

**RESILIENCE IN FAMILIES LIVING WITH A CHILD DIAGNOSED WITH
CEREBRAL PALSY**

by

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DECLARATION

I, *Renée Frances Small* (*Student Number: 201301377*), hereby declare that this treatise submitted in partial fulfilment of the requirements for the degree of *Magister Artium in Clinical Psychology* is my own work and that it has not previously been submitted for assessment to another University or for another qualification.

Signature

Date

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ABSTRACT

Cerebral Palsy is a complex, non-progressive condition that manifests in various forms of motor impairments. This life-long condition holds numerous challenges for the entire family throughout the family life-cycle. While the challenges that these families have to face are many, families seem to have the ability to ‘bounce back’ and to be resilient. Research on the construct of resilience and more specifically family resilience has increased in recent times. South African family resilience research is relatively limited. This study aimed to identify, explore and describe the resiliency factors that facilitate adjustment and adaptation in families that include a child living with Cerebral Palsy. The Resiliency Model of Family Stress, Adjustment and Adaptation was used to conceptualise the level of family adaptation. The study was triangular in nature, with an exploratory, descriptive approach. Non-probability purposive and snowball sampling techniques were employed. The sample consisted of 30 female caregivers. Biographical questionnaires with two open-ended questions, in conjunction with seven structured questionnaires were used to gather the data. Descriptive statistics were used to analyse the biographical information. Correlation and regression analysis was used to analyse the quantitative data, while content analysis was used to analyse the qualitative data. The results of the quantitative component of the study indicated five significant positive correlations with the FACI8. These variables were family hardiness (measured by the FHI), family time together and routines (measured by the FTRI), social support (measured by the SSI), relative and friends support (measured by the RFS), and spiritual support (measured by the F-COPES). The results of the qualitative analysis revealed that social support, the caregivers’ acceptance of the condition, and spirituality and religion were the most important strength factors that contributed to the families’ adjustment and adaptation. Although the sample was small and the study has

limitations, it could be used as a stepping-stone for future research on resilience in families living with a child with a physical disability and will contribute to the broader context of family resilience research in South Africa.

Key words: Cerebral Palsy; family resilience; coping; adjustment; adaptability; Resiliency
Model of Family Stress, Adjustment and Adaptation.

CHAPTER ONE

INTRODUCTION: BACKGROUND AND MOTIVATION FOR THE STUDY

1.1 INTRODUCTION

Chapter One provides an introduction to the paradigm within which the study was conducted. An overview of the research on family resilience and families living with a child diagnosed with Cerebral Palsy is provided. The context of the research is described and the motivation for the study is outlined following which, the aim of the study is presented. The chapter is concluded with an explanation of the chapters to follow.

1.2 CONTEXT OF THE RESEARCH

The following section focuses on the context of the research looking at literature on resilience particularly with regard to families living with a child diagnosed with Cerebral Palsy. The present study aimed to identify strengths which contribute to growth and promotion of the family system. A motivation is thus provided using the strengths-based perspective of resilience. A brief description of Cerebral Palsy and associated difficulties is first provided.

1.2.1 Cerebral Palsy

Cerebral Palsy is a complex condition, characterised by varying degrees of disturbance of voluntary movement caused by damage to the brain (Capute, 1975). A recent definition of Cerebral Palsy describes this condition as "... a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain" (O'Shea, 2008,

p. 36). The manifestation of the disorder varies tremendously, with some children only lightly affected, while other children are more seriously affected and disabled. The degrees of functional impairment range from immobility and complete dependency on others, to functional abilities of talking, self-care, walking, running and other skills, although with some clumsiness (Levitt, 2010), which may cause a variety of challenges for children and their families. It stands to reason then, that all family members are affected when families have a member with special needs (Fewell, 1986). The families that provide the lifetime care for the child with Cerebral Palsy are no different and they, too, face unique stressors and demands (Cowan, 1991). In addition to this, their ability to adjust to such long-term disabilities may be exhausted over time as changes occur in their family circumstances (Cleveland, 1989).

It is essential, therefore, that when families are faced with challenges of this nature, they are able to tap into and mobilise resources that will aid them in adapting to the situation. A small number of studies have explored the stress responses of, and coping strategies in, these families (Germishuys, 1992; Mweshi, 1999; Pugin, 2007; Selkon, 2007), but few studies to date have explained, using an explicit conceptual framework, how family coping behaviours and processes might contribute to adaptation in the families living with a child with Cerebral Palsy. Consequently, it was important to gain an understanding of the resiliency processes in families living with a child diagnosed with Cerebral Palsy and to identify the factors that are essential for their recovery when faced with the prolonged stress associated with the diagnosis. The following section outlines the paradigm and key concept that underpins this study.

1.2.2 Positive Psychology and Resilience

In recent times the human sciences have experienced a noticeable shift in thinking from pathogenesis to salutogenesis, where the focus has changed from dysfunction and illness to strengths and health (Antonovsky, 1987). This change from a deficit-based approach to a strengths-based approach is referred to as ‘positive psychology’ (Compton, 2005; Seligman, 1998). An important concept found in positive psychology that has received much attention during the past two decades is that of resilience (Walsh, 2003a).

Resilience refers to “the ability to withstand and rebound from adversity” (Walsh, 2002, p. 130). It refers to a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar, Cicchetti, & Becker, 2000). Initially, the resilience theory focused primarily on the individual (Walsh, 2003b). Resilience is often discussed in terms of risk and protective factors i.e., those factors that seem to help shape the individual’s ability to endure in the face of adversity (Rutter, 1987). They operate over time and may have a direct or indirect influence on processes and interpersonal reactions within the family (Hawley & De Haan, 1996; Rutter, 1985). Initially, resilience was seen as an innate characteristic of individuals, and families were viewed as contributing to risk, but not to resilience. However, during the past two decades, the concept of resilience has been extended to the family system where families in crisis situations are seen as being challenged rather than damaged, and as successful as opposed to deficient (Hawley & De Haan, 1996; Walsh, 1996; 2003c).

This paradigm shift has led to the development of the term *family resilience* which is defined as “characteristics, dimensions, and properties of families which help them to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (McCubbin & McCubbin, 1988, p. 247). This approach fundamentally altered the perception of viewing

troubled families as damaged and beyond repair, to seeing them as challenged by life's adversities with potential for fostering healing and growth in all members (Patterson, 2002b). This perspective enables one to focus on factors which aid survival and success instead of focusing on what contributes to failure. Highlighting family strengths shifts our attention away from intervention programmes and more towards proactive prevention programmes (Walsh, 1996).

Walsh (2003a) was of the opinion that serious crises and persistent adversity impacts the whole family. By encouraging key processes for resilience, families are empowered to potentially emerge stronger and more resourceful through their shared efforts in meeting challenges (Walsh, 2002). A crisis can become an opportunity for reappraisal of priorities, stimulating greater investment in meaningful relationships and life pursuits (Walsh, 2003a), allowing the family to bounce back from a family crisis situation more easily (McCubbin, McCubbin, Thompson, Han, & Allen, 1997).

1.2.3 Families Living with a Child diagnosed with Cerebral Palsy

When parents learn that their child has been diagnosed with a lifelong condition such as Cerebral Palsy, their reactions to the news may vary tremendously (Raina et al., 2004). Common reactions include shock, denial, suffering and depression (Vijesh & Sukumaran, 2007). Most families generally feel unprepared to cope with the news of the diagnosis (Phelps, Hopkins, & Cousins, 1958). While some parents of children with disabilities may experience the situation as not very stressful, others may experience greater difficulty (McCubbin & McCubbin, 1992) as the realisation hits them that this condition will pose many challenges for the family as a unit and

that these challenges will change continually as the child moves through the various developmental stages and the family resources also, inevitably change (Hirose & Ueda, 1990).

It goes without saying that all of the family members would, more than likely, need to make certain sacrifices as a result of the child's disability and that living with the stress of having a child with a disability can potentially unbalance the functioning of the family system (Walsh, 2003a), which has a ripple effect on all the family members. This, in turn, affects the relationships within the family, the family's economic situation (Vijesh & Sukumaran, 2007), daily lifestyle, and plans and expectations for the future (Sen & Yurtsever, 2007).

It is therefore important to understand the resiliency processes in families living with a child diagnosed with Cerebral Palsy and to identify the factors that are essential for their recovery when faced with the prolonged stress. A family's ability to make changes in their roles, rules and relational patterns in the attempt to adjust and adapt to the unique needs of a child diagnosed with Cerebral Palsy would be evidence of resilience (Patterson, 2002a). The protective factors that are identified in assisting these families in the process of adaptation will be useful in guiding future intervention and prevention programmes in similar families.

1.3 PRIMARY AIM OF THE RESEARCH

The primary aim of the present study was to identify, explore and describe the resilience factors that facilitate adjustment and adaptation in a family living with a child diagnosed with Cerebral Palsy.

1.4 DELINEATION OF CHAPTERS

Chapter One provides an introduction to the present study. In this chapter the context of the research, the motivation for the study and the aim of the study are outlined.

Chapter Two presents the development of both individual and family resilience and describes the evolution of family resilience research. A detailed explanation is then given of the conceptual model that was used in this study, namely, the Resiliency Model of Family Stress, Adjustment and Adaptation.

Chapter Three presents the history, characteristics, prevalence and aetiology of Cerebral Palsy. A description of the different types of Cerebral Palsy is provided, as well as common problems that are related to the disorder. Typical treatment and management of Cerebral Palsy is described followed by an overview of the impact of Cerebral Palsy on the family.

Chapter Four describes the research design and methodology that was employed in this study. The research design, sampling procedure, the measures used together with the data analysis employed are discussed. The ethical considerations are highlighted.

Chapter Five provides a discussion of the results obtained from the data analysis. The results are interpreted in terms of the literature presented in Chapters Two and Three.

Chapter Six describes the conclusions of the study, which are based on the research results. The limitations are discussed and recommendations for future research in this field are made.

1.5 CONCLUSION

A brief outline of the current study was provided in this chapter. The impact of Cerebral Palsy on both the child and family was discussed, as well as the need for resilience in the family in an attempt to adjust and adapt to the crisis faced. The motivation for the study was briefly

outlined and the aim of the current study was introduced. Chapter One concluded with a delineation of the current research. Chapter Two provides an overview of the concept of resilience, looking specifically at the family resilience framework used as the conceptual basis in this study.

CHAPTER TWO

RESILIENCE

2.1 INTRODUCTION

During the first half of the twentieth century, health and social disciplines were characterised by a pathogenic paradigm. However, since the 1970s, the focus has shifted from treatment of an existing illness, towards illness prevention and health enhancement (Kiser & Black, 2005; Patterson, 2002a; Strümpfer, 1999). One of the driving forces of this field was Antonovsky, who coined the term ‘salutogenesis’, literally meaning “the origins (*genesis*) of health (*saluto*)” (Antonovsky, 1979). The concept of salutogenesis creates a multidimensional continuum that runs between two extreme poles – absolute health and absolute illness. This approach allows one to identify the factors pushing a person to one end of the continuum or the other (Antonovsky, 1979). This change from a deficit-based approach to a strengths-based approach is referred to as ‘positive psychology’, a term coined by Martin Seligman in 1998 (Compton, 2005; Seligman, 1998). The study of family resilience, therefore, adopts a salutogenic approach in acknowledging that families possess the inherent capabilities to deal with most major crises, and crises provide an opportunity for families to grow closer and to change in constructive ways (Marsh & Lefley, 1996). It is a strengths-based approach in that it encompasses ideas such as vitality and the promotion of health in aiding the prevention of disease (Antonovsky, 1979).

This chapter provides a brief overview of the history of the concept of resilience and more specifically, of family resilience. After illustrating the concept of family resilience using the Resiliency Model of Family Stress, Adjustment and Adaptation, research regarding protective

factors that enhance resilience is presented. Finally, the applicability of the Resiliency Model to families living with a child diagnosed with Cerebral Palsy is highlighted.

2.2 RESILIENCE AS A CONSTRUCT

Historically, society has focused on the roots of disease, deficits, and behavioural problems. In the past, most of the literature focused on the negative impact or outcomes for families who were faced with challenges (Nichols & Schwartz, 2001; Walsh, 2003b). In recent times, however, researchers have questioned how some people are able to stay healthy and do well in the face of risk and adversity while others do not (Patterson, 2002a; Zimmerman & Arunkumar, 1994). A construct that focuses on strengths during adversity is resilience. Resilience, the ability to withstand and rebound from disruptive life challenges, has become an important concept in mental health theory and research over the past two decades (Walsh, 2003a). It refers to a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar et al., 2000). Resilience is described in the literature in numerous ways. Rutter (1987) referred to it as “individual variation in response to risk” (p. 317), Werner (1993) described it as “successful adaptation following exposure to stressful life events” (p. 72), and Garmezy (1993) stated that it is “functioning following adversity” (p.129).

