hospital with a buggy. She is still in the buggy. She was scared to go outside even. When we took her out for a day it's like, "No, people are going to stare". She was very conscious of herself. Very conscious. "No, people are going to stare". I had to beg her most of the time, "No come, let's go outside", every time I had to beg her. It's like a drama playing off. "Now come [name of child], I need to take you outside. You can't just lie there...like that".*

#### **5.4.5 Effects on relationships**

Almost all participants spoke of the effects of their child's illness on their relationships – with friends, family or partners. There were both losses and gains with some experiencing abandonment and others experiencing extra closeness with others during

this stressful period in their lives. As they noted who remained committed to them and who disappeared from their lives a new perspective was sometimes gained as they saw these relationships in a different light.

#### **5.4.5.1 Negative**

##### *5.4.5.1.1 Partnerships*

*Participant 1: Anyway, and um, [name of child] had the transplant so I thought maybe this will bring us closer together because we also had our ups and downs, and that, closer together and that, and then he didn't come for a month, he didn't come for two months, and what. And I didn't know if he left me or whatever, and I just told myself, if this is the way it's going to be then I have to do this on my own, because I've been doing it now... So he's staying away and he even tell me he got involved with someone. And I'm like, yes that's good, and I'm glad, and I'm happy for you, but inside it was hurting me, because he was telling me all this things.*

It seems that some partners were not able to provide support to the mother or the child when a crisis hit the family

*Participant 6: And then the single parent bit...it wasn't easy at all. Called in the father...he wasn't here...not one single day...I had a relationship of six years that also took a blow. Because there I got to learn what kind of person really he was. He was there in the beginning, but he got tired of it. He got tired of...it's not his kid, so I*

*don't have to be there. She was in hospital for almost 2 months when he actually came up to come and see her. I had to force him that morning...just come and have a look...that child is looking for you. And now he comes there, he still comes there, but only once in 2 weeks when I call him and say, listen I don't have a lift, [name of child] must be fetched, he will come and do it. But I can see it's against his will, so that's gone for me. That's over. And that is actually the best thing that came out of this because now I get to know the person I was prepared to share my life with. So, that's over. It's a lot of things that have happened.*

This mother also had to manage her child's illness alone and face the disappointment of a partner who wasn't able to be there to support her or the child. She said this experience showed her things about her partner that she wouldn't have known had they not been through such a stressful life event. She is able to see the loss of him in a positive light and feel grateful that she learnt of his inability to provide the kind of support she needed sooner rather than later.

The following participant found it easier to concentrate on taking care of the children without her new husband as he was an added burden to her care-taking role.

*Participant 8: My late husband, the first one, he passed away...(pauses) last winter it was 50 years, and I had to raise my children all alone, and as I said I was sorry I ever got married again, because instead of helping me I had to help him. So I just let go of everything and did it on my own.*

The following parents reported having a close and warm partnership. It seems that the ability to understand where the difficulties come from, for example from tiredness, helps these partners to not catastrophise their minor irritations with each other.

*Participant 2: With my husband and me, I think we are getting tired now. Especially the beginning in [name of town] when she had the original kidney failure and ended up in hospital...she really almost died...And I must say that was actually the third time that she was that close to death. But I can tell you that the feeling we had that night was indescribable. And you sit there, and you can't comfort each other because you don't know what to say, you know, you don't know what to do. But since then, obviously as things get better in the hospital you feel better. But then we do get irritated now. I think it's tiredness and we will snap at little tiny things, but luckily it's over in a few seconds and so I know that that is happening. I can see it, especially in the evening. But it's fine, we're not having big fights about anything.*

#### 5.4.5.1.2 Friendships

*Participant 1: Friends! When I, I don't know. The friends, ooh. Ja, I had a lot of friends, but now. I don't know what went wrong. When last I talked to them and this. Like they are going out, and partying and that and, here I'm sitting here, and you know what I mean. And ja. But I prefer it like this. Ja. And I don't regret having him. Yes, I had my reasons for wanting to abort him and giving him up for adoption, but I'm glad I didn't.*

This mother is aware that her friends are carrying on with their lives without her and feels a keen sense of loneliness from time to time.

*Participant 4: It has yes (affected my social life), before we used to go out with my sister and so to clubs and stuff, but I haven't been out for years...going out with them and socialising with anybody because of my child. I can't leave him by anybody. It's only now that his sister's old that I could leave him now. But I don't go out anymore...with friends or anything...anywhere.*

*Participant 6: Sometimes I do get a lift by family members and friends and so forth. Family support was quite nice in the beginning. They were here. Like the first two weeks, and after that I was sitting here alone.*

*Participant 7: Yeah, ah, it is just that I didn't have I, I don't have many friends (laughs)...it is just that my friends are usually...like my neighbours...um so I, I will go and see them so but I couldn't go like on outings (laughs) go like to the movies or something...someone had to take care of her if...sometimes I will ask her aunt, or she will just have to go to her father's house if she needs to be taken care of. Then I will go when they have taken care of her...but...but...it (laughs) ur it is bad...no it (seeing her friends) doesn't happen often.*

Most parents spoke of a life without friends since their child became chronically ill. It seems that there is no time or energy to keep up friendships as the child takes up all the time available to them.

#### **5.4.5.2 Positive**

Other participants spoke of positive experiences with friends and family in which they felt cared for and supported, and sometimes the parents became much closer to these people through sharing their experiences of having a child with a chronic illness.

*Participant 1: But now [name of child] has really brought me and my granny closer together. Now I can speak to her about anything. She can tell me anything. And so we just close now. She's like my mother now, so, ok she's always been like my mother, but like a mother and daughter relationship we have now.*

*Participant 2: And me and my husband are very strong, you know very strong considering (what we have been through)[husband's name] is wonderful.*

*Participant 2: So I could say just family-wise and friendship-wise my eyes have just been opened to see how many people really care. You don't really realise that until something like this happens, and it's just, they just keep, you know, people bringing us food and offering help.*

*Participant 6: But when I started now back at the house things are even better than they were before. Now we can really talk. And she (her best friend) will constantly ask me...even if I explain it to her 20 times already, she will always ask me, what has it really been like for me? She always wants to know.*

One participant spoke of the experience of belonging to a group of friends, and found this particularly supportive.

*Participant 2: And in [name of town] there are friends, almost like you see at birthday parties, or stork parties, you know, that kind of friendship that you have, it wasn't a close friendship. And there's people that give you money. It's amazing. We play tennis, me and my husband, and the tennis club, you know it's only people you have contact with when you play league, it's older people, and you know they only contact you when they need to for the games, but they were contacting me everyday and had organised a prayer group for her...Yes the prayer thing just went over the top.*

## **5.5 COPING STRATEGIES AND RESOURCES**

### **5.5.1 Emotion-focused coping**

The theme “Emotion-focused coping is divided into two sections – “Relational aspects” and “Internal aspects”. Relational aspects includes all coping efforts that involve interactions with others, and internal aspects refers to coping strategies that occur within a person’s thinking.

#### **5.5.1.1 *Relational aspects***

This theme overlaps somewhat with the previous theme “Effects of relationships: Positive”. It is included here because social support is a major resource that participants drew on in order to cope with their child’s illness. There appeared to be two aspects to this that were helpful. The first was the experience of “Being listened to” – just simply listened to. The second aspect was the experience of “Mutual support in a shared predicament” – the special bond of support that is created between parents going through a similar experience.

##### **5.5.1.1.1 *Being listened to***

The experience of being listened to was a source of great support to participants, and reaching out in this way to others was a strategy used in order to cope emotionally with the stressors that went with having a chronically ill child. Even talking to the interviewer seemed to be a helpful experience for a number of participants who commented on this. It

made a difference to these participants for another person, even a stranger, to know what they were going through.