These definitions encompass a number of common ideas. Firstly, resilience appears to surface in the face of family difficulties or hardships (McCubbin & McCubbin, 2001; Walsh 2003c). Secondly, inherent in resilience is the element of buoyancy. This assumes that individuals exhibiting resilience are able to ‘bounce back’ or ‘rebound’ from adversity, reaching or even surpassing a pre-crisis level of functioning (Hawley & De Haan, 1996). Finally, resilience is viewed in terms of competence rather than pathology. The study of resiliency aims

at identifying those factors that contribute to healthy family functioning as opposed to searching for deficits or pathology in families (Hawley & De Haan, 1996; McCubbin & McCubbin, 2001; Seligman, 1998). Initially, the resilience theory focused primarily on the individual (Walsh, 2003b). Resilience was seen as an innate characteristic of individuals, and families were viewed as contributing to risk but not to resilience. However, during the past two decades, the concept of resilience has been extended to include family resilience (Walsh 2003c).

2.3 HISTORICAL OVERVIEW OF THE CONCEPT OF RESILIENCE

Most research to date has focused on individual resilience (Walsh, 2003a). The term resilience emerged from a longitudinal study conducted by Emmy Werner and Ruth Smith starting in the 1950s (Johnson & Wiechelt, 2004; Richardson, 2002; Walsh, 2003a). These studies aimed to identify resources in children who revealed no obvious signs of damage, regardless of having been exposed to stressors that were known to exercise a negative impact on them (Garmezy, 1993; Masten & Coatsworth, 1998; Walsh, 1996). The term used to refer to these children was ‘invulnerability’ (Walsh, 1996). The term invulnerable, however, implies an inability to be wounded or harmed, an assumption that researchers found to be incorrect. The word resilience was chosen as a more appropriate term to describe these individuals.

Following Werner’s groundbreaking studies on children in Hawaii (Werner, Bierman, & French, 1971; Werner & Smith, 1977), research on resilience expanded to include multiple adverse conditions such as socioeconomic disadvantage and associated risks (Garmezy, 1991; Rutter, 1979; Werner & Smith, 1982; 1992), parental mental illness (Masten & Coatsworth, 1998), maltreatment (Beeghly & Cicchetti, 1994; Cicchetti & Rogosch, 1997; Cicchetti, Rogosch, Lynch, & Holt, 1993; Moran & Eckenrode, 1992), urban poverty and community

violence (Luthar, 1999; Richters & Martinez, 1993), chronic illness (Wells & Schwebel, 1987), and catastrophic life events (O'Dougherty-Wright, Masten, Northwood, & Hubbard, 1997). In the 1980's, increasing evidence was found that the same adversity may result in different outcomes, which challenged the prevailing deterministic assumption that traumatic experiences, especially in childhood, are inevitably damaging. In surveying these findings, Rutter (1987) noted that no combination of risk factors, regardless of severity, gave rise to disorder in more than half the children exposed. Although many lives were affected by the adverse conditions, others overcame similar high risk conditions and were able to lead loving and productive lives and parents were able to raise their children optimally. To account for these discrepancies, early studies (Luthar & Ziegler, 1991) focused on personal traits for resilience, or hardiness, reflecting the dominant cultural ethos of the "rugged individual" (Walsh, 1996, p. 262). As work in the area evolved, researchers increasingly acknowledged that resilience may often derive from factors external to the child. Researchers moved toward recognition of an interaction between nature and nurture in the emergence of resilience.

Resilience is often discussed in terms of risk and protective factors. The factors that seem to shape the individual's ability to endure in the face of adversity are referred to as protective factors and risk factors (Rutter, 1987), for example, parental divorce, poverty and physical or mental illness, operating over time and directly and indirectly influencing processes and interpersonal reactions (Hawley & De Haan, 1996; Rutter, 1985). Hawley (2000) suggested that certain risk factors increase the likelihood of barriers to effective functioning arising for an individual, either in childhood or throughout the lifespan. The family is sometimes viewed as a risk factor which resilient individuals have to overcome (Hawley, 2000). Resilience factors are made up of two categories, namely protective factors and recovery factors. Protective factors are

resources that buffer individuals from a stressor (Hawley, 2000; Hawley & De Haan, 1996; Rutter, 1985) and recovery factors on the other hand, are factors that help a person to restore effective functioning after a crisis period (McCubbin, Thompson, & McCubbin, 2001). There are three recurrent themes in the literature regarding resilience factors: those in the individual, those in the family and those in the community (Garmezy, 1993; Lam et al., 1999; Marsh & Lefley, 1996; Masten & Coatsworth, 1998; Mederer, 1999). Werner described four main protective factors prevalent in resilient adults: to have developed at least one personal, healthy relationship within infancy and childhood; to be responsive, affectionate and good-natured as an infant and child; to have had friends during their school years and to participate in various school events and youth groups; and to have good language and reasoning skills in relation to their peers during their school years (Johnson & Weichelt, 2004). British psychiatrist, Michael Rutter, conducted various studies on inner-city London youth and echoed Werner's work. This researcher contributed to the list of protective factors and included attributes such as self-efficacy, self-mastery, and planning skills (Rutter, 1985). In 1984, Norman Garmezy and colleagues conducted the Minnesota Risk Research Project. Garmezy (1984) identified three common categories of protective factors for resilient children. These include an easy temperament, a supportive family environment and a strong external support system. Wolin and Wolin (1993) have identified seven protective characteristics namely insight, independence, relationships, initiative, humour, creativity, and morality. In general, resilience is most likely to be found when risk factors are minimised and protective factors are present.

During the last two decades, the focus of empirical work also shifted away from identifying protective factors to understanding underlying protective processes that may contribute to positive outcomes (Luthar et al., 2000). Resilience came to be viewed as an interplay of multiple

risk and protective processes over time, involving individual, family and larger sociocultural influences (Garmezy, 1991; Masten, Best, & Garmezy, 1990; Patterson, 2002b; Rutter, 1987). Systems-based researchers and family therapists also made the shift towards a focus on identifying and enhancing family competencies and strengths, thereby facilitating a clearer understanding of the key processes of healthy family functioning (Walsh, 2003c). This paradigm shift has led to the development of the term family resilience, defined by McCubbin and McCubbin (1988) as “characteristics, dimensions, and properties of families which help them to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (p. 247). As with resilience in the individual, multiple descriptions of family resilience exist in the family literature. McCubbin et al. (1997) defined family resilience as “the property of the family system that enables it to maintain its established patterns of functioning after being challenged and confronted by risk factors” (p. 2). As a family level construct, resilience is conceptualised as a dynamic, relational process that develops over time, as opposed to a fixed set of attributes of temperament, personality and intellect in its individuals (Hawley, 2000; Hawley & De Haan, 1996; Kiser & Black, 2005; Lee et al., 2003; McCubbin et al., 2001; Robinson, 2000; Walsh, 1996; 2003b). As Rutter stated (1985), “Resilience resides primarily in how people deal with life changes and what they do about their situations as opposed to the buffering effect of some supportive factor operating at one point in time” (p. 608). A more recent definition of family resilience is offered by McCubbin et al. (2001, p. 5) and refers to:

The positive behavioural patterns and functional competence individuals and family members demonstrate under stressful or adverse circumstances, which determine the family’s ability to recover by maintaining its integrity as a unit

while insuring, and where necessary, restoring the well-being of family members and the family unit as a whole.

This approach fundamentally altered the deficit-based lens from viewing troubled parents and families as damaged and beyond repair, to seeing them as challenged by life's adversities with potential for fostering healing and growth in all members (Patterson, 2002b). A basic premise in this systematic view is that serious crises and persistent adversity have an impact on the whole family (Walsh, 2003a). Family resilience goes beyond merely surviving a crisis and encompasses the potential for growth that may well be borne of adversity (Boss, 2001). By encouraging key processes for resilience, families can emerge stronger and more resourceful through their shared efforts in meeting future challenges (Walsh, 2002). A crisis can become an opportunity for reappraisal of priorities, stimulating greater investment in meaningful relationships and life pursuits (Walsh, 2003a). Family protective factors, in combination with family recovery factors, facilitate the family's ability to bounce back from a family crisis situation (McCubbin et al., 1997). Through years of research, some general resilience factors (protective and recovery) that are associated with both adjustment and adaptation in the family system have been identified (McCubbin et al., 1997). Walsh (1998b; 2003a) identified three key family processes in resilience: 1) a positive belief system, 2) the family's organisational processes and 3) the family's communication processes.

An affirming belief system provides the family with a shared set of guidelines to behaviour based on shared morals, values and a bigger purpose. To develop a sense of coherence or togetherness, the family needs to be able to normalise and contextualise their experience and to construct meaning from it (Walsh, 2003a). The following resilience factors facilitate adaptation: affirming belief systems (Walsh, 1996); unifying values and beliefs (Cohen, Slonim, Finzi, &

Leichtentritt, 2002; Walsh & Pryce, 2003); a shared, positive perception of their family unit (Hawley, 2000; Lee et al., 2003); and hope, optimism, humour, trust and a sense of security (Cohen et al., 2002; Lee et al., 2003).

Resilience factors in the organisational patterns in the family unit refer to features of the family unit itself, and family processes that facilitate coping and adaptation. Resilient families are more likely to be characterised as coherent, meaning that they are able to reframe a crisis as a challenge that is comprehensible, meaningful and manageable and that they generally believe that adverse circumstances will eventually result in a favourable outcome (Lee et al., 2003). A related concept found in resilient families is a sense of cohesion characterised by mutual support, collaboration and commitment (Cohen et al., 2002; Garmezy, 1993; Marsh & Lefley, 1996; Masten & Coatsworth, 1998; Walsh, 2003a). Resilient families are committed to a shared goal (Daly, 1999) and have a strong collective sense of 'we', as opposed to an individualistic sense of 'I' that normally dominates Western culture (Lee et al., 2003; Walsh, 2003a).

Other resilience factors found in the family unit include mutual understanding and attachment among family members (Cohen et al., 2002; Hall, 2004; Lee et al., 2003); a climate of mutual trust, empathy and tolerance for individual differences (Cohen et al., 2002; Walsh, 2003a) and possessing and maintaining rituals in the family (Barnard, 1994). Flexibility is also a key element to family resilience and involves the system's ability to appropriately shift roles as needed (Cohen et al., 2002; Hall, 2004; Lee et al., 2003; Walsh, 2003a). Organisation patterns include commitment and collaboration and the ability to mobilise resources, delegate tasks and share responsibility (McCubbin et al., 2001).

Communication is the basis of many family processes. Families adapt better to crises when there is clear, congruent, open communication and emotional expression among family members,

together with the freedom and safety to express both positive and negative emotions (Walsh, 2003a). This enables constructive conflict resolution, collaborative problem-solving and effective, joint decision making (Cohen et al., 2002; Lee et al., 2003; McCubbin et al., 1997; Walsh, 1996). Lam et al. (1999) specifically cited good communication between parents. These three processes largely predict how the family will be able to recover from misfortune (Walsh, 1998b; 2003a).

Research consistently supports the notion that social support is a resilience factor in that it encourages and reinforces coping efforts. This includes support from extended family, friends, neighbours, community groups, faith congregations and colleagues (Cohen et al., 2002; Garmezy, 1993; Hall, 2004; Lam et al., 1999; Marsh & Lefley, 1996; Masten & Coatsworth, 1998; Walsh, 1996). However, Rutter (1985) cautioned that it is not sufficient to simply have a large social support system. It is not the extent or frequency of social contacts that matters, but rather individuals' satisfaction with their relationships.

Religion and spirituality have been identified as resiliency factors on both individual and family levels (Beavers & Hampson, 2003; Cohen et al., 2002; Hawley, 2000; Kiser & Black, 2005; Marsh & Lefley, 1996; Thompson, 1999; Walsh & Pryce, 2003). Walsh and Pryce (2003) defined religion as "an organised belief system that includes shared, and usually institutionalised, moral values, beliefs about God or a Higher Power, and involvement in a faith community" (p. 339). Spirituality, on the other hand, is a broader term encompassing transcendent beliefs and practices which may be experienced within or outside of an organised religion. Involvement in a faith community has a number of advantages including health and social benefits and support during difficult times (Walsh & Pryce, 2003).

This section has provided an overview of the development of the construct of resilience, looking specifically at individual and family resilience. Furthermore, general resilience factors that have been identified thus far through research were outlined. The following section focuses on family resilience research within the context of South Africa.

2.4 RESILIENCE RESEARCH IN THE SOUTH AFRICAN CONTEXT

While the concept of resilience has been studied to a great extent on an individual level, looking at resilience on the family level has only recently gained momentum. In South Africa, various studies were conducted on individual resilience by Strümpfer (1993; 2005), a researcher from the University of Cape Town, and Wissing (1996), from the University of Potchefstroom. However, as interest in the field of salutogenesis and positive psychology developed, more researchers turned to investigating resilience from the perspectives of families who were faced with adverse circumstances (Greeff, 2004).

Greeff (2004), from the University of Stellenbosch, made significant contributions to South African research publications on the topic of family resilience. Some of the vulnerable family populations that were investigated included poor single parent families (Solomons & Greeff, 2001); families in which a parent accepted a voluntary retrenchment package (Der Kinderen & Greeff, 2003); families in which a parent had died (Greeff & Human, 2004); divorced families (Greeff & Van der Merwe, 2004); single-parent families (Greeff & Aspeling, 2004; Greeff & Ritman, 2005); and resilience in families with an autistic child (Van der Walt & Greeff, 2006). In addition, Redinger (2005) looked at family resilience in response to extra-familial child sexual abuse.

The most recent research undertaken at the Nelson Mandela Metropolitan University has focused on the resiliency factors of families with a child that has autism (Hanekom & Brown-Baatjies, 2006); families with a Type 1 diabetic child (Coetzee, Brown-Baatjies, & Fouché, 2006); family resilience in step-families (Robinson & Brown-Baatjies, 2006); families where a member had been diagnosed with schizophrenia (Haddad, Brown-Baatjies, & Howcroft, 2007); families with a child with attention deficit hyperactivity disorder (Theron, Howcroft, & Brown-Baatjies, 2008); and families where a parent misuses alcohol (Fisher, Brown, & Howcroft, 2009).

The results from the South African family resilience studies conducted on families in a variety of socio-economic, cultural and crisis contexts were found to be similar to those of international studies and indicate that social, emotional and practical support from extended family and friends (Greeff & Human, 2004; Greeff & Van der Merwe, 2004) contributes greatly to the family's resilience. The researchers also found that the family's hardiness plays a considerable role in its adaptation to crises (Coetzee et al., 2006; Robinson & Brown-Baatjies, 2006; Greeff & Human, 2004; Greeff & Van der Merwe, 2004; Haddad et al., 2007; Theron et al., 2008). Hardiness can be described as a family's internal strengths, their ability to work together and to depend on each other (McCubbin et al., 1986). The importance of the support and utilisation of members of the immediate family, the extended family and friends was also highlighted (Greeff & Human, 2004; Greeff & Van der Merwe, 2004; Haddad et al., 2007; Theron et al., 2008). The following resilience factors were commonly identified: communication (Coetzee et al., 2006; Robinson & Brown-Baatjies, 2006; Greeff & der Kinderen, 2003; Greeff & Human, 2004; Greeff & Le Roux, 1999; Haddad et al., 2007; Holtzkamp, 2004; Theron et al., 2008), social support (Coetzee et al., 2006; Greeff & der Kinderen, 2003; Greeff & Human, 2004; Holtzkamp, 2004; Theron et al., 2008), intrafamilial emotional and practical support (Greeff & Human, 2004; Holtzkamp, 2004),

family time spent together (Coetzee et al., 2006; Robinson & Brown-Baatjies, 2006; Greeff & Le Roux, 1999; Haddad et al., 2007; Theron et al., 2008), religion and spiritual support (Coetzee et al., 2006; Greeff & der Kinderen, 2003; Greeff & Le Roux, 1999; Holtzkamp, 2004), coherence and the family's internal strengths, ability to work together and to depend on each other (Greeff & Human, 2004) and individual characteristics of family members (Greeff & der Kinderen, 2003; Holtzkamp, 2004). In a qualitative study, Greeff and Ritman (2005) found that the specific individual characteristics of resilience reported as contributing to family resilience were optimism, perseverance, religion and spirituality, expression of emotion and self-confidence.

Overall, it is apparent that even though South African research on family resilience is limited, the interest in the field is growing and contributing to the existing knowledge of family life in South Africa. From the available South African studies, it has been concluded that South African families do have the capacity to preserve family stability and harmony and have the capacity to restore the family's functioning following crises. The following section considers the advantages of using a Family Resilience Framework when assessing and intervening with vulnerable families who face a potential crisis.

2.5 ADVANTAGES OF A FAMILY RESILIENCE FRAMEWORK

A family resilience framework focuses on strengths, acknowledging the uniqueness of each family and viewing processes for optimal functioning as varying across the life cycle requiring collaborative effort from the whole family to overcome crises (Walsh, 2002; 2003a). Assessment and intervention are redirected from how problems were caused to how they can be resolved, identifying and amplifying existing and potential competencies (Walsh, 2003a). A family resilience framework can serve as a valuable conceptual map to guide prevention and

intervention efforts to support and strengthen vulnerable families in crisis. This framework recognises the potential for personal and relational transformation and growth that can be forged out of adversity.

A resilience framework is timely in helping families to manage unprecedented challenges as they, and the environment around them, change at an accelerated pace (Walsh, 2002). Although no single model of family health fits all, a family resilience-based approach to practice stems from a strong conviction that families have the potential to recover and grow from adversity (Walsh, 2002). A family resilience framework can be applied with a wide range of crisis situations and persistent life challenges. Interventions use principles and techniques common amongst many strength-based approaches, but attend more centrally to links between presenting symptoms and significant family stressors, identifying and fortifying key processes in coping and adaptation (DeFrain, 1999). The family resilience framework selected for the purpose of this study is the Resiliency Model of Family Stress, Adjustment and Adaptation (hereafter referred to as the Resiliency Model). This model was used to conceptualise the families' resilience since it represents the most recent development in the field of family resilience frameworks (McCubbin & McCubbin, 2001). The Resiliency Model is discussed in the following section.

2.6 CONCEPTUAL FRAMEWORK

McCubbin and McCubbin (2001) made a significant contribution to the development of a model of family resilience. McCubbin et al. (2001) developed a cyclical model of family resilience which aims to explain why, when faced with similar circumstances, certain families adapt and cope with crises and can be referred to as resilient, whilst other families deteriorate. This model – the Resiliency Model of Family Stress, Adjustment and Adaptation – is based on

four models, the first of these being Reuben Hill's ABCX Model proposed in 1949 (Hill, 1949). Hill's model grew out of the roller-coaster model that was first proposed by Koos (1946). The ABCX model focuses on the pre-crisis functioning of the family and emphasises the interaction of three components in producing a crisis (X), namely: the stressor (A), the family's resources for dealing with the stressor (B), and the family's interpretation of the stressor (C) (Golby & Bretherton, 1999; McCubbin & McCubbin, 2001). The second and third models expanded on Hill's ABCX model to include a focus on both pre- and post-crisis factors and processes, which enable a family to adjust to and prevail over adversity. The first of these two models is the Double ABCX Model proposed by McCubbin and Patterson in 1983, which particularly focuses on coping and social support, and emphasises that crisis resolution is a process, and not simply a once-off event (Golby & Bretherton, 1999; McCubbin & McCubbin, 2001). In the same year, McCubbin and Patterson extended the Double ABCX model to include the Family Adjustment and Adaptation Response (FAAR) model. The emphasis in the FAAR model is on comprehensively describing the family processes involved in the efforts to equalise demands and resources (McCubbin & McCubbin, 2001). The FAAR model emphasises domains such as the coping mechanisms, problem solving and coping skills that the family employs during the adjustment processes (McCubbin et al., 2001). This emphasis on the dynamic processes of both adjustment and adaptation inspired further examination into the role of family typologies (core family patterns of functioning) as core family competencies in shaping outcomes, adjustment and adaptation. This led to the development of the fourth model known as the Typology Model of Family Adjustment and Adaptation in 1989, developed by McCubbin and McCubbin. This model incorporated both pre-and post-crisis factors, but included an emphasis on the role of levels of family appraisal and the typology of established patterns of family functioning in

adjustment and adaptation (McCubbin & McCubbin, 2001). The typologies of regenerative family systems (with core strengths in hardiness and coherence), versatile family systems (with core strengths in bonding and flexibility), rhythmic family systems (with core strengths in family time and routine and the valuing of both) and traditionalistic family systems (with core strengths in traditions and celebrations) emerged in the literature as both core protective factors and recovery factors across the family life cycle (McCubbin, Thompson, Pirner, & McCubbin, 1988). The fifth and final model, referred to as the Resiliency Model of Family Stress, Adjustment and Adaptation, was developed in 1989 by McCubbin and McCubbin. The important difference in this model in comparison to previous ones is an emphasis on the family's post-crisis situations that have an impact on their long-term soundness (McCubbin & McCubbin, 2001).

The Resiliency Model is based on five fundamental assumptions about family life: (1) families face hardships and changes as a natural and predictable aspect of family life over the life cycle; (2) families develop basic competencies, patterns of functioning and capabilities designed to foster growth and development of family members and the family unit and to protect the family from major disruptions in the face of transitions and changes; (3) families develop basic and unique competencies, patterns of functioning and capabilities designed to protect the family from unexpected or non-normative stressors and strains and to foster the family's recovery following a family crisis or major transition; (4) families draw from and contribute to the network of relationships and resources in the community, including its ethnicity and cultural heritage, particularly during periods of family stress and crises; and (5) families faced with crisis situations demanding changes in the family's functioning work to restore order, harmony and balance even in the midst of change (McCubbin & McCubbin, 2001; McCubbin et al., 2001).

As its name indicates, the Resiliency Model involves two distinguishable, yet interrelated processes – adjustment and adaptation – that uniquely promote the family’s ability to adapt and bounce back after a family crisis situation (i.e., its resiliency) (De Haan, Hawley, & Deal, 2002; McCubbin et al., 1997; McCubbin & McCubbin, 1988; McCubbin & McCubbin, 2001, McCubbin et al., 2001). The adjustment phase deals with family stress, defined by McCubbin and McCubbin (2001) as “a state of tension brought about by the demand-capability imbalance in the family” (p. 22). This phase is influenced by protective factors, which buffer the family from the impact of a stressor. The adaptation phase, on the other hand, deals with family crisis defined as “a state of imbalance, disharmony, and disorganisation in the family system” (p. 22). In this phase recovery factors play a big role in enabling the family to ‘bounce back’ from the impact that the stressor has had. Consequently, adjustment represents recovery from a stressor prior to reaching crisis proportions, whilst adaptation represents recovery following a situation having already reached crisis proportions (McCubbin & McCubbin, 2001). The following sections outline the dynamics of these two processes.

2.6.1 The Process of Adjustment

The adjustment phase involves the influence of family protective factors in promoting the family’s ability and attempts to maintain their level of functioning and integrity and complete normative developmental tasks in the face of adversity (McCubbin et al., 1997). It involves a sequence of interacting elements that determine the outcome of the family’s exposure to a stressor (McCubbin & McCubbin, 2001; McCubbin et al., 2001). A stressor can be described as any demand placed on the family that may produce changes in the family system. Such changes may influence all areas of the family’s life, including the marital relationship, family goals,

parent-child relationships and the family's normal levels of balance and harmony. The severity of the stressor may be determined by the extent to which it threatens the family stability, disturbs family functioning or places demands on or depletes family resources and capacities (McCubbin et al., 2001).

A Stressor (A) and its severity interact with the family's level of Vulnerability (V). Family vulnerability can be described as the family's susceptibility to deterioration and dysfunction in the face of adversity (McCubbin et al., 1997). The family is seldom in a situation where they are dealing with only one stressor. The family's level of vulnerability is affected by the pile-up of strains and transitions all occurring simultaneously with the stressor, as well as where in the family life cycle they are positioned at the time (McCubbin et al., 2001).

The family's level of vulnerability also interacts with the family's typology of established patterns of functioning (T). These components (A, V and T) then interact with the family's resistance resources (B) and the family's appraisal of the stressor, which finally interact with the family's problem solving and coping strategies to produce an outcome. The family becomes vulnerable (V) as a result of a pile-up of stressors. The family's level of vulnerability interacts with the family's current and established patterns of functioning or typology (T). Family resistance resources refer to the family's abilities and capabilities to tackle and manage the stressor and maintain and promote harmony and balance in the face of adversity. The family's goal would naturally be to avoid a crisis, disharmony and significant changes in the family's established patterns of functioning (McCubbin et al., 2001). In order to do this effectively, family resources become an integral part of the family's capabilities for resisting a crisis and promoting family resilience ultimately leading to successful adjustment. Some of the more essential family resistance resources include social support, cohesiveness, financial stability,

flexibility, hardiness, shared spiritual beliefs, open communication, and traditions. In turn, the family's resistance resources (B) interact with the family's appraisal of the stressor (C). The family's appraisal of the stressor refers to the family's definition of the significance of the stressor and the resultant difficulties encountered by it. The definition of a stressor may range from being uncontrollable (i.e., something that could possibly lead to the family's downfall), to viewing it as a minor incident and a challenge to be met with growth-producing outcomes (McCubbin et al., 2001). The family's appraisal of the stressor (or the way it is viewed by them) will have a direct bearing on the problem-solving and coping strategies (PSC) they may wish to employ in order to successfully manage or eliminate the stress and the related hardships. In the process of problem solving, the family organises stressors and hardships into manageable tasks, explores alternative options to manage each component, takes active steps to resolve issues, and adopts more constructive patterns of problem solving communication. Some of the strategies that a family could consider in an attempt to restore balance and harmony include adopting more effective communication styles, seeking help from friends, and taking advantage of the help that is offered by friends (McCubbin & McCubbin, 2001; McCubbin et al., 2001). This process is represented in Figure 1.