*Participant 1: Like I say, it has made me more open, and it has made me talk about my feelings and all of this. If I didn't do that, I still would have been this alone, and in a shell, and they wouldn't know what is bothering me, what I need. Stuff like that. So...Ja... (sigh)...Sometimes I just need to talk to someone that, um. The person doesn't even need to know what you're going through and that, just for the person to listen, you know, and the person doesn't even have to say anything, just to, you know, just to listen and that.*

*Participant 2: Well, you can ask me again anything more you want to know. It has felt good to talk. My shoulders feel lighter.*

*Participant 3: That's why I say...an affect...to tell you the truth...my sister is always there...and I can speak to her about anything, besides, like, help in the house, but if I need someone to talk to she is there. She will listen to me. Well, she is younger, but, um, I will speak to her and she will speak to me. That is just to release any pressure that we're under.*

*Participant 6: Wonderful. They have been wonderful (her friends). I am actually surprised to see that. I have a friend [name of friend] in the road, a grown woman, a married woman, but she always makes time for me to talk. We can speak for hours.*

*She will sit up until past 1 at my house... We can just talk. I can tell her anything. She is my confidant. She knows my life in and out. I'm glad to have someone like that...*

Participants seemed to experience talking to friends and family as a release of pressure, as an escape from loneliness, and as a lifting of the burden that they carry. To have their experiences known and understood appeared to be very important when they were going through such tough times, so important that it gave them more energy and courage to carry on. To be listened to seemed to be more helpful than to be responded to or given any kind of advice.

#### 5.5.1.1.2 *Mutual support in a shared predicament*

Some participants spoke of how much it meant to share a friendship with another mother in the hospital whose child had the same condition as her own. They were able to be a source of comfort to each other.

*Participant 1: ...when I came here I didn't have anyone to talk to and that and then I met this friend. And then she also had this child with billiary artesia and then I, she was talking to me, and I was talking to her, and we were growing really, really close. So... And I got very attached to her little one 'cause oh she was a girl she was the sweetest thing.*

These two mothers shared such a special bond that when a liver became available for a transplant the friend donated the liver to the participant's son because she believed that he

was much sicker than her daughter. This huge sacrifice shows that through their shared experience they had grown to care for each other's children as though they were their own.

*Participant 1: ...But the thing is that the liver that [name of child] had wasn't meant for [name of child] it was meant for her little one but I think they had the same blood type but it was meant for her little one. And then she told me, No, to see [name of child] suffer like that. Her one had never suffered like that. And she'd rather give it to [name of child]. And since then we've been very close, and so on.*

One participant spoke of how moving it was to return to the ward in which her daughter had been now she had recovered and to see another child with the same condition and have the opportunity to offer encouragement to her and to her mother.

*Participant 6: They took us to bed number 1 after that, and there there was an 11-year-old Guillianne Barre patient laying there, also a girl, and that took me. I just went out and cried in front of everybody. The doctor asked me, "Mommy, why are you crying because you never used to cry in front of your child?" I said, "If these four walls could talk they would tell you a different story cause I never cried in front of her, but I am doing it today because my child is standing in front of this child's bed. And she can tell that child that she is going to get better like her. And I can tell the Mom that her child is going to recover. There is proof. There's living proof. It just*

*took my emotions, seeing from the outside in, and I saw what the nurses saw, and I saw what the staff saw.*

Another mother shared how interacting with other mothers whose children had recovered helped her to cope by giving her hope. This experience provided a long-term perspective to the situation she was in currently through hearing how hopeful the future could be for her child, given the outcome for the other children.

*Participant 7: It is more encouraging here because we can see them ... talk about um it helps it helps because ur ... when we came here in May ... just for the check up ... she didn't have a transplant by then, I've seen other two mothers who had a transplant in January so they were waiting just to be discharged. and I was so happy to see their children when they told me that their children were exactly like her yellow jaundice, scratching, and after the transplant everything just goes away and their eyes comes white and I was so excited happy that ... she is also getting that chance. Yes, to hear their stories...it's encouraging.*

### **5.5.1.2 Internal aspects**

#### *5.5.1.2.1 Making meaning*

Making meaning is the process by which participants tried to find reasons for the experience they had been through with their children's illnesses. Participants tried to

create meaning out of their experiences in a number of different ways, which will be presented as follows:

#### 5.5.1.2.1.1 Why me?

“Why me?” is a painful stage that a few parents went through in which they battled to understand why this incredibly difficult experience had happened to them and to their child. In most cases this question was addressed to a higher power.

*Participant 1: Why must I go through all this?, I ask myself. What did I do to deserve this? What did I do to get a child like this with sickness and that?*

This participant goes on to speak about the loss of her special friend in hospital when she left to go home. She is full of questions and does not understand why she has to suffer the grief of losing her friend and therefore face being alone again on top of trying to cope with her son’s illness. She feels that what she has to go through is unfair, and wonders what she has done to deserve it.

*Participant 1: Now I feel, ok now I feel that I’m back to square one. I’m going through this again alone now. I mean there was someone that understood what I was going through and that. And she understand the medication and all of these things and...This whole story she understands, but now she’s gone. It’s not fair. Why? It feels like the Lord gave me something and then he took it away again. It feels like this space in my heart that just, I want to be filled so.*

Another participant looks for a reason for her daughter's illness in something that she might have done, and comes to the conclusion that she could not have done anything to prevent her illness. She also turns to a higher power to ask why this happened to her, but feels in the end that she will not find answers to her question of "Why me?" and will have to simply accept that it did happen to her.

*Participant 2: We were obviously very shocked, and you know, you don't feel well about it, you think "why is this happening to me" you know, and in her case I had a viral infection when I was pregnant, and everything else I did was right. You know, I ate the right foods, and it's something that happened, and I couldn't do anything about it, and I didn't even know that I had it, so also there is also lots of questions, maybe faith questions as well, but that didn't last long. You know (laughs) you can't, you can't ask God why this happened to you. So, you know it's something that you had to accept...*

A different mother also asked herself why this was happening to her, and whether there was a reason for it. She wondered whether the illness was a result of someone holding jealous feelings towards her and wishing her and her child harm. She also looked towards a higher power for answers as to why this had happened to her. She comes to the conclusion that in comparison to the illnesses that some children suffer from she should see her child as healthy, and be grateful.

*Participant 9: I thought that someone was cursing my child, or something like that man. I even went to a spiritual healer to ask if there's someone that's jealous on me or on my child, but he said nothing, it's just a medical condition. But I just got frustrated for being...for looking like that and for being like that...I ended up crying, like, arguing with my maker that why must he give this illness to...thinking, there's children worse off than my child still, just take her as a healthy child. This illness is not that bad this eczema. There are children suffering more severe illnesses. So I just handled it like that.*

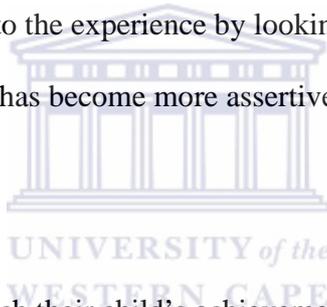
#### 5.5.1.2.1.2 Positive reappraisal

Every parent in the study sought the positives in their experience as a way of coping through accepting what had happened to them. Positive reappraisal is the act of re-defining an experience that might have had negative effects as one that has been beneficial in the end. These parents spoke of their difficult experiences as being worth the pain they had gone through.

*Participant 1: ...all those times I felt so alone and that but felt for me like it was worth it cause look how he's now, he's happy and smiling and all this stuff...I'm just glad that everything turned out so. And I say till today that if it is the same outcome that it is now that I would do it a hundred times over and over...And it helped me also (the experience of having a sick child), it's like, um, it's also like I was very quiet and then I didn't talk to anyone but this has helped me to speak out what happened to me and to talk to people and you know what I've gone through, and you know just be*

*open and communicative. So...And I wasn't usually like this, talk to anyone and that. But now I'm, it's like I want to stand there on the roof and shout and so, man, that really I opened myself and I've come out of this, the shell that I've been in. While I've been shy, since I was little one, but now growing up, and this whole experience has really changed me as a person.*

This mother says that she would go through the same experience a “hundred times over and over” despite the emotional pain of it all in order for her child to be well and happy. She seems to be saying that it has all been worth the pain that she has been through. She is able to find further meaning to the experience by looking at the ways that it has changed her for the good – she has become more assertive and able to be open about herself.



Some parents spoke of how much their child's achievements meant to them, and how watching them improve was very moving for them.

*Participant 2: But another thing to be positive about...you know every little thing that she does we're so proud of. You know, the first time she actually noticed her own hand she was 8 months old, and children do that from a very early stage. We had this beautiful moment where she was just lying in her cot and we walked past and she was lying there looking at her hand. And it was beautiful. We were crying!..So, I can say that the first 3 years of her life I cried a lot, you know cried a lot and didn't feel well*

*about it. And then you see that actually she is doing little things, and you know you are so proud. Every little thing that she does is wonderful. So we got better...*

*Participant 6: Every single thing that my child do, every week she comes home and says “Look here what I can do”. And it just takes away the pain of the week, that loneliness, it just takes it away. And you’ve got something to celebrate every week. She actually pulled me through this... And now she has learnt to appreciate life more. That is the lesson that she got out of it. Appreciating every single thing that happens. Even the small things that matter, she has learned to accept it and appreciate it now. Things that we never saw. As I say, every day is a milestone, every single, single day.*

A few parents compared their situation with other parents and children they saw in the hospital who seemed to have more serious conditions than their own child in order to see their lives in a more positive light.

*Participant 3: And I always ask myself, “Who is better off? Me or them?” And I think I’m better off. Because their children need 24-hour looking after, and for me...he can...they can do everything by themselves. It is only when they are sick that they need help, and that will only take a couple of days. And that is for the rest of their lives (the other children). And actually...it’s an inspiration for me. And I will always talk to my friends about it, and I say, “you know what, we think our lives are so difficult, but if you just go to [name of hospital], if you just go sit and see the parents come in with their children who can’t do nothing for themselves, or see the children*

*who are lying there, whose parents have to stay there at the hospital. Sometimes the children have to stay there for a whole year, and there is nothing they can do about it. It is just what happens. And that is actually a big part. Compared with that our lives is easy.*

*Participant 5: Oh, I was very sad bring him here. I was very...oh you know, it's just something that everybody...or most people have to go through. I mean, it's very heart sore having to see the kids especially. I mean, when I used to come here I used to think well thank God that my child only has asthma. You know, there were other children who were worse than what he was. So, for me it was very...I can cope with this. It was fine.*

Other parents mentioned positives, such as the trip to the hospital as an outing for the child and a day away from school, seeing more of family since the child's sickness, having more time to read whilst sitting by the child's bedside, and even how taking the stairs every day had been good exercise

#### 5.5.1.2.1.3 One day at a time

Some participants spoke about finding it helpful to think about what they needed to cope with in small increments, i.e. day by day. This day by day thinking is included in this "Making meaning" section because it is a way of seeing life, it is a perspective that is developed in order to cope with difficult circumstances, and it seems to help these mothers to get through the experience of their child's illness. In response to the question

“How do you cope?” a few mothers gave this type of response: “You just take one day at a time”. The challenges are broken up into daily challenges rather than looking at the whole picture over long time frames of caregiving that may overwhelm these parents. This first mother speaks of how the months her child has been in hospital have flown by without her realising how she managed them.

*Participant 1: Aah, I don't know (how I'll cope with fears for him in the future). Still I'm, thinking how did I get through this five months with this thing, eight months since the first time I came here to [name of hospital]. I still don't know. I just, I don't know, I'm just taking it day-by-day and so forth. Ja.*

This next participant uses the ‘one day at a time’ mentality to manage the worry of caring for sick children. Staying in the present moment and dealing with the current situation with its particular needs and demands seems to be a strategy that she has developed over years in order to cope with the anxiety of perpetual stress that a child’s illness brings.

*Participant 8: Just worry as it comes along. Today it will be a good day, tomorrow they might all be sick at the same time. Or the one will start getting sick...the other one is better. It is like a rotating machine. And that's how it goes. (Pauses)... I just take one day at a time.*

‘One day at a time’ thinking was also used to appreciate the positives about a parent’s situation as in this example.

*Participant 2: Appreciating every single thing that happens. Even the small things that matter, she has learned to accept it and appreciate it now. Things that we never saw. As I say, every day is a milestone, every single, single day.*

#### 5.5.1.2.1.4 Hopes for the future

Most of the parents were able to see positive things about the future to look forward to, and holding this perspective appeared to help them cope with the present stressors in their lives. Some were hopes for the child and some were hopes for themselves. The hopes for themselves revolved around having more freedom and time for their own pursuits, for example, to be able to study or work again. This mother, whose child was disabled from birth with cerebral palsy, hoped to have another child one day who would be healthy.

*Participant 2: Ja, you know, we will have another one when I think she is in school and...that's another thing that's in the future for us...having another one, but we just want to get her to a good point. And ja, I'm 30 now so I still have some time (laughs).*

The following mother wants to write a book about her experiences of parenting a child with a chronic illness in order to support other parents who are living through similar circumstances. She also wants her daughter to tell her own story, bringing inspiration to others through the story of her recovery from Guillane Barré Syndrome.

*Participant 6: I see great things for her especially, because she can go out and she can tell her story to the world, because she has a very, very big testimony to give. She*

*can inspire a lot of kids, adults as well, cause she's done it so far... She's matured a lot, and in future I can see this child going places. Really, I can see her going places, cause I want her to take this now, what has happened to her, and never ever forget it. She has a story to tell to the world, and I want her to tell it.*

For some the near future was still uncertain, but they were nevertheless able to look further down the road to hold hopes for a brighter outcome in the long term. These parents hoped for normality one day, and the promise of this possibility seemed to act as a steady anchor in the midst of the present illness experience.

*Participant 7: I'd like to see her grow ... I think one day she will become a doctor but ur ... the doctors when they see her painting they say she will be an artist (laughs)...I think for now we have peace ... but I know it is still a long road, it has been a long road because they say ur ... things will get stable after two years or one year after the transplant for now we still have to watch out (laughs) ... um for now yeah so ah ... in two years time (laughs) ah ... I don't know I don't know what to say ...but I think after two years ... in two years time she will be like normal child. She will go, she will do what ever she needs to but just to take her medication ... she'll have to know that she has to take her medication for the rest of her life ...yeah ... but other than that ... she will be fine (laughs).*

#### 5.5.1.2.2 *Spiritual wellbeing*

##### 5.5.1.2.2.1 Spiritual beliefs

Over half the participants spoke of a relationship with God that helped them to cope with the stress of having a child with a chronic illness and the emotions that they had to deal with as a result. For some, speaking to God was a comfort in an otherwise lonely experience.

*Participant 1: Then I wasn't really a person who, um, how can I say, Ok, I went to church and that, but I wasn't really a religious person and... I started to believe. I can remember my pastor told me, before the transplant he told me that everyone can pray. Your family can pray, your friends can pray, and they can believe that everything will be fine, but if you don't pray and you don't believe then nothing will come from it and I just started to believe.*

This next mother speaks of prayer as “all I could do”. Holding onto the faith that there was a greater power watching over her and protecting her appears to be a coping strategy used to combat the despair that she felt at the relentless nature of her child’s illness.

*Participant 6: It was constant prayer that was all I could do. I would pray...I learn to cope. Because I draw my strength from God because that is the only way...So, just looking at her things I really didn't even want to get up in the morning. Really, I didn't want to...because...I want my child at home, you see. But I take my bible, and I*

*draw my strength from that. I don't know how it works, but it's just there, and afterwards I do feel better. And I go on with my day.*

Participants described drawing immense strength from their spiritual beliefs, giving them the energy and the courage to manage the intensity of their caregiving.