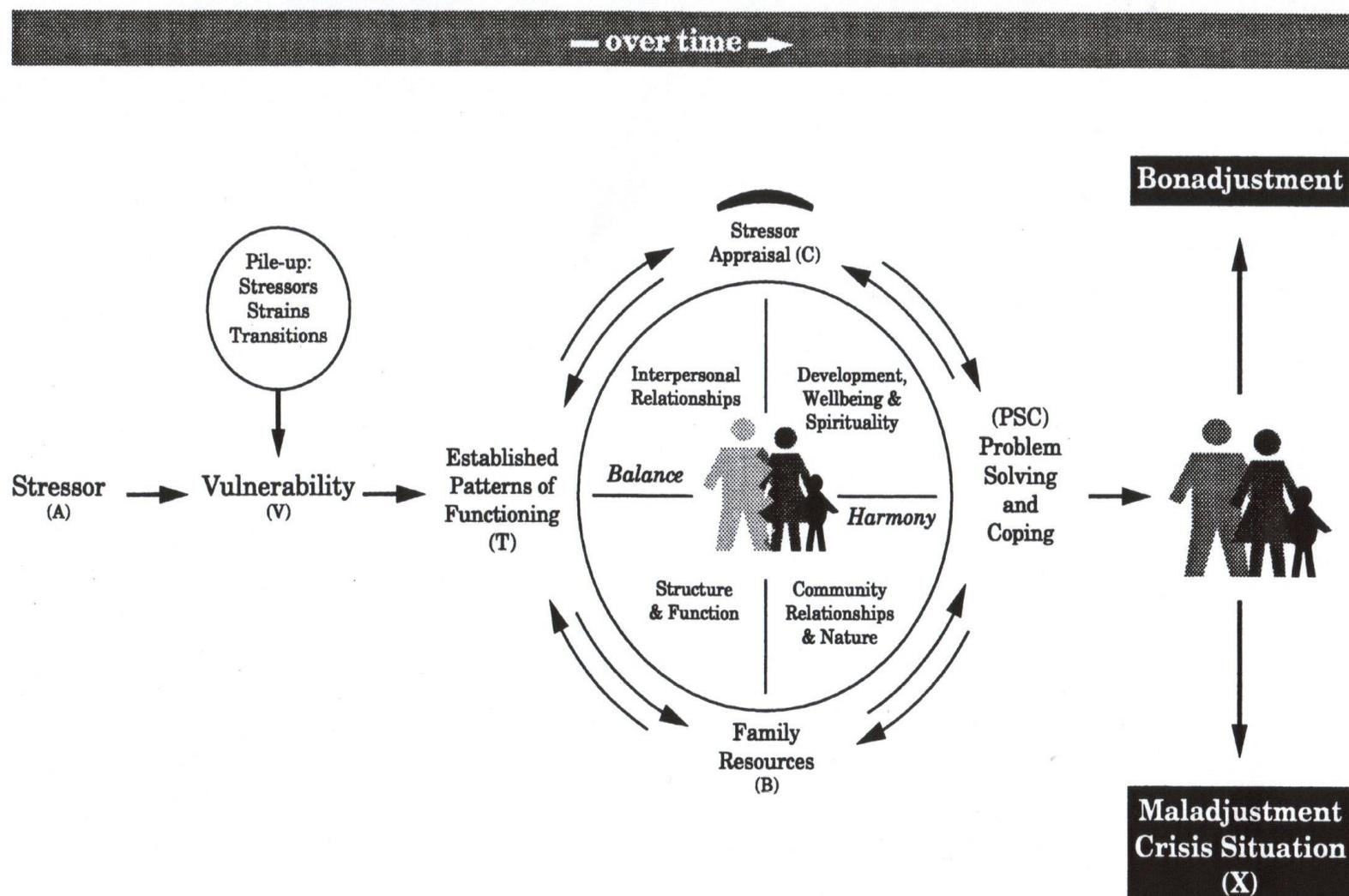


Figure 1. The Adjustment Phase of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin et al., 2001, p. 15).

The outcome of the adjustment phase falls on a continuum ranging from bonadjustment, which is the ideal towards which families strive, to maladjustment, which would necessarily imply a family crisis (X) situation. If the family achieves a state of bonadjustment, the existing family typologies are maintained and very little, or no change at all, is required. However, the crisis situation that results from maladjustment to a stressor forces the family to adjust its typologies so as to attain equilibrium, i.e., harmony and balance. In the event of this crisis situation occurring, the adjustment process ends, and the need for more permeable and possible structural changes to restore stability arises (McCubbin, 1998; McCubbin & Thompson, 1991; Walsh, 1996). The family then moves into the adaptation phase of the Resiliency Model (McCubbin & McCubbin, 2001).

2.6.2 The Process of Adaptation

The process of adaptation is concerned with the recovery factors which promote the family's ability to bounce back after a family crisis has been endured (McCubbin & McCubbin, 1988; McCubbin et al., 2001). This phase is precipitated by a family crisis situation, which is defined as "a state of imbalance, disharmony and disorganization in the family system" (McCubbin & McCubbin, 2001, p. 22). Family crisis is consequently set in motion by normative or structural changes, which are characterised by a demand for change in order to restore normal family functioning (McCubbin & Thompson, 1991). This entry into the phase of family adaptation requires the resilient family to use instrumental and expressive resources from within and outside the family to protect and promote adaptation (McCubbin & McCubbin, 1988). Adaptation (XX) is the term that is used to describe the outcome of family efforts to facilitate a new level of balance and harmony after a crisis has been experienced (McCubbin & Thompson, 1991). This

adaptation phase thus entails restorative action by the family during which it alters its internal functions such as behaviours, rules and roles, and external reality to achieve a family-environment fit and to restore stability (McKenry & Price, 1994).

The adaptation phase of the Resiliency Model was the main focus of the present research project. For the purpose of this study, the identified family crisis was that the family had to be living with a child diagnosed with Cerebral Palsy. A family member diagnosed with Cerebral Palsy can be viewed as a family stressor when this condition produces demands on the family with which they cannot cope. Stress results when there is a perceived or actual imbalance between the family's capabilities and demands of the disability and this can leave the family in a state of crisis. For the family to regain their sense of harmony and balance, they have to attend to the stressor (in this case, the management of the demands of the disability) and adapt to it (McCubbin & McCubbin, 1993). There are several interacting components that form part of the adaptation phase and which influence the family's level of adaptation (McCubbin & McCubbin, 2001). Figure 2 provides a diagrammatical representation of the adaptation phase of the Resiliency Model. An explanation of the interacting components follows the diagram.

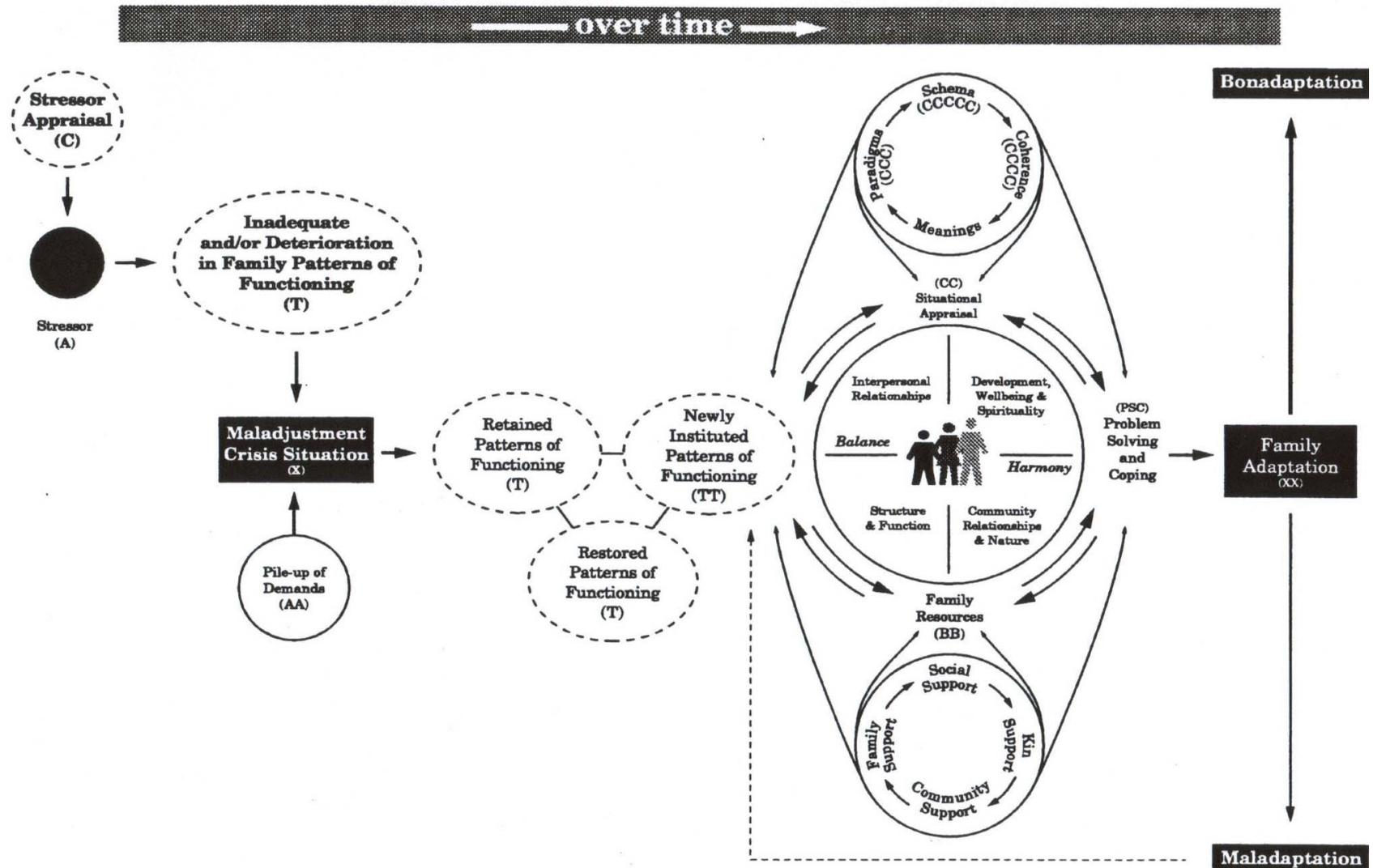


Figure 2. The Adaptation Phase of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin et al., 2001, p. 25).

2.6.2.1 The Pile-up of Demands and Stressors (AA)

Families are in a continuous cycle of development and are part of an ever-changing social context. They do not exist in isolation and therefore they seldom deal with only one stressor such as a physical, emotional or psychological disorder. Demands tend to accumulate (AA), which has an impact on the family's level of vulnerability (V) (McCubbin & McCubbin, 1993). The family's level of vulnerability will contribute to the crisis situation and have an impact on the ease with which that family achieves harmony and balance (McCubbin et al., 2001). Pile-up of demands (AA) refers to the accumulation of pre- and post-crisis stressors. A pile-up of demands is therefore common and is especially significant if families are dealing with chronic stressors, such as caring for a disabled child (McCubbin et al., 2001). McCubbin et al. (2001) identified nine broad categories of stressors and strains that contribute to the pile-up of family demands and impact on the family's level of vulnerability.

The first of these categories refers to the *initial stressor and its related hardships which develop over time*. Such difficulties may include problems in the marital or sibling relationships, parent-child conflict, community conflict and decreased resources, which may be emotional or financial (McCubbin et al., 2001).

Normative changes in the family unit and individual family members represent the second category. Such changes are normal and predictable and take place as a result of normal growth and development of the family and its individual members. These changes may take place concurrently with a crisis situation, making the crisis more difficult to resolve (McCubbin et al., 2001).

The third category involves *prior family strains that have accumulated over time*. Such strains may be residual strains resulting from earlier stressors, or they may be inherent in certain family

roles such as parenthood. These strains may be aggravated by new stressors and thus contribute to the family's pile-up of demands (McCubbin et al., 2001).

The fourth category focuses on unexpected *situational demands and contextual difficulties*. These are demands created by society that adversely affect family functioning and the family's ability to cope with the crisis situation. Such demands include the threat of job loss, government policies (e.g. closing down of facilities for special schooling), social tendencies (e.g. crime waves), the economy (e.g. rising inflation rates and increased prices on consumer products) and neighbourhood responsibilities (e.g. financial burden of employing neighbourhood security).