*Participant 8: (How I cope is...) Just by saying prayers every time if something happens, and at night, in the morning, or anytime during the day if I feel that it's just getting too much I just pray and ask God to help me. And really, I just go on with the rest of my day as if nothing has happened.*

#### 5.5.1.2.2.2 Cultivating a spirit of gratitude

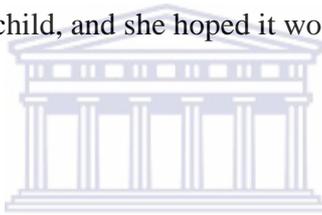
Participants spoke of the gratitude that they felt for the care they received from hospital staff. As a response they wanted to give back in some way, either to the hospital staff or to future parents and children going through similar experiences. This sense of thankfulness seems significant in helping them to feel more buoyant. For the next participant it was a life-changing experience.

*Participant 1: You see I feel that I'm so glad for what [name of the hospital] did for me that I want to give something back. I want to be a nurse or a sister, anything, just to help them and that. Because they, they really have helped me a lot...And like I said, when I, um, when I finished school I didn't know what direction to go into but this whole experience for me has been so interesting, man, and um, it's like it was a*

*turning point in my life, you know, and now I, like um, when we're going get out now and all this, and then, um, I will now do nursing.*

*Participant 6: So, they were great, they were wonderful. If I could give them whatever, I would, I would (laughs). But there's no way I can repay them for this, for what they did for my child. They were there for us. They were really, really there.*

This participant wanted to share her story with the world by writing a book. She wanted to share the ways in which the experience of having her child in hospital had changed her outlook on life, and that of her child, and she hoped it would bring comfort and hope to other parents.



*Participant 6: I'm on my way to writing a book. Me and a teacher at the hospital, we spoke, and I'm going to do it. Cause there's a lot to tell. A whole lot to tell there, cause this child is a very good testimony, cause a normal healthy child, quite a selfish girl also she was, had her life turned around just like that.*

This participant's spiritual faith kept her going, and amidst all the stress that she felt she was able to feel grateful for her life.

*Participant 8: Plain and simple. I mean...my life is plain and simple. As I said I just thank the Lord every day to open my eyes, and I close them at night for a good night's sleep. And then tomorrow again. That is all I do.*

#### 5.5.1.2.2.3 Time alone

Time alone was something that participants spoke about as necessary to keep them going. This time was used to rest physically and recharge their batteries, but also to reconnect with themselves and process the emotions that came up inside them whilst caring for a sick child.

*Participant 4: You know when he started school it was the first time that he went to school and I had time to myself from 8 o' clock when he was in school till 1 o' clock and it was my time...the time I had to rest...till he came home already. It made a big difference. When he was 6 years old he started primary school. It was the first time...Time to myself, yes. I love that time. Even now, when they leave for school between 8 o' clock and 10 o' clock I just rest...that's my time...sit and talk...to myself or whatever, and then I do my housework. You know, cause once the children come you haven't got time to do rest, and everything like that. (Pauses).*

*Participant 7: Yeah but sometimes I just want to be alone and just cry...sometimes it helps.*

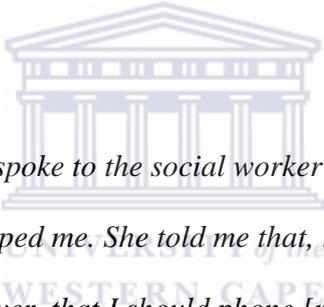
*Participant 8: And even if they go out and they come back then they look for me. Sometimes I hide myself. "Where were you?" "I was here". "You weren't here". And so it goes on. I must explain to them what I did for the whole day while they were away. And then I just sit and relax, doing nothing, cause I know I must now cause I know now that I must get some steam and energy so I can go and start with them when they get home.*

## **5.2.2 Problem-focused coping**

Problem-focused coping involves strategies aimed at solving problems externally. There seemed to be two ways in which participants did this – they either sought practical assistance from friends, family or hospital staff, or they sought knowledge as a means to cope better with their child’s illness.

### **5.5.2.1 Practical assistance**

Many participants spoke of the practical help they received from friends and family. This ranged from financial help, to help with looking after the children, to help with housework.



*Participant 1: And then I spoke to the social worker and I tell her the situation now and whatever, and she helped me. She told me that, um, even if I don't have transport money or whatever, that I should phone [name of the hospital] and they will send someone to pick me up and that.*

*Participant 2: And we have another aunt that also gave us money for the first week because what happened was that we didn't want to drive in and out from [name of town] everyday cause I want to be here in the mornings, so what happened was we stayed in [name of town] for a week and the aunt actually sponsored us for that week.*

*Participant 4: My family...we're a very close family. My family...we were 7 children. I have 5 sisters and 2 brothers. And we're all very close you see. So, even if I wanted to go to the town for the day...they say bring [name of the child] I'll look after him. They are really helpful. Even if I want to go weekends away and I say I'll take him with, they say leave him here and go spend time on your own...and I say okay. They are very helpful. My mother also...I mean she was over...she was always there for me. She used to come over weekends and help me clean the house because she knows I never used to have time to do that. You know, during the week with a child that is sick, I never used to have time to do that. She was always very helpful.*

One participant moved from Johannesburg to Cape Town in order to receive practical assistance with her child.



*Participant 2: ...we decided to move from Joburg to Cape Town to be closer to grandparents. And I think that was a very good move because we didn't have really support in Joburg.*

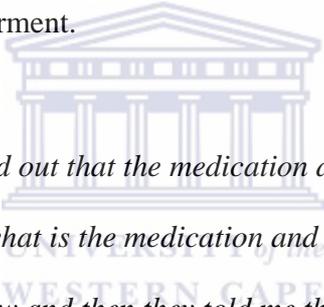
The children's friends were also a source of practical help sometimes.

*Participant 6: ...but her friends have also been great. They will do the small little things like fetching her a drink, holding it to her mouth, all those things. They did it for her. They will even brush her teeth for her.*

Drawing on practical resources was a very important way in which the participants learnt to cope with the demands of having a child with chronic illness. Together with the benefits of the actual practical support, participants found that being helped in this way also made them feel cared about by others.

#### **5.5.2.2 *The empowerment of knowledge***

As we saw in the first theme “Encountering the medical system”, not understanding the cause of their child’s sickness was a source of enormous anxiety to parents. Some participants actively sought knowledge in order to help them to cope with this anxiety, giving them a sense of empowerment.



*Participant 1: Then they find out that the medication doesn't work. And then I started asking questions. Now for what is the medication and all this? And they saw that I'm interested in wanting to know and then they told me this whole thing, this liver disease and how it happened.*

*Participant 2: And from there on there was an MRI and we realised that something wasn't right, she had brain damage, it was calcifications, and what I did was, cause that's what I do, is that I started reading as much as I could, you know internet, wherever I could find out more about what's going on... We do ask a lot of questions. We do question some of the things they do, but usually it is answered with politeness and whatever, and you feel relaxed after their answers.*

Participants really appreciated the doctors open responses to their questions and found that there were benefits in raising the issues they were concerned about.

*Participant 4: All the doctors I have been seeing so far have all been fantastic cause I will ask them “What is this for? What is that for?” and they’ve been fantastic, cause they’ve always been open with you, they never used to hide anything away...Yes, I did learn a lot (about the things that would help my child). Like I told the doctor last time he likes swimming. And the doctor said “No, go for it. Do it”. Cause I thought it would hurt his chest, but the doctor said exercise is good for him, you know, swimming, soccer, all of that stuff is good for him. And since then I’ve been putting him in the swimming club and he’s been swimming, and he’s been loving it (laughs).*

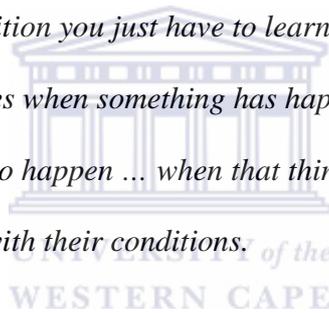
Two participants had knowledge from previous experiences with other family members who also suffered from severe asthma, which they found helped them know how to deal with their own child’s condition.

*Participant 5: And because my whole family...even I had asthma till I was 18 years old. I grew out of it, which they say you never really do when you are asthmatic, but um, because we have a background of asthma in the family it was something that I could deal with, and my family they knew, or how, to treat it. : Ja, it made it easier (because I understood it).*

*Participant 8: And it's all in the same field...the allergies. And that's what actually helps me get along because I know what they had to do those years with my children, so I know what I have to do with them now.*

One mother spoke of how it was very helpful to have knowledge about symptoms before something happened with her child. Having an explanation seemed to make the experience less frightening for her.

*Participant 7: Yes, yes, yes, yes, yes (I have had to learn a lot of medical knowledge), it is just that with this condition you just have to learn fast...you just have to know everything ... and sometimes when something has happened ... I think you must know before hand what is going to happen ... when that things happens you already know that ... it is what happens with their conditions.*



# **CHAPTER SIX**

## **6. DISCUSSION**

### **6.1 INTRODUCTION**

This discussion section will present both the strengths and limitations of the study. A summary of the themes generated from the thematic analysis will be presented, and how they interlink, followed by conclusions and recommendations.

### **6.2 STRENGTHS AND LIMITATIONS**

This study used a qualitative method of enquiry in order to attempt to access the subjective meaning-filled experiences of the participants who were interviewed. The richness in the quality of data generated seems to support the utility of qualitative methods in this area. Participants seemed to be sufficiently comfortable with the open-ended interview style to speak quite deeply and personally about their experiences of parenting a child with a chronic illness.

The study was limited to 9 participants for the purposes of this in-depth approach, but it is likely that with a larger sample more would be learned about the experiences of a wider cross-section of caregivers at the hospital. The sample was made up of caregivers of both inpatients and outpatients, and although there was a lot to be found in common across their caregiving experiences, especially as the outpatient sample from the Asthma and Eczema clinic were severely affected by their conditions, it would be interesting to focus

future studies on either an inpatient or an outpatient sample population. Parents of children who are inpatients have to deal with daily travel to and from the hospital, with the time and costs this involves, and their relationships with hospital staff are necessarily more involved. Their children are more critically ill, and whilst both categories of parents faced the threat of losing their child, the inpatient caregivers faced this threat of loss in a more sustained way and with greater uncertainty.

The data generated from this study came from one source – caregivers of children receiving hospital treatment for a chronic illness – and there is no way to verify their experiences of the medical system, the nature of their parenting or their relationships. It would add richness to a study such as this one to additionally interview hospital staff, partners, friends and children in order to create a fuller picture of the challenges that these parents/caregivers face when looking after a sick child. Further, the caregivers in this study were interviewed at one point in time, capturing how they felt on a particular day, and it is possible that an interview with the same participant at another time would generate different reflections on the caregiving experience, given the changing nature of human emotional and thought processes, and perspectives. Caregivers' reported experiences also rely on memory, and cannot be seen as an objective verifiable truth. Such data, though, falls in line with a constructivist understanding of the subjective creation of meaning, which aims to illuminate the storied 'realities' of individual lives. Within the constructivist view, it is the subjective nature of experienced reality that is of most interest to the researcher, as it is in the individual life-world that the meanings of social circumstances are to be found.

## **6.3 SUMMARY OF MAJOR THEMES**

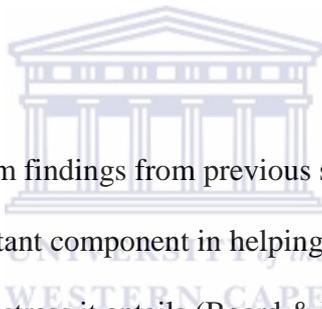
To reiterate, the themes that were generated by the thematic analysis were the following:

- Encountering the medical system
- Contextual stressors
- Specialised parenting
- Impact on emotional and social wellbeing
- Coping strategies and resources

### **6.3.1 Encountering the medical system**

The research found that a significant proportion of caregiver experience was located within the new medical world that they had encountered with the discovery that their child had a chronic illness. Caregivers started a journey through this medical system from the time that they felt there was something wrong with their child, after which they often experienced a period of the child being misdiagnosed, and finally reached the stage in which there was a correct diagnosis and appropriate medication and treatment regimes were established. Many caregivers reported that their interactions with staff at the hospital where the study took place were positive and supportive ones, and this seemed important to their overall ability to cope with the experience. The support the staff offered ranged from practical assistance (such as arranging lifts to the hospital), to technical expertise, to emotional support. Participants liked the fact that they were free to ask questions and that staff took time to answer them.

Some participants reported very positive experiences of emotional support received from the staff. This layer of the data speaks of parts of the medical system that were attuned and receptive to the experience of parents and able to hear and respond to parents' narratives of their children's illness. It tells of an organisation which, despite the enormous demands on its human and material resources, seems to be succeeding, at least in part, in maintaining an empathic space which is cognizant of the unique struggles and needs of parents. With available information it is difficult to know whether these positive experiences stem from the quality of individual staff members or characteristics of the organisation as a whole.

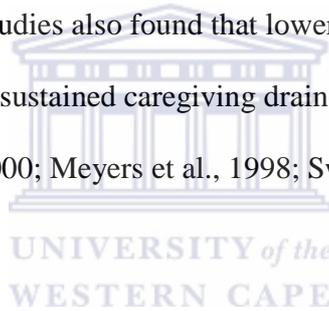


The data from this study confirm findings from previous studies that good relationships with hospital staff are an important component in helping caregivers manage the burden of caring for their child and the stress it entails (Board & Ryan-Wenger, 2003; Miles, Carlson & Brunssen, 1999; Melnyk, 2000; Swallow & Jacoby, 2001a). Many participants spoke of how important it was to feel cared about by staff, and how this decreased their levels of stress. It has been suggested that medical staff are uniquely placed to provide support to parents who are struggling with the challenges that caring for a chronically ill child presents (Kratz et al., 2009). Such support may entail communicating an understanding of parents' circumstances, recognising the environmental hospital-related sources of stress, facilitating parent-to-parent relationships, and investing in positive and empathic relationship building with parents (Board & Ryan-Wenger, 2003; Kratz et al., 2009). Balling and McCubbin (2001) describe the benefits of this type of relationship: "A

mutual trusting relationship enhances the parents' and professionals' ability to become co-workers in providing care and also increases quality of care" (p. 111).

### **6.3.2 Contextual stressors**

Contextual stressors refer particularly to financial hardships, and these added to the burden of caregiver stress by creating extra worry and anxiety around the provision of food, shelter and travel costs. The child's illness impacted directly on family finances through preventing caregivers from working in order to take care of the child full time, as well as through the extra costs incurred for such things as travel to and from the hospital, and for medication. Previous studies also found that lower-income households suffer an extra burden of stress, and that sustained caregiving drains families financially (Clawson, 1996; Goble, 2004; Melnyk, 2000; Meyers et al., 1998; Swallow & Jacoby, 2001a; Williamson et al., 2002).



A greater understanding is needed of the specific and longitudinal contribution that economic factors make to the stress experienced by caregivers, but it is clear from the number of participants suffering financial hardship that it is an issue pertinent to the mediation of caregiver stress. Further studies may generate deeper and more precise knowledge on the wider socio-economic forces at play in these caregiver's lives (such as the influence of race, gender and class on health system experiences), and the particular outcomes that South Africa's health and economic policies have on such parents.