The fifth category relates to the *consequences of the family's efforts to cope*. Families adopt various coping strategies in the adjustment phase that appear to be effective in the short-term but in fact produce greater difficulties in the long-term. Such coping strategies include taking on an extra job in order to alleviate financial problems, suppressing feelings of frustration, or alcohol consumption to alleviate the psychological tension arising from the stressor (McCubbin et al., 2001).

The sixth category includes *intrafamily and social ambiguity* resulting from inadequate societal guidelines on how to cope effectively. Crisis situations are generally coloured by ambiguity and uncertainty. Families may rely on guidelines from the community on how to act appropriately in their given crisis situation. In some cases, these guidelines may be inadequate or absent, resulting in families experiencing a greater degree of tension relating to their situation (McCubbin et al., 2001).

Newly instituted patterns of family functioning (TT), demanding additional changes in family functioning, represents the seventh category. McCubbin et al. (2001) asserted that new patterns of functioning focus on five domains of family functioning. These include patterns that involve

changes in: (1) the family's rules and boundaries, (2) the family's routines, relationships and roles, (3) coalitions in the family unit, (4) the family's patterns of communication and (5) the family's transactions and interactions with the community. The role of new patterns of functioning is to bring about change in the family dynamics, to manage the stressor and the pile-up of demands as well as to restore family harmony and balance to achieve adaptation. In revitalising, introducing, replacing or modifying old patterns of functioning, the family unit will also determine the efficacy of these changes by contrasting and screening the changes with the family's values, beliefs, expectations and rules which are integral to the family's appraisal processes (McCubbin, Thompson, & McCubbin, 1993). Although these newly instituted patterns of functioning are most likely to bring about balance and harmony in the long-term, they may lead to added strain in the short-term, as families struggle to make sense of their new roles, values, rules and relationships. This may prolong the crisis situation by bringing about greater disharmony (McCubbin et al., 2001).

The eighth category refers to the *newly established patterns of family functioning*, which are incongruent with the family's schema (e.g. values and beliefs) or the family's paradigms (e.g. rules and expectations). Existing patterns of family functioning are often difficult to replace by the much-needed new patterns, as family members resist changes to their own routines. This links up to the ninth and final category which includes the *old established patterns of functioning* which are incongruent or incompatible with newly adopted patterns of family functioning (McCubbin et al., 2001). The following section addresses the family resources (BB) component of the Resiliency Model.

2.6.2.2 The Family Resources (BB) – Strengths and Capabilities

The Resiliency Model defines family capabilities as “a potential the family can call upon or can create to meet the demands it faces in a crisis situation, if it chooses to do so” (McCubbin et al., 2001, p. 32). Three potential sources of resources can be identified, namely individual family members, the family unit and the community. McCubbin et al. (2001) define a resiliency resource as a “characteristic, trait, or competency of one of these systems that facilitates adaptation” (p. 33). Resources may be either tangible (e.g. money) or intangible (e.g. integrity, cultural heritage, self-esteem). These include: (1) traits and abilities of individual family members, such as economic well-being, education and health; (2) the family system’s internal resources, such as family adaptability, cohesiveness, problem-solving ability and management of resources; (3) social support involving network and esteem support; as well as (5) a cognitive coping strategy regarding the perception of the stressful situation (Lavee, McCubbin, & Patterson, 1985; McCubbin et al., 2001).

Personal resources include the innate intelligence of family members; knowledge and skills; personality traits; physical, emotional and spiritual health of family members; a sense of mastery; self-esteem; sense of coherence; and the ethnic identity, cultural heritage, and world view adopted by the family (McCubbin et al., 2001). The two prominent family system resources considered are cohesion (the bonds that tie a family together which include aspects such as trust, support and respect) and adaptability (the ability to change course when confronted with obstacles) (Bayat, 2007). Family organisation, including agreement, clarity, and consistency in family roles and family rules; shared parental leadership; and clear generational boundaries are also important family system resources. Communication skills, family problem-solving, hardiness, family time together, and family routines have also been identified as family system

resources that play a significant role in family adaptation to the crisis situation (McCubbin et al., 2001). The third system is the community. Social support is considered to be one of the most important resources. Social support includes all people or institutions that the family unit or individual family members may turn to for assistance in the face of a crisis situation. Supports include both informal sources such as other family members, extended family and friends, as well as formal sources such as medical or social services, schools, churches and national government policies (McCubbin et al., 2001). Families who are able to develop and use social support in the form of practical or financial assistance as offered by relatives, friends, work associates or church organisations are both more resistant to major crises and better able to recover and restore stability after a crisis (Walsh, 1996). The following section considers the appraisal processes of the family unit.

2.6.2.3 Family Appraisal Processes

In the adjustment phase, the family's stressor appraisal plays a role in the process. The family's perception of the pile-up of demands, the resources available to them and their appraisal of what needs to be done in order to cope, are all critical factors in predicting the family's ability to adapt to the situation they may be facing (McCubbin & Patterson, 1983; McCubbin & Thompson, 1991; McKenry & Price, 1994). McCubbin and McCubbin (2001) defined five fundamental levels of the family's appraisal processes in crisis situations, all of which are influenced by, *inter alia*, the ethnicity and culture of a family. These levels are schema (CCCCC), coherence (CCCC), paradigms (CCC), situational appraisal (CC) and stressor appraisal (C). The stressor appraisal (C) is the family's definition of the stressor and how they foresee it impacting on them. In the adaptation phase however, it is the family's situational

appraisal (CC) which has an impact on the process. Situational appraisal (CC) is the relationship between the way the family views the stressor and the capabilities that they believe they have in order to deal with the stressors. The other levels of appraisal further influence situational appraisal (CC) (McCubbin et al., 2001). These levels of appraisal are briefly discussed.

A family's schema (CCCC) is described as “a structure of fundamental convictions, values, beliefs and expectations” (McCubbin et al., 2001, p. 39) that plays a fundamental role in the development of the family meanings (McCubbin & McCubbin, 2001). It is expressed through the family's worldview and includes family values and beliefs for such activities as respecting and maintaining the family's ethnic heritage and respecting one's elders. Not only does it give order, harmony, balance and structure to family life, it also significantly influences the shaping and justification of old, established, newly instituted and maintained patterns of functioning, as well as problem-solving and coping behaviours and patterns (McCubbin et al., 2001). According to Hawley (2000), families with healthy schemas tend to focus more on a collective 'we' than an individual 'I', are able to accept less perfect solutions to challenges and tend to have a view of the world relative to their place in it. Although the family schema is generally seen as a relatively stable construct, McCubbin et al. (1993) emphasised that under drastic conditions family schemas are reshaped, or reframed in response to modifications which the family makes in its established patterns of functioning in order to cope with the crisis.

Family coherence (CCCC) is “the motivational and appraisal basis for transforming the family's potential resources into actual resources, thereby facilitating changes in the family systems, coping, and promoting the health of family members and the well-being of the family unit” (McCubbin et al., 2001, p. 42). The family's sense of coherence refers to the dynamic feeling that the world is comprehensible (internal and external environments are structured,

predictable and explicable), manageable (resources are available to meet the demands), and meaningful (life challenges are worthy of investment by the family) (Antonovsky, 1979; Hawley, 2000; McCubbin et al., 2001).

Family paradigms (CCC) are understood to be the “expectations and rules which are shaped and adopted by the family unit to guide the family’s development of specific patterns of functioning around specific domains or dimensions of family life” such as child rearing, work and family communication, and spirituality (McCubbin et al., 2001, p. 42).

The above-mentioned levels of appraisal also have an impact on the definition of the stressor (C) that was initially made by the family (McCubbin et al., 2001). According to McCubbin and Patterson (1983), family efforts to redefine the crisis situation as a challenge or an opportunity for growth, and to give the crisis a meaning, appear to play a useful role in facilitating family coping and eventual adaptation. Finally, the established patterns of functioning, resources, and levels of appraisal influence and are influenced by the family’s problem-solving and coping strategies (PSC) which are discussed in the following sub-section.

2.6.2.4 Problem Solving and Coping (PSC)

In the process of adaptation, the family also employs their problem-solving and coping resources (PSC) which represent the process of obtaining, assigning and utilising resources in order to meet the demands associated with the crisis situation (McCubbin et al., 2001). Within the Resiliency Model, family coping refers to the attempt made by the individual and family to reduce or manage demands on the family system (McCubbin & Thompson, 1991). The problem-solving process prompts changes within the family as well as in the family’s relationship to the larger community and environment. McCubbin et al. (2001) identified four ways in which

coping facilitates adaptation to a crisis situation. These include reducing or eliminating stressors, acquiring additional resources to manage the stressors, ongoing management of tension within the family system that results from persistent strain associated with chronic stressors and finally, shaping the family's appraisal at both the situational and schema level. Retained and restored patterns of functioning (T) and the new patterns of functioning (TT) dynamically interact with the family's appraisal processes (CC), resources (BB), and problem solving and coping ability (PSC) in a cyclical manner to produce the outcome of family adaptation (XX).

Again, the outcome of this adaptation process, involving restructuring and consolidation, falls on a continuum bound on the positive side by bonadjustment (an exit from the crisis), and on the negative side by maladjustment (a reversion into crisis and exhaustion) (McCubbin & Patterson, 1983; McKenry & Price, 1994). In the event of bonadjustment, established patterns of functioning are adopted and maintained and family adaptation is achieved. In the event of maladjustment, an unsatisfactory level of adaptation is achieved and families sacrifice personal growth and development as a result. The family can then return to any part of the adaptation process and the cycle repeats itself until such time that new patterns are adopted and the family adaptation is achieved (McCubbin & McCubbin, 2001).

From the above it is clear that family resilience encompasses the maintenance of internal conditions conducive to communication, the positive growth of its members, the maintenance of family bonds, formation and maintenance of social support outside of the home and an attempt to minimise the impact of a stressor on the family (McCubbin et al., 2001). The indication of the degree to which the family is successful in doing so is evident in their level of adaptation. The most commonly identified outcomes of family resilience are family adjustment and adaptation, as well as family well-being (Lee et al., 2003). Although De Haan et al. (2000) agreed that

families progress through a series of stages in response to major stressors, they stress that not all families go through the same stages or follow the same trajectory. Some will skip stages while others might vacillate between stages. Due to the different structural, interpersonal, social, socioeconomic, cultural and religious factors that interact with family processes over time, resilience presents itself in a unique manner in each family (De Haan et al., 2002; Hawley, 2000).

2.7 THE APPLICABILITY OF THE RESILIENCY MODEL TO THE PRESENT STUDY

Parenting any child is a challenging, dynamic process. When parents learn of the fact that their child has Cerebral Palsy, the family is generally unprepared to cope with it, and the emotional turmoil it creates can be catastrophic (Phelps et al., 1958). When the family is faced with a crisis or persistent problem, the family unit as a whole is impacted. These stressors can unbalance the functioning of the family system and have ripple effects on all the family members and their relationships (Walsh, 2003a).

Cerebral Palsy is a complex condition that poses persistent, life-long challenges for the child as well as their entire family, creating a significant strain on the family functioning processes (Jones, Morgan, Shelton, & Thorogood, 2007; McCubbin & Huang, 1989; Schleichkorn, 1983). In addition, societal conditions such as poverty, high crime rate and poor community support resources only add to and intensify the challenges that families face these days. Unfortunately, such societal conditions are a reality for many South African families. Identifying the protective factors that assist these families to emerge from their adversities as stronger units, even under

such negative societal conditions will provide important information with regard to future intervention and prevention programmes in similar families.

Stress results when there is an imbalance between the family's coping capabilities and the demands of the disorder, whether actual or perceived. To cope with the demands of Cerebral Palsy, the challenges that the child faces also have to be managed in an attempt to adapt. Families must find strategies for adjusting and adapting to the daily medical, behavioural and practical needs of the child. Lin (2000) suggested that five factors underlie family coping behaviours for families living with a child with Cerebral Palsy. These include a positive family appraisal, support from concerned others, spiritual support, personal growth and advocacy, and positive social interaction. However, Masten (2001) reminded us of the "ordinary magic" (p. 232) associated with the adaptive capacities of all children and the families within which they reside. This author asserted that resilience is more common than not and concluded that very little evidence has emerged to indicate that severe adversity has major lasting effects on adaptive behaviours in the environment, unless important adaptive systems are compromised prior to or as a result of the adversity.

In summary, the diagnosis of Cerebral Palsy in a child will have an impact on the entire family system and will challenge the family's established patterns of functioning to a lesser or greater degree, depending on certain factors inherent in the family structure. This appears to be in line with one of the basic assumptions of a family resilience framework, namely that crises and challenges impact the whole family, and in turn, family processes mediate the adaptation of all members and the family unit (McCubbin et al., 2001). The emergence of research with a focus on enhancing the capacities of at-risk children and families has contributed to the

reframing of mental health issues in terms of resilience rather than psychopathology (Ungar, 2004).

There have been few studies in South Africa that have focused on the treatment and physical management of Cerebral Palsy. A small number of studies have explored the stress responses and coping strategies identified in these families (Germishuys, 1992; Mweshi, 1999; Pugin, 2007; Selkon, 2007), however there has been limited research to date on the resilience in families living with a child diagnosed with Cerebral Palsy and the factors that contribute to the adjustment and adaptation of these families based on a specific conceptual framework designed to explain coping and adaptation in families. It is therefore important to gain an understanding of the resiliency processes in families living with a child diagnosed with Cerebral Palsy and to identify the factors that are essential for their recovery when faced with the prolonged stress that such a diagnosis brings with it. A family's ability to make changes in their roles, rules and relational patterns in the attempt to adjust and adapt to the unique needs of a child diagnosed with Cerebral Palsy would be evidence of resilience (Patterson, 2002a). Since the outcome of the Resiliency Model is adjustment and adaptation, the model was found to be relevant to the present study. In addition, the Resiliency Model provides a framework to explore and describe factors that contribute to families' adaptation and creates a better understanding of these factors which in turn would contribute to theory-building in this area. In the future, this information could be used to inform the development of professional support and counselling for families to build resilience in the face of adversity (Shapiro, 2002).

2.8 CONCLUSION

Chapter Two provided a brief overview of the development of the construct of resilience in the field of positive psychology. In the past, resilience was viewed as an individual, innate quality, but with time researchers began to recognise the importance of the individual's family and larger community as contributing factors to resilience in the individual. Furthermore, as individuals do not live in isolation, it became important to look beyond individual resilience and to gain greater insight into the factors that tend to aid families when they are faced with a crisis situation. By focusing on family strengths, resiliency theory can contribute to providing families with alternative perspectives to their crisis situations, enabling them to work towards optimal family functioning by focusing on the positive aspects that their family already possesses.

A detailed description of The Resiliency Model of Family Stress, Adjustment and Adaptation which depicts the family's response to stress and crises was provided. This model was used to conceptualise the adaptation processes in a family after a child had been diagnosed with Cerebral Palsy.

From the limited literature available, it is evident that families with a child living with Cerebral Palsy are facing life-changing stressors and hardships. These families do, however develop and acquire a diverse range of resilience resources to help the family cope as a unit and as individuals. Chapter Three provides more insight into the impact of Cerebral Palsy on the family.

CHAPTER THREE

CEREBRAL PALSY

3.1 INTRODUCTION

The previous chapter provided an overview of individual and family resilience with a specific focus on the Resiliency Model of Family Stress, Adjustment and Adaptation. The purpose of this chapter is to present an overview of the crisis that some families face when a child is diagnosed with a disability, in this case Cerebral Palsy.

Cerebral Palsy, sometimes referred to as Congenital Spastic Paralysis, is characterised by varying degrees of disturbance of voluntary movement caused by damage to the brain (Capute, 1975). The term ‘cerebral’ refers to the brain, while ‘palsy’ refers to weakness or lack of control (Bleck & Nagel, 1975). Cerebral Palsy was first described by William John Little, an English orthopaedic surgeon, in 1862 and was referred to as Little’s Disease. Little believed that Cerebral Palsy was caused by obstetrical complications at birth which led to a lack of oxygen to the brain, resulting in damaged brain tissue. William Osler, a British medical doctor, later introduced the term Cerebral Palsy in 1888 (Murphy & Such-Neibar, 2003). Later, Sigmund Freud, a neuropathologist at the time, suggested that Cerebral Palsy may originate during the development of the brain in the womb. He also related abnormal development to factors that influence the developing foetus (Accardo, 1982).

The present chapter provides a brief history of Cerebral Palsy as well as an overview of the characteristics, prevalence and aetiology of Cerebral Palsy. A description of the complex classification of Cerebral Palsy and associated problems is provided in order to illustrate some of the stressors that the family might have to face and which may impact the family’s adjustment

and adaptation. An overview of the treatment and management of Cerebral Palsy is provided, followed by a discussion of the impact of Cerebral Palsy on the family, the parents (or caregivers) of the child, the child and the siblings.

3.2 CHARACTERISTICS OF CEREBRAL PALSY

Cerebral Palsy has been described as an ‘umbrella term’ to refer to children with a wide range of static cerebral disorders with associated motor impairment (Badawi et al., 1998). Cerebral Palsy is a difficult disorder to define as the motor symptoms are present in many different forms. It can be accompanied by different cognitive impairments, and the causes of the disorder are diverse (Kolb & Whishaw, 1999). There is agreement among experts in the field that Cerebral Palsy is a complex of characteristics attributed to brain injury. A commonly used definition of Cerebral Palsy, developed more than 50 years ago, described the condition as “a disorder of posture and movement due to a defect or lesion of the immature brain” (O’Shea, 2008, p. 35). More recently, in 2004, The International Working Group on Definition and Classification of Cerebral Palsy defined Cerebral Palsy (CP) as “... a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain” (O’Shea, 2008, p. 36).

CP is the most common form of disability amongst physically disabled children and also the most diverse with respect to degree of severity (Cruickshank, 1976). The most visible characteristic, however, is likely to be impaired control of motor functions, which has the potential to have a negative effect on the overall development of the child (Jan, 2006; Jones et al., 2007). Some of the negative phenomena associated with the motor deficits of CP include

muscle weakness, fatigue, and un-coordination, while some of the positive manifestations include spasticity, clonus, rigidity, and spasms (Jan, 2006). The clinical manifestations of CP often differ according to the gestational age of birth, the chronological age, the distribution of the lesions and the underlying disease (Kuban & Leviton, 1994). Depending on the affected area of the brain, the child with CP may experience hearing loss, poor vision (Menacker, 1997; Pellegrino, 1997), disturbances of the sensation of touch or difficulties with perception (Wessels, 1997). Some children are so lightly affected that no serious disability is evident, while others are more seriously affected and may exhibit clumsiness in their walk or experience difficulties in using their hands or even manifest speech difficulties. Some children, however, may be completely dependent on others for the activities associated with daily living (Wessels, 1997). In summary, the presentation of CP varies greatly depending on the aetiology, the developmental period of the brain damage, and the area of the brain lesions. The following section considers the prevalence of CP.

3.3 PREVALENCE OF CEREBRAL PALSY

The history of CP has illustrated that this condition has been known for centuries. The overall estimated prevalence rate of CP internationally is placed between 1.0 to 2.3 per 1000 live births (Jones et al., 2007; Murphy & Such-Neibar, 2003). In recent years, as a result of improved medical care, the rate of CP per 1000 live births has increased in the at-risk population groups, such as the low birth-weight groups (Clover et al., 2000; Kuban & Leviton, 1994; Vincer et al., 2006; Wilson-Costello, Friedman, Minich, Fanaroff, & Hack, 2005; Winter, Autry, Boyle, & Yeargin-Allsopp, 2002).

According to the South African White Paper on Integrated National Disability Strategy (1997), reliable research regarding the nature and prevalence of disabilities in South Africa is scarce. The White Paper (1997) attributes a number of factors to influencing the lack of reliable statistics. These include the varying definitions of disability; the different survey technologies that are used to collect information; the negative traditional attitudes towards people with disabilities as well as the poor service infrastructure for people living with disabilities in underdeveloped areas. Botha (1991), however, estimated that the incidence of CP in South Africa ranges from 1.5 to 3 cases per 1000 live births. Whilst the statistical figures for South Africa are lacking, it is likely that the figures closely correlate with those of international studies.

The most common age of onset for CP is 2 to 5 years of age (Kuban & Leviton, 1994; Nuttall, Romero, & Kalesnik, 1992; Palfrey, Singer, Walker, & Butler, 1987). Kuban and Leviton (1994) suggested that a definitive diagnosis of CP should be deferred until the child's second birthday. Should the physician suggest the diagnosis before the end of the child's first year, it should be presented to the family in tentative terms (Cooley, 2004; Ford, Kitchen, Doyle, Richards, & Kelly, 1990). The various aetiological factors associated with CP follows.

3.4 AETIOLOGY OF CEREBRAL PALSY

Through the years, numerous aetiological opinions have been proposed. Cruikshank (1976) reported that an initial theory by Little, in 1862, described a disorder that affected children in the first year of life, affected the development of their skills and that did not improve over time. In addition, Little connected this disorder to a lack of oxygen during birth (Jones et al., 2007). Some years later, in 1897, Freud suggested that CP might represent "symptoms of deeper-lying influences which have dominated the development of the fetus" (Kuban & Leviton, 1994, p.

188). Until the 1980's, the single cause of CP was believed to be birth asphyxia. In recent times, however, it is believed that CP is congenital, meaning damage to the brain has occurred during pregnancy or at birth. However, infections, diseases or severe head injuries can cause CP at any age or stage of life (Jansen, 1995).

Approximately 50 percent of CP cases do not have any identifiable underlying aetiology (Taft, 1995). Many conditions or risk factors associated with CP can be divided into those occurring in the prenatal, perinatal or postnatal periods (Ellenberg & Nelson, 1981; Ingram, 1964; Jansen, 1995; Reddihough & Collins, 2003). CP may result from one or more aetiologies, with the actual cause being difficult to identify in all cases (Jones et al., 2007; Keats, 1965).

Prenatal risk factors associated with CP include hypoxia, genetic disorders, metabolic disorders (e.g. maternal diabetes), multiple gestations, intrauterine infections, thrombophilic exposure, chorioamnionitis, maternal fever, exposure to toxins (e.g. toxic substances in X-rays), malformation of brain structures, intrauterine growth restriction, abdominal trauma, vascular insults, rubella in the mother during the first trimester of pregnancy and maternal anoxia (Gibson, MacLennan, Goldwater, & Dekker, 2003; Han, Bang, Lim, Yoon, & Kim, 2002; Kuban & Leviton, 1994; Naeye, Peters, Bartholomew, & Landis, 1989; Nelson & Ellenberg, 1986; Reddihough & Collins, 2003).

Perinatal risk factors include asphyxia, premature birth (<32 weeks or <2500 g) (Jan, 2006), rhesus incompatibility, infection, abnormal foetal presentation (breech delivery), placental abruption, cord prolapsed and instrumental delivery (Gibson et al., 2003; Han et al., 2002; Kuban & Leviton, 1994; McCance & Huether, 1994; Naeye et al, 1989; Nelson & Ellenberg, 1986; Reddihough & Collins, 2003). As a result of increased rates of survival, CP in low-birth-weight babies is increasing (Hagberg, Hagberg, & Zetterstrom, 1989; Stanley, 1994). Twins with low

birth weight appear to be at special risk for CP (Nelson, Swaiman, & Russman, 1994). If one of the twins dies at or before birth, the remaining twin appears to be at high risk for CP (Szymonowicz, Preston, & Yu, 1986).

Postnatal risks include asphyxia, low APGAR scores, seizures within 48 hours of birth, cerebral infarction, hyperbilirubinemia, sepsis, respiratory distress, syndrome/chronic lung disease, meningitis, postnatal steroids, intraventricular haemorrhage, periventricular leukomalacia, shaken baby syndrome and head injury (e.g. as a result of motor vehicle accidents and physical abuse) (Gibson et al., 2003; Han et al., 2002; Jan, 2006; Jones et. al., 2007; Kuban & Leviton, 1994; Naeye et al., 1989; Nelson & Ellenberg, 1986; Nelson & Leviton, 1991; Phelps et. al., 1958; Reddihough & Collins, 2003).

3.5 CLASSIFICATION OF CEREBRAL PALSY

CP consists of many subtypes which share the common symptoms of movement disorder, early onset and no progression of the disorder (Nelson et al., 1994). Many classification systems have been developed (Cruikshank, 1966; Gaddes, 1980; Keats, 1965) using different clinical data as their focus point and these continue to be used to date. Some systems classify CP according to subtypes depending on the nature of the predominant motor disorder, others according to the topographic distribution of the limb involvement (monoplegia, hemiplegia, diplegia and quadriplegia), while others classify CP according to the severity of the motor involvement (mild, moderate, severe) (Jan, 2006; Jones et. al., 2007; Murphy & Such-Neibar, 2003; O'Shea, 2008). Monoplegia is characterised by the involvement of only a single limb, while diplegia is characterised by involvement of the lower extremities, although the upper extremities are also slightly involved. Hemiplegia is where one whole side of the body is involved, with the arm

typically more affected than the leg, and quadriplegia is characterised by the involvement of all four limbs (Jan, 2006; Levitt, 2010; Murphy & Such-Neibar, 2003). Children can also be diagnosed with double hemiplegia or triplegia CP, however this is not common (Jan, 2006). Another method of classification divides CP into two major physiological classifications – pyramidal or extra-pyramidal – according to the nerve cell group that is involved (Jones et al., 2007). The pyramidal type of CP refers to the spastic CP group because the usual nerve cell involved in this disorder is shaped like a pyramid. Extra-pyramidal CP refers to all the other types of CP in which the area of the brain affected is composed of conglomerates of nerve cells (Capute, 1975). This type of CP involves problems with posture, involuntary movements, hypertonia, and rigidity (Nelson et al., 1994).