### **6.3.3 Specialised parenting**

Specialised parenting refers to the particular style of parenting that evolves out of responding to the needs of a chronically ill child. This includes the need to develop medical knowledge and technical skills to treat the child's symptoms at home. Children who are sick often struggle emotionally with the pain and discomfort their illness brings, and therefore a parent often has to deal with more challenging behaviour that arises from their emotional struggles, and to contain the feelings of sadness and anxiety that the child feels from time to time. The need to hold and soothe the child emotionally is added to their own needs for comfort and reassurance during what is an anxiety-provoking experience for the parent too. An aspect that came through strongly in the data was the sacrifices that a caregiver makes for their child through putting their own needs aside in various ways in order to care for the child's needs. Some participants spoke of a deep love that they had for their child from which flowed a generous willingness to put the child first. Often, the ill child was not the only child that the parent cared for, and meeting the needs of healthy siblings was an extra task of parenting in these families. Sometimes these siblings suffered from lack of the parents' time and acted out their distress, making parenting more challenging for the participants. In other cases, siblings became a part of the caregiving and supported their parents in looking after the sick sibling.

The finding that the effort involved in bringing up a child with a chronic illness is greater than that involved in parenting a normal child echoes the findings of Ray (2002) who, in her analysis, coined the term "Special needs parenting", which she used to describe the extra tasks implicated in raising a child with a chronic illness. Similarly, these involved

‘medical care’ such as the monitoring of symptoms and the use of technical skills to care for the child’s condition. Ray (2002) also found that parents needed to try to ‘close ability gaps’ for their child, i.e. compensate for developmental delays, and to ‘pave the way’ – in other words, “to create social opportunities for their child and bolster his or her self-confidence in preparation for the public’s reaction to disability” (p. 428). One parent reflected on this aspect, but perhaps this would have been found more often with a larger sample. Ray’s third element of ‘special needs parenting’ was ‘working the systems’, which involved dealing with health services, social services and educational systems. Parents spent up to 2 years trying to set up services for their child, and found the inconsistency in coordinated professional contact frustrating (Ray, 2002). The parents in this study did not mention any difficulties they had with these systems, except that the grants they received did not cover all of their needs. Ray’s study was completed in a Western context in which social service systems are likely to be more established, and perhaps parents’ sense of entitlement to services is different from the developing context of South Africa. This particular finding in the data may also simply be due to a lack of emphasis on these issues in the interview schedule.

There is a wealth of literature pertaining to the experiences of siblings in families in which there is a chronically ill child to care for. Caregivers in the study mentioned an awareness of the needs of siblings, but the rich descriptions found in the research record suggest that this area requires more examination within developing contexts.

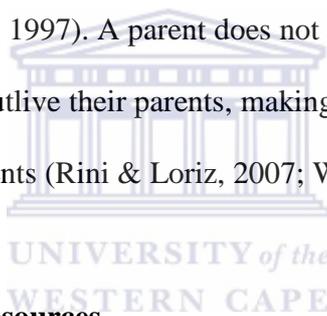
### **6.3.4 Impact on emotional and social wellbeing**

A significant feature of the experiences shared by participants was the effects that parenting a child with a chronic illness had on their emotional and social wellbeing. Evidence was found for indicators of depressed mood in many participants, including feelings of sadness, helplessness, fatigue, guilt and loneliness. These aspects were found in addition to the presence of anxiety and feelings of trauma. Participants spoke of how difficult it was to live with the unknown concerning their child's illness and its course – whether their child would recover and how long this might take. The participants spoke of their interactions with the outside world and how they managed the attitudes and comments of others regarding their child's appearance or difference from other children. Most found this particularly difficult and personally painful. Having a child with a chronic illness almost invariably affected caregivers' social lives, with a marked decrease of time spent with friends since their child became sick. There was also an impact on intimate partnerships due to the stress of caring for a sick child, and the time taken up in caregiving. Participants also recounted stories of support and caring received from friends and family, which helped to sustain them during stressful times.

The findings from this study confirm the psychological vulnerability of this group of parents. Parents in the study consistently suffered emotional strain with the diagnosis and ongoing care for their child, creating a further level of suffering to the already distressing circumstances of caring for a chronically ill child. It is clear from the research literature in this area that such parents are at risk for ongoing psychiatric morbidity, including the phenomenon of chronic sorrow and vulnerability to the onset of symptoms of post-

traumatic stress. The painful emotional symptoms they describe seem often to warrant mental health intervention, for the benefit of parents and children alike.

On top of this, parents often had to face the risk of losing their child – a “frightening” and “terrifying” experience. In one instance a mother spoke of how she couldn’t really deal with the reality of the possibility of her child dying until her child was out of danger. This may be a natural response to trauma of this nature – a severity of stressor too extreme to take in all at once (Herman, 1997). Contemplating the loss of a child is frighteningly outside of the realms of everyday existence and is consistent with the notion of psychological trauma (Herman, 1997). A parent does not expect to have to face the loss of a child as children usually outlive their parents, making the threat of this experience intensely heart-rending for parents (Rini & Loriz, 2007; Wallbank, 1996).

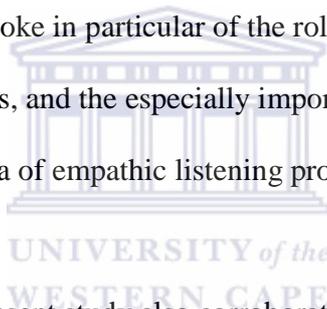


### **6.3.5 Coping strategies and resources**

Each participant spoke of ways in which they kept themselves going, or learnt to cope with the stressors that they encountered whilst caring for a sick child. These coping strategies fell into two categories – emotion-focused and problem-focused coping. Within emotion-focused coping participants described drawing on social support to help them to cope, in particular they found that just being listened to by another person was immensely helpful. When participants had a relationship with another caregiver in similar circumstances to themselves this contact and support seemed to alleviate some of the burden they felt. Finding meaning in their caregiving was a significant coping strategy, and positive reappraisal was most often used as a way of seeing the good in a situation.

Many participants had spiritual beliefs that offered them support, comfort and guidance. For some participants, spending some quiet time alone and dwelling on the positive aspects of their largely very challenging life situation brought some respite. Participants used problem-focused coping in the ways they sought and received practical assistance from friends, and the ways they obtained knowledge about their child's condition.

These findings are consistent with the literature on stress and coping by authors Lazarus and Folkman (Folkman, 1984; Folkman, 1985; Folkman, 1997; Folkman, 2009; Lazarus & Folkman, 1984), in particular the use of emotion-focused and problem-focused coping strategies. Some participants spoke in particular of the role of friendships in helping them to cope with their circumstances, and the especially important function of being listened to, similar to the theoretical idea of empathic listening proposed by O'Brien et al. (2009).



The data generated from the present study also corroborate previous findings on the importance of positive meaning making as an activity that gave caregivers the strength and courage needed to cope with their circumstances (Folkman, 1997). Specifically, participants reiterated Folkman's (1997) observation that amidst incredibly stressful circumstances caregivers are able to create new or closer bonds to others and clarify which goals and priorities are important to them now.

In addition, participants used the coping strategies of comparing themselves to others less fortunate than themselves, 'counting their blessings', and looking towards the future to provide a perspective for the present (Folkman, 1997; Park & Folkman 1997).