Once the distribution of the limb involvement is established, the quality of the muscle tone and involuntary movement is assessed to determine the nature of the motor disorder. Some early indications of CP include developmental delays, walking on toes, persistently holding the hands in a fist position, micro-cephaly, epilepsy, irritability, poor sucking, predominance of handedness before the age of two years (indicating hemiparesis), scissoring of the lower limbs (McMurray, Wilson-Jones, & Khan, 2002), and the persistence of primitive reflexes (Jan, 2006).

Functional impairment and degrees of disability vary considerably within the subtypes, making it difficult to clinically distinguish between them (Murphy & Such-Neibar, 2003). The range of severity of disability also ranges from complete immobility and dependency on others to functional abilities of talking, self-care, walking, running and other skills, although with some clumsiness (Levitt, 2010). A multidisciplinary evaluation of a child who presents with early indications of CP is therefore recommended. Input from physiotherapy, occupational therapy, ophthalmology, audiology, orthopaedics, radiology, neurology, genetics, developmental

paediatrics, and social services may be necessary for an accurate diagnosis of CP (Jan, 2006). The specific types of CP are now described.

3.5.1 Pyramidal / Spastic Cerebral Palsy

This classification is the most common type of CP, occurring in approximately 70 percent to 80 percent of children with CP (Jones et al., 2007) and in 90 percent of cases where children have a very low birth weight (O'Shea, 2008). Spasticity refers to an increase in muscle tone (Nelson et al., 1994). Stiffness of the muscles in spastic children occurs when there are defects or damage in the brain's corticospinal pathways (Jones et al., 2007). This type of CP is characterised by a loss of voluntary motor control. When the child initiates voluntary movement, the movement is likely to be slow and laboured, jerky and explosive with lack of control in the body extremities (Denhoff & Robinault, 1960). This disability may affect any or all limbs, and therefore may be termed hemiplegic, diplegic and quadriplegic (Botha, 1991).

3.5.2 Extra-pyramidal / Non-spastic Cerebral Palsy

Extra-pyramidal CP is typically divided into two subtypes, dyskinetic and ataxic CP. These subtypes are described below.

3.5.2.1 Dyskinetic Cerebral Palsy

Dyskinetic CP is the most common type of CP and results from extrapyramidal damage. It is often associated with a severe handicap in movement and tends to be difficult to treat (Beckung & Hagberg, 2000). Dyskinetic CP is further divided into athetoid and dystonic CP (Rosenbaum, 2003). *Athetoid CP* is characterised by irregular, spasmodic, involuntary movements of the

limbs or facial muscles and is the second largest group of the CP population, occurring in approximately 20 percent of CP children (Cruickshank, 1976). The movements are very large and are marked by slow, irregular, twisting movements seen mostly in the upper extremities (Ellison & Semrud-Clikeman, 2007). Children with this type of CP frequently have speech production problems, with unexpected changes in rate and volume (Ellison & Semrud-Clikeman, 2007). This type of CP has been most clearly associated with birth asphyxia and oxygen deprivation (Nelson et al., 1994). *Dystonic CP* is characterised by reduced activity and increased tone (O'Shea, 2008), resulting in rigid posturing of the neck and trunk (Jones et al., 2007).

3.5.2.2 Ataxic Cerebral Palsy

Ataxia refers to a loss of orderly muscular coordination resulting in movements being performed with abnormal force, rhythm, and accuracy (O'Shea, 2008). Ataxic CP is associated with injury to the cerebellum (Hagberg, Hagberg, & Olow, 1975). The muscles of the ataxic child are normal, though the muscle tone may be lowered. There is no spasticity or involuntary movement and reflexes are normal (Botha, 1991).

Hypotonic CP is also often mentioned as a classification of CP as a result of the observed motor delays (Jones et al., 2007). CP with hypotonia is characterised by floppy movements with marked decrease in overall muscle tone. Children who suffer from hypotonia display significant delays in motor milestones and often experience associated problems with feeding as a result of their weak facial and oral muscles (Jones et al., 2007).

3.5.2.3 Mixed Cerebral Palsy

This variation of CP is a combination of the other types of CP, with one type predominating (Cruickshank, 1976; Jones et al., 2007). Approximately 30% of individuals with CP present with the mixed type (Cruickshank, 1976).

3.6 OTHER DIFFICULTIES ASSOCIATED WITH CEREBRAL PALSY

Individuals with CP often experience disabilities or handicaps that require special needs and that result in further complications which may affect their quality of life and life expectancy (O'Shea, 2008). When combined with other disabilities, these complications can have proportionately greater effect on the child's education (Gordon, 1976). The fact that CP results from an abnormality of the developing brain "predisposes this population for consideration that its members may possess all the various disabilities and disorders that have been demonstrated or inferred to result from brain dysfunction" (Hardy, 1983, p. 180). In 2004, the International Workshop of Definition and Classification of Cerebral Palsy added the following sentence to their definition: "The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviors, by epilepsy, and by secondary musculoskeletal problems" (O'Shea, 2008, p. 37). Some of these associated problems include poor coordination of sucking, chewing and swallowing, which would influence the levels of nutrition and growth rate (Jan, 2006). In addition, children with CP are prone to urinary incontinence, constipation, sleep disturbances and drooling (Jan, 2006). Some of these associated problems of the disorder are outlined below.

3.6.1 Cognitive and Intellectual Functioning Deficits

CP does not necessarily result in cognitive impairment in all children (Jan, 2006). While most studies of intellectual functioning indicate that children with CP range from the level of profound retardation to the superior category (Kuban & Leviton, 1994; Simeonsson, 1986), many studies indicate that half of all children with CP have intellectual levels falling in the mentally retarded range (i.e. I.Q. below 70) (Cruikshank, 1976). There is however a correlation between the severity of CP and mental retardation (Russman & Ashwal, 2004). In addition to their lowered intelligence, children with CP have a greater chance of having figure ground, visual perceptual and visual motor problems (Cruikshank, 1976; Wessels, 1997). Exteroceptive and proprioceptive sensations can also be impaired in children with CP (Gordon, 1976), which may impact on their ability to learn. The findings that many children with CP have associated learning disabilities, cognitive retardation, and attention deficit disorders present significant implications for educational planning (Blondis, Roizen, Snow, & Accardo, 1993). Additional factors that are associated with increased cognitive impairment include epilepsy and cortical abnormalities on neuroimaging (Jan, 2006).

3.6.2 Epilepsy

The prevalence of epilepsy in patients with CP varies greatly, with estimates ranging between 12 and 90 percent of children diagnosed (Aksu, 1990; Aicardi, 1990; Ashwal et al., 2004; Edebol-Tysk, 1984; Rossiter, Hallows, & Pearson, 1977). It has been found that approximately one third of patients with CP experience seizures; these figures are influenced by the degree of motor and cognitive disabilities (Suma et al., 1988). The prevalence of seizures in children with hemiplegia is 50 percent (Kuban & Leviton, 1994), while those with the spastic type are at 86

percent (Wessels, 1997). The presence of epilepsy can be an indication of the severity of the neurological injury or insult (Fennell & Dikel, 2001). Focal seizures are the most common (Jan, 2002). A more recent study indicates that the strong predictors of epilepsy in children with CP include if a child with CP experiences seizures within his or her first year of life, or during the neonatal period, and if there is a family history of epilepsy (Bruck et al., 2001). The seizures may lead to difficulties related to school and add greater anxiety to parents (Gordon, 1976).

3.6.3 Visual and Hearing Impairments

Visual impairments are common in children with CP, affecting approximately 28 percent of children diagnosed (Ashwal et al., 2004). A recent study by Odding, Roebroek and Stam (2006) reported that approximately three-quarters of all children with CP suffer from low visual acuity. Hardy (1983) estimated that 25 to 50 percent of all individuals with CP have some kind of visual defect. These individuals have a greater chance of suffering from nystagmus (muscle imbalance resulting in involuntary rhythmical eye movement), strabismus (poor muscle control resulting in squints), refractive errors (long and short sightedness), hemianopsia (loss of vision in half of each eye), optic atrophy (damage to the optic nerve), and amblyopia (poor vision in a physically normal eye) (Schenk-Roolieb, van Nieuwenhuizen, van der Graaf, Wittebol-Post, & Willemse, 1992; Wessels, 1997), and partial deafness (Gordon, 1976). Approximately 12 percent of children with CP experience hearing impairments (Ashwal et al., 2004). Woods (1957) described two common types of hearing problems in children with CP. These included high frequency deafness and auditory agnosia. If hearing and visual impairments are not detected and managed early, these deficits could interfere with developmental progress and rehabilitation later on (Jan, 2006).

3.6.4 Speech and Language Development

Oral-motor dysfunction such as speech and articulation (tongue and lip mobility), abnormal breathing patterns, feeding and drooling problems and delayed understanding of language are frequently related to CP (Ashwal et al., 2004; Wessels, 1997). Odding et al. (2006) reported that up to 80 percent of people with CP have some type of speech impediment. CP is the result of poor brain development or brain damage, therefore higher cerebral functions such as language and communication frequently suffer. This is due to the effects of the cerebral lesion(s) which impacts the neuromuscular control of the speech mechanisms, such as dysarthria (Pennington & McConachie, 2001a, 2001b). The levels of severity of the CP will also then impact on the child's abilities to speak which in turn will have an influence on the degree to which that child is able to make themselves understood (Kennes et al., 2002). In addition, many children with CP display delays in their development of narrative skills and functional communication (Pennington, Goldbart, & Marshall, 2004). They cannot go out and explore their environment and learn from their actions as 'normally developed' children would do, inevitably limiting the formation of concepts which are fundamental to developing perceptual and language function (Gordon, 1976; Uvebrant & Carlsson, 1994). In addition to this, brain damage and lack of experience can and often do also lead to the learning difficulties so commonly associated with children with CP (Gordon, 1976).

3.6.5 Gross Motor Problems

A variety of orthopaedic problems are associated with CP. Spasticity may result in progressive joint contractures, shortened muscles and hip or foot deformities, which would influence the child with CP's mobility and capability of independent functioning (Jan, 2006).

Non-ambulatory children are at a greater risk for hip dislocation (Wheeler & Weinstein, 1984) and of developing spine curvature scoliosis (Jan, 2006; Samilson, 1981).

3.6.6 Psychological and Social Problems

Growing up and adapting to development particularly during adolescence, is a challenging process for all children. The child with disabilities faces an even greater challenge even if only in terms of coming to terms with their physical disability (Gordon, 1976). According to Mulderij (2000), children with motor disabilities are at great risk of focusing on their body. In addition, adolescents with CP are prone to regarding their bodies as unreliable, dependent on others for assistance and as catching the attention of other people (Hammar, Ozolins, Idvall, & Rudebeck, 2009). Adolescents with CP have a less positive body image than their non-disabled counterparts (Hammar et al., 2009). Emotional control develops over a longer period of time and the situation is complicated by the emotional immaturity that is prevalent among children with CP (Gordon, 1976). Children with disabilities have a greater chance of developing behaviour disorders, higher frustration levels resulting from their physical disability, depression, over-active behaviour and apathy (Gordon, 1976). The following section addresses the various treatment approaches used for CP and its associated problems.

3.7 TREATMENT OF CEREBRAL PALSY

There is no cure for this condition, however, therapy, education and technology can enhance a child's life by improving functional abilities and maximising potential (Jones et al., 2007). Early identification of CP, development of appropriate intervention programmes and the use of a multidisciplinary team approach have been found to be of great benefit to a child diagnosed with

CP and are also strongly linked to later success in school and in general life (Rowan & Monaghan, 1989). Current interventions used for CP include physical therapy, orthotic devices, occupational therapy, speech therapy, behavioural therapy, surgery as well as alternative therapies, such as massage therapy (Hernandez-Reif et al., 2005; Jan, 2006). Physical therapy aids in motor development and in the prevention of deterioration of muscles, orthotic devices and braces are used to stretch spastic muscles, which can improve balance and motor development, and occupational therapy helps with the development of daily living skills, such as feeding, dressing, and toileting. Speech therapy assists with the development of communication and language skills, while behavioural therapy promotes the development of socially acceptable behaviours. Surgery is used to treat severe contractures of muscles which limit mobility or to place feeding tubes in severe cases of swallowing problems and malnutrition (Hernandez-Reif et al., 2005; Jan, 2006). Alternative therapies, such as massage therapy, are used to aid physical symptoms associated with CP and to enhance development and independence (Hernandez-Reif et al., 2005). Approximately 50 percent of people with CP use assistive devices to aid in the development or maintenance of their mobility (Ashwal et al., 2004).

Kohn (1990) reported a strong association between psycho-education, family and vocational support and positive outcome. Recommendations were made for paediatricians to make early referrals to community resources for early childhood programmes for young children with CP.

3.8 CHALLENGES FACED BY FAMILIES LIVING WITH A CHILD DIAGNOSED WITH CEREBRAL PALSY

CP is a lifelong condition that holds many challenges for the child, the caregivers and the family as a whole. When a child is diagnosed with CP, the family is faced with a dilemma.

Society generally has positive perceptions of parenthood, but more negative views of the birth of a disabled child. This ambivalence contributes to the family's internal stress (Vijesh & Sukumaran, 2007). When parents learn that their child is disabled, they experience mixed emotions that evoke fairly clear reaction patterns. They experience a crisis in which their expectations are disrupted (Sen & Yurtsever, 2007). The typical reactions of parents are grouped under three primary categories (Abidoğlu & Gümüşçü, 2000; Kearney & Griffin, 2001). The primary reactions include shock, denial, and suffering and depression (Vijesh & Sukumaran, 2007); the secondary reactions include experiencing feelings of guilt, indecision, anger, and shame; while the tertiary reactions include bargaining and acceptance and adaptation.

As the child with CP goes through the various developmental stages and their family resources change, so the family, naturally faces differing challenges (Hirose & Ueda, 1990). The severity of the disability in terms of the level of independent functioning in daily life contributes to the stress of these challenges (Baird, McConachie, & Scrutton, 2000; Button, Marvin, & Pianta, 2001; Ong, Afifah, Sofiah, & Lye, 1998). The child's disability may obligate all members of the family to make sacrifices. It may affect the relationships within the family, the family's economic situation (Vijesh & Sukumaran, 2007), daily lifestyle, and plans and expectations for the future (Sen & Yurtsever, 2007). Evidence suggests that the caregiver's adaptation to such stressors and demands varies tremendously (Raina et al., 2004) as some parents of children with disabilities may experience the situation as not very stressful, while others may experience greater difficulty (McCubbin & McCubbin, 1992). As a result of these varying experiences, it is important that, when health care professionals are dealing with families with a disabled family member, they should be careful not to make service decisions based on the assumption that the family functioning is related to the family member with a disability.

Each family member should rather be carefully assessed for their individual strengths, weaknesses and needs (Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001). The specific impact of CP on the different aspects and particular members of the family are discussed below.

3.8.1 Impact on the Marriage

Marital functioning has been found to have a buffering effect on parenting stress (Saddler, Hillman, & Benjamins, 1993) which is expectantly similar for those parents of children with CP (Britner, Morog, Pianta, & Marvin, 2003). According to Shakespeare (1975), coping with a physically disabled child does not necessarily affect the relationship of the parents however an already strained marriage may be further perturbed by the need to cope with a physically disabled child. Featherstone (1980) maintained that a child's disability evokes powerful emotions in parents, restructures the family and creates an environment that is prone to conflict. Added stresses of blame, guilt and anxiety regarding the child's diagnosis may also serve to intensify the stress placed on a marital relationship (Vijesh & Sukumaran, 2007). Lack of assistance and support from family and friends may result in feelings of isolation adding to marital stress (Erlank, 1984). It was found that parents with a disabled child experience less satisfactory marriages, less social support, less religiosity and less psychological well-being than parents of non-disabled children. In addition, parents of disabled children had fewer psychosocial resources with which to buffer the stress related to coping with their child (Friedrich & Friedrich, 1981). South African studies evaluating stress in families with a physically disabled child have concluded that parents with a physically disabled child, as opposed to parents of non-disabled children, reported a lack of family integration, financial

problems and a lack of family opportunities which included family members having to forfeit job opportunities, education and social activities (Jansen, 1991; Lombard, 1992).

3.8.2 Impact on the Parents

In spite of the changes in gender norms, women remain more personally invested in child-rearing than men. Studies have shown that mothers of children with CP experience higher levels of stress or lower levels of mental health than those mothers of ‘typically’ developing children (Britner et al., 2003; Florian & Findler, 2001; Rentinck, Ketelaar, Jongmans, & Gorter, 2007; Vijesh & Sukumaran, 2007), less positive feelings towards their children and greater anxiety about their children when compared to mothers’ reactions to the birth of their physically normal children (Brantley & Clifford, 1980; Lombard, 1992; Jansen, 1991; Vijesh & Sukumaran, 2007). A study conducted by Kazak and Marvin (1984) found that mothers of physically disabled children experienced more depression linked to parenting issues, felt less competent as mothers and had less free time for themselves or to spend with their spouse than did mothers of non-disabled children. A number of studies identified time demands as a significant stressor for mothers of disabled children (Bresleau, Weitzman, & Messenger, 1981; Jansen, 1991; Lombard, 1992; Schilling, Schinke, & Kirkham, 1985).

McCubbin and Figley (1983) conducted a study that investigated the difference in the coping styles of mothers and fathers of disabled children. Based on a sample of parents of children with CP, the results indicated similar coping profiles between mothers and fathers. It was however noted that mothers sought opportunities to discuss their feelings with their friends, while fathers preferred to discuss important concerns privately with their spouses. In another study it was found that mothers experienced a greater personal burden than fathers. Mothers tended to be

more emotional in their reactions, while fathers were more objective and realistic. Furthermore, this study indicated that mothers seemed to seek comfort from other mothers, while fathers were prone to rather keeping their problems to themselves (Hirose & Ueda, 1990). Binger (1973) also found that fathers were inclined to find ways to distance themselves from painful involvement with their families suggesting the use of avoidance as a coping mechanism. Studies in South Africa that examined the differences between stress and coping responses of mothers and fathers of physically disabled children found very few differences between the stress and coping profiles of mothers and fathers (Jansen, 1991; Lombard, 1992). These researchers however reported that both mothers and fathers of physically disabled children when compared to mothers and fathers of non-disabled children experienced more over-commitment and overprotection towards their child (Jansen, 1991; Lombard, 1992).

3.8.3 Impact on the Child

Infants and young children develop and learn through mastering specific developmental tasks related to early socialisation. The presence of a disability during these early years can negatively impact the mastering of these developmental tasks (Hymovich & Hagopian, 1992) resulting in developmental delays in the child living with CP. As previously discussed, children with disabilities face great challenges with accepting their disability (Gordon, 1976) and when children undergo developmental transitions like attending school for the first time or transitioning into puberty, they are likely to have decreased ability to tolerate the stresses and frustrations that might occur with a physical disability (Lavigne & Ryan, 1979). Adjustment can either be facilitated or inhibited by the parents' reaction to the problem. The disabled child may encounter some or all of the following typical adjustment problems – lack of self-confidence,

conduct disorder resulting from frustration and anger, separation anxiety, and feelings of rejection and/or depression (Anderson, Clarke, & Spain, 1982). These findings were confirmed by Jansen (1991) and Lombard (1992).

Bakwin and Bakwin (1982) reported that CP children often also experience more emotional problems than the normal child, such as emotional immaturity, poor social skills, introversion, withdrawal and depression. Dallas, Stevenson and McGurk (1993a) found that CP children often displayed more passivity and less assertiveness than their siblings and were generally treated as if they were younger than their chronological age by others. Similarly, Dallas, Stevenson and McGurk (1993b) found that the tendency toward sibling and maternal control of interactions with the child with CP resulted in lower self-efficacy and poorer development of social skills in children with CP. Various studies however concluded that the presence of behavioural problems in the child with CP was related to parental stress (King, King, Rosenbaum, & Goffin, 1999; Mobarak, Khan, Munir, Zaman, & McConachie, 2000; Wanamaker & Glenwick, 1998). Although physical disability increases the risk of a child developing emotional and behavioural problems, many children seem to cope relatively well (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980).

3.8.4 Impact on the Siblings

Siblings adjust in diverse ways to having a brother or sister with a disability. Research indicates that, while the majority of siblings are well adjusted, a small number of siblings are at risk of developing significant adjustment difficulties (Giallo & Gavidia-Payne, 2006; Rossiter & Sharpe, 2001). As siblings are more likely to spend more time together than any other subsystem,

siblings of disabled children are often caring and supportive however, they are also affected by the stress of coping with a disabled person in the home (Russell, 1978).

Shakespeare (1975) reported that the basic reactions that siblings of physically disabled children experience include guilt feelings resulting from having 'pestered' their parents for a brother or sister, jealousy of the attention given to the disabled child, the experience of embarrassment and difficulty in explaining their sibling to their peers or strangers and the feeling that the disability reflects negatively on the family. In addition, siblings may be affected by the parental anxiety toward the disabled child, particularly during periods when the disabled child is hospitalised. The family routine is likely to be disrupted during such a period, and healthy siblings may feel rejected and unimportant (Burton, 1975).

3.9 CONCLUSION

This chapter has delineated some of the complex dynamics related to CP. It is clear that while the child is the diagnosed individual, the impact of the disability has a ripple effect that extends to the whole family and the environment. It is therefore beneficial to focus on the strong and positive relationships which parents and families develop enabling them to rise above their crisis. It is thus both important and necessary to explore and gain an understanding of how families with a child diagnosed with CP are able to adjust and adapt when faced with this crisis. The design and methodology of this study is discussed in the following chapter.

CHAPTER FOUR

RESEARCH DESIGN AND METHODOLOGY

4.1 INTRODUCTION

This chapter provides an overview of the research design and methodology that was utilised in this study. The discussion begins with an outline of the primary research aim and is followed by an explanation of the research design, the identification of participants, including a demographic description of the sample, the measures used, the research procedure and finally the data analysis methods. The chapter is concluded with an outline of the ethical issues that were considered in this study.

4.2 AIM OF STUDY

The primary aim of the present study was to explore and describe the resiliency factors that facilitate adjustment and adaptation in a family with a child that has been diagnosed with CP.

4.3 RESEARCH DESIGN

A combination of quantitative and qualitative research designs have been recommended when researching resilience (Walsh, 2003a). For the purpose of this study, triangulation of method was employed, with an exploratory, descriptive approach. Triangulation of method refers to mixing quantitative and qualitative research approaches (Neuman, 2006). Struwig and Stead (2001) stated that, when using triangulation, researchers are able to complement data from quantitative sources with qualitative data and vice versa. An advantage of triangulation of

method is that it enables the researcher to look at a phenomenon from different perspectives and thus gain a fuller picture of what is being studied (Struwig & Stead, 2001).

In triangulation of measures, multiple measures are used to explore the same phenomena (Neuman, 2006). For this research, quantitative data was gathered by means of structured questionnaires, while qualitative data was obtained from open-ended questions in the biographical questionnaire. The open-ended questions requested participants' opinions on factors of strength that they believed helped them as a family to adapt to living with a child diagnosed with CP and an explanation of the limitations that their child diagnosed with CP experiences. An exploratory-descriptive research design was employed for the purpose of this study. Each of the components of this research design is now discussed.

4.3.1 Exploratory Research

An exploratory research design is typically used to examine a relatively new topic or issue, or when the subject of the study is itself relatively new and unstudied (Neuman, 2006). In spite of exploratory research not yielding definite answers, it is, nonetheless regarded as an essential step in research, since it creates a foundation for further research inquiry (Gravetter & Forzano, 2003; Neuman, 2006; Rosnow & Rosenthal, 1993). Although the concept of resilience is widely researched on an individual level, the study of family resilience is a rather more recent trend. Furthermore, research within the South African context regarding family resilience is limited, however, the study of this concept is slowly gaining momentum. A number of researchers have investigated resilience from a family perspective. Solomons and Greeff (2001) investigated family resilience in poor, single parent families, Greeff and Human (2004) examined families in which a parent had died, Greeff and Van der Merwe (2004) looked at divorced families, Greeff

and Aspelting (2004) studied resilience in single-parent families, Redinger (2005) studied family resilience in response to extra-familial child sexual abuse, and Van der Walt and Greeff (2006) examined resilience in families with an autistic child.

The most recent research undertaken at the Nelson Mandela Metropolitan University has focused on the resiliency factors of families with a child that has Autism (Hanekom & Brown-Baatjies, 2006), Coetzee et al. (2006) focused on families with a Type 1 Diabetic child, Robinson and Brown-Baatjies (2006) examined step-families, Haddad et al. (2007) examined families where a member had been diagnosed with Schizophrenia, while Theron et al. (2008) investigated families with a child with Attention Deficit Hyperactivity Disorder.

There have been a few studies in South Africa that have focused on the treatment and physical management of CP. A small number of studies have explored the stress responses and coping strategies identified in these families (Germishuys, 1992; Mweshi, 1999; Pugin, 2007; Selkon, 2007), but there has been limited research to date on the resilience of families living with a child diagnosed with CP based on a specific conceptual framework designed to explain coping and adaptation in families. Consequently, it was important to gain an understanding of the resiliency processes in families living with a child diagnosed with CP and to identify the factors that are essential for their recovery when faced with the prolonged stress associated with the diagnosis.

4.3.2 Descriptive Research

Struwig and Stead (2001) explained that descriptive studies attempt to provide a complete and accurate description of a situation. Descriptive research is therefore regarded as extremely valuable in psychology as it presents a picture