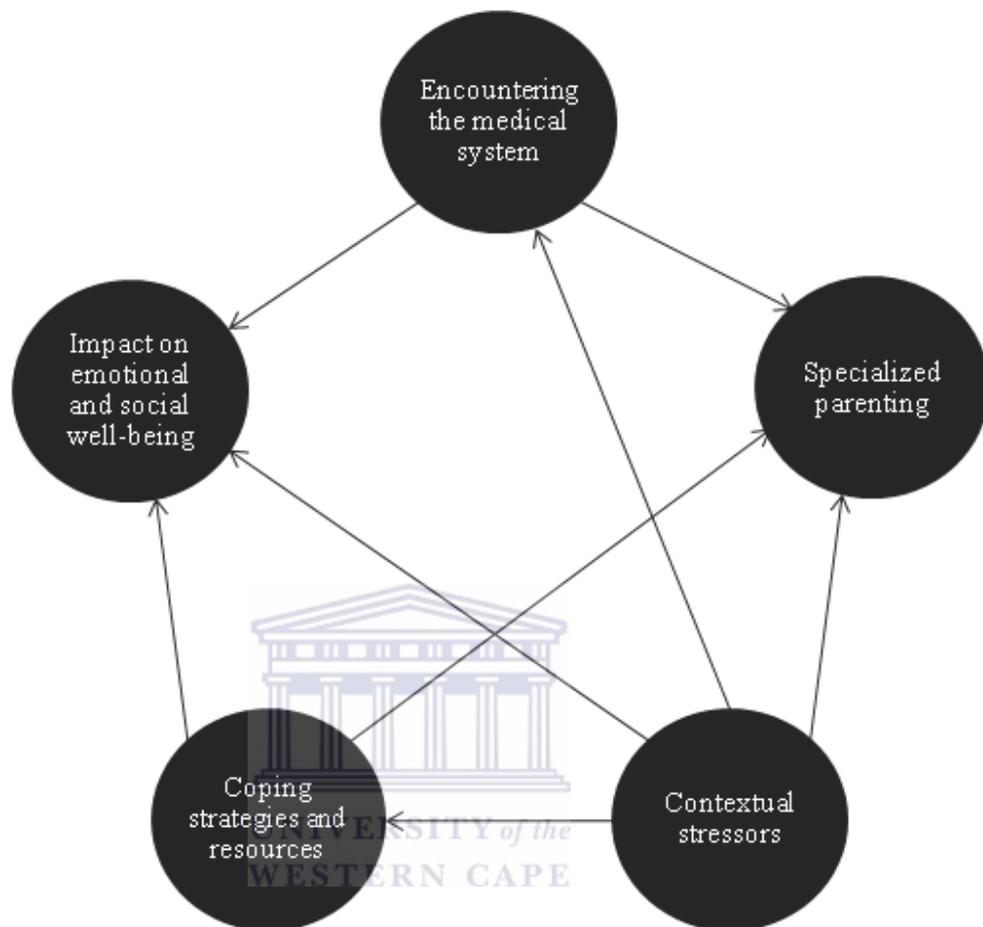
Participants also spoke of deriving personal satisfaction from their caregiving roles (Haley et al., 1996). The evidence for the role of spiritual beliefs in the coping process also confirmed the findings of previous studies in this area (Idler et al., 2003, Newton & McIntosh, 2010; Pargament, 1997, as cited in Banthia, et al., 2007; Park et al., 1990).

#### **6.4 THE INTERACTION OF THE MAJOR THEMES**

Data analysis suggested that the above themes interact with each other in the following ways (see diagram on p. 133):

##### **6.4.1 “Encountering the medical system” → “Impact on emotional and social wellbeing”**

Parents’ experiences of diagnosis and consequent encounters with the medical system seem to impact on their emotional and social wellbeing because both the experience of the actual diagnosis of their child, and the previous phase of not knowing what their distressing symptoms meant, led to feelings of anxiety and fear. Positive experiences with hospital staff mediated the negative impact of the child’s illness on the parents’ emotional wellbeing. In terms of social wellbeing, the child’s illness itself impacts on the participants’ relationships with others as they either experience support and extra closeness with others, or experience the loss of friends and family who are not able to provide the support that they need.



**Diagram:** The interaction of major themes

#### 6.4.2 “Encountering the medical system” → “Specialised parenting”

Coming into contact with a medicalised world affects the style of parenting that the participants develop. Due to their illnesses their children require a specialised form of caregiving in which medical and technical knowledge needs to be developed. The particular emotional and behavioural needs of children who suffer from chronic illnesses draws out a certain style of caring and concerned parenting, which has the tendency to dominate the lives of the participants involved in the study.

#### **6.4.3 “Coping strategies and resources” → “Impact on emotional and social wellbeing”**

The coping strategies and resources that the participants used to manage their circumstances influences the impact their child’s illness has on their emotional and social wellbeing. For example, having the ability to reappraise their situations in a positive light will lighten the effects of depressive and anxious feelings, and spiritual beliefs were spoken of as being a source of great strength to participants, helping particularly with the loneliness that they felt.

#### **6.4.4 “Coping strategies and resources” → “Specialised parenting”**

The strategies that parents use to cope, and the resources they are able to draw on influence their approach to the role of specialised parenting. For example, seeking knowledge is a coping strategy that affects the development of medical expertise, and feeling emotionally supported by friends and family through being listened to is likely to affect the parents’ ability to contain the child’s difficult emotions.

#### **6.4.5 “Contextual stressors” → all themes**

Contextual stressors impacted on all other categories of participant experience, with financial and environmental burdens (e.g. inadequate housing) added to the difficulties that the parents faced in caring for a sick child. Financial hardship seemed to compound the full range of experienced difficulties, making every aspect of parenting harder through the unreliability of material resources.

## 6.5 CONCLUSIONS AND RECOMMENDATIONS

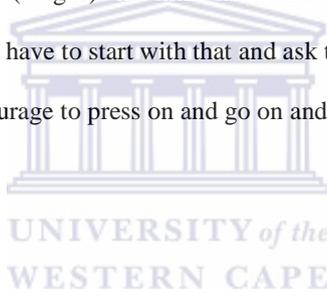
The findings from this study particularly underscore the importance of financial and emotional needs within this vulnerable population of caregivers. If there is to be some improvement in the levels of stress experienced by these caregivers then it appears that each of these needs must be addressed. The financial needs are perhaps more complicated to address, and are not within the power of health care workers or psychological support services to change. Poverty is a complex societal issue rooted in a range of historical and political factors, which are way beyond the control or influence of health care systems. It does feel possible, however, to make a difference to the emotional experiences of these caregivers in quite simple and straightforward ways. The participants spoke of how important it was for their sense of wellbeing to be listened to – simply *listened to*.

Two types of intervention have been used for parents of hospitalised children that have been found to ameliorate some of the negative emotional effects of the caregiving experience. One approach is to help parents with understanding their role in the hospital setting in partnering with medical practitioners in caring for their child. This may be done by supplying easily accessible information, creating an environment of inclusiveness about decisions involving their child's care, valuing parent's expertise, and distributing materials that encourage parent-child interaction. In these programmes parents are also taught how to facilitate their child's adjustment to ongoing illness, and what behavioural changes to expect from their child and how to manage them (Melnyk, 1994; Melnyk, Alpert-Gillis, Hensel, Cable-Beiling & Rubenstein, 1997; Melnyk,

Feinstein & Fairbanks, 2006). The need for these types of interventions was strongly supported by data in this study.

The second strategy aims to facilitate supportive relationships between parents suffering similar circumstances, through the establishment of therapeutic support groups (Phillips, 1990). Supporting the appropriateness of this type of intervention, one mother in the study commented as follows:

Participant 7: And I think it will be better ... if we had some support groups. I think to sit with other mothers and talk...(laughs) and think that will be better ... but ur I don't think it will happen ...but I think I have to start with that and ask the other mothers. I think it will give ur us courage to courage to press on and go on and be encouraged and never lose hope.



Such moving accounts emphasise the need for emotional support and validation experienced by people facing the struggles of providing care to a chronically ill child. Exactly how to do this, and whether enough caregivers of children at the hospital are interested in such supportive services, will require further exploration.

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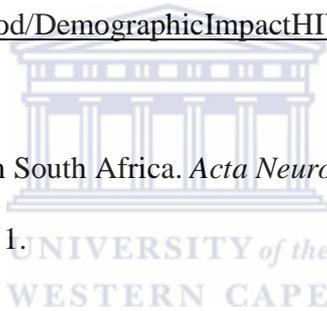
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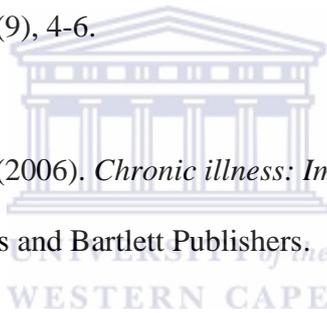
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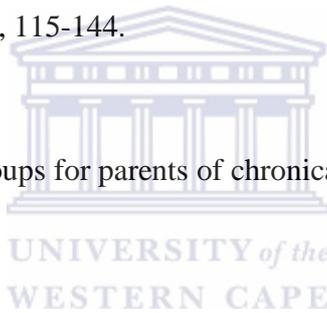
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## APPENDIXES

### APPENDIX A



## UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

*Cell: xxxxxxxx Fax: 27 21-959-3515*

**E-mail:** rachael.sheriffs@gmail.com



### INFORMATION SHEET

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**Project Title:** Exploring the experiences of caregivers with a child receiving hospital treatment for a chronic illness.

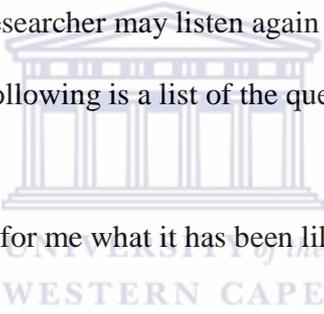
#### **What is this study about?**

This is a research project being conducted by Rachael Sheriffs at the University of the Western Cape. We are inviting you to participate in this research project because you are the caregiver or parent of a child who is currently receiving treatment for a chronic illness at the Red Cross Children's Hospital. The purpose of this research project is to find out what the experience of having a child with a chronic health problem is like for caregivers / parents. This information may be communicated to hospital management so that they

may know how to best support caregivers / parents caring for a child in the hospital setting in the future.

**What will I be asked to do if I agree to participate?**

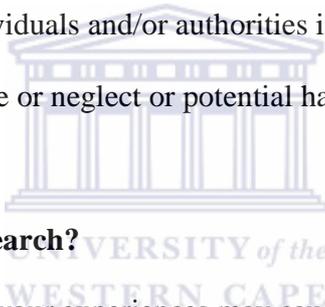
You will be asked to share your experiences of having a child with a chronic illness, and the way it may affect you in different areas of your life. This requires that you are comfortable to talk openly about experiences that may be of a personal nature. If you agree to participate then an interview will be arranged and will be conducted in a private room at the hospital. The interview will last for about half an hour. The interview will be recorded onto tape so that the researcher may listen again to what has been said and transcribe it into written text. Following is a list of the questions that will be asked:

- 
1. Please can you describe for me what it has been like for you to come to hospital with your child?
  2. How has your child's illness affected you personally?
  3. How has your child's illness affected your family life?
  4. How has your child's illness affected your social life and friendships?
  5. How has your child's illness affected your work or occupational life?
  6. How has your child's illness affected your role as a parent/guardian?
  7. What are your expectations for the future?
  8. Is there anything else you would like to speak about in connection to the experience of having your child in hospital?

**Would my participation in this study be kept confidential?**

Your personal information will be kept confidential. To help protect your confidentiality, your name will not be used in the research project. The recordings of the interview and the written transcripts will be kept in a locked filing cabinet, and destroyed at the end of the research project. The researcher and supervisors will be the only people with access to the recordings or the transcripts. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will have to disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others.



**What are the risks of this research?**

It is possible that talking about your experiences may cause you to feel emotional as caring for a child with a chronic illness can be stressful for parents / caregivers. The researcher is trained in counselling skills and will do her best to offer a supportive and respectful space in which you can speak about your experiences. If you feel upset after the interview the researcher will put you in touch with a counselling service that will be able to offer you help to deal with any emotions that may come up.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about what it is like for caregivers / parents to have a child who

needs hospital care for a chronic illness. We hope that, in the future, other people might benefit from this study through improved understanding of parents' needs for support in the hospital setting.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify, neither will your child's care in the hospital be compromised in any way.

**Is any assistance available if I am negatively affected by participating in this study?**

As mentioned above you will be referred to a counselling service should talking about your experiences be distressing for you.

**What should I do if I want to take part in the research?**

If you would like to be a part of this research study then please indicate so to the researcher when she next comes to the ward, and give her your cell phone number so she may set up a time with you for the interview to take place. Otherwise let the nursing staff know that you would like to take part, and they will communicate this to the researcher.

**What if I have questions?**

This research is being conducted by *Rachael Sheriffs, Department of Psychology*, at the University of the Western Cape. If you have any questions about the research study itself, please contact Rachael Sheriffs at: Department of Psychology, University of the Western Cape, Private Bag X17, Bellville, 7535. Tel: 084-671-9343 or via email on [rachael.sheriffs@gmail.com](mailto:rachael.sheriffs@gmail.com).

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Prof. K. Mwaba, or

Dean of the Faculty of Community and Health Sciences: Prof. R Mpofu

University of the Western Cape  
Private Bag X17

Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.



**CONSENT FORM**

**Title of Study: Exploring the experiences of caregivers with a child receiving hospital treatment for a chronic illness.**

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I understand that the findings of the research may be shared with other researchers and hospital management, but that my identity will not be disclosed in the research report.

I agree to be audiotaped during my participation in this study.

I do not agree to be audiotaped during my participation in this study.

I understand that in accordance with legal requirements and/or professional standards, any information that I may share concerning child abuse or neglect or potential harm to myself or others must be disclosed to the appropriate individuals and/or authorities.

**Participant's name**.....

**Participant's signature**.....

**Date**.....

**Witness Name**\_\_\_\_\_

**Witness Signature**\_\_\_\_\_

**Date**\_\_\_\_\_

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

**Study Coordinator's Name: Rachael Sheriffs**

**Department of Psychology**

**University of the Western Cape**

**Private Bag X17, Belville 7535**

**Telephone: 021-959-2453**

**Cell: xxxxxxxxxxxxxx**

**Email: [rachael.sheriffs@gmail.com](mailto:rachael.sheriffs@gmail.com)**



Participant	1	2	3	4	5	6	7	8	9
Caregiver's race	Coloured	White	Coloured	Coloured	Coloured	Coloured	Black	Coloured	Indian
Caregiver's first language	Afrikaans	Afrikaans	English	English	English	English	Zulu	Afrikaans	English
Home town	Mitchell's Plain	Somerset West	Steenberg	Mitchell's Plain	Woodstock	Mitchell's Plain	Durban	Cape Town	Cape Town
Child's age	14 months	4 years	11 years	10 years	8 years	12 years	4 years	7 years	22 months
Child's gender	Male	Female	Male	Male	Male	Female	Female	Female	Female
Child's diagnosis	Biliary arteria; liver disease; transplant (30/06/09)	Cerebral Palsy; Kidney failure; previously pneumonia, dehydration, a fit.	Asthma	Asthma and allergies (peanut)	Asthma	Guillian Barre Syndrome	Biliary artesia; liver disease; transplant (18/07/09); previously TB, internal bleeding, infections.	Asthma and hayfever	Eczema
Date of diagnosis	10/03/09	7/10/09 (kidney failure)	2000	1999 (at birth)	2002	20/02/2009	09/05	2004	11/03/08 (2 months old)
Date of first hospital admission	9/03/09	7/10/09	2002	1999 (5 months old); 2001 (2 years for a week).	2002 (1 night)	20/02/2009	09/05 (1 month old)	2004 (2 years old); +/- 2006 (4 years old)	10/09/09 (1 night)
Length of current hospital stay / outpatient visits	6 months	3 weeks	Outpatient visits every 1 to 3 months	Outpatient visits every 3 months	Outpatient visits every 3 months	2 months Red Cross; 7 months St. Josephs (current)	Avg of 3 x per year (3 days to 1 week); Outpatient visits monthly	Outpatient visits every 3 months	Outpatient visits monthly

## APPENDIX C: Biographical details of participants



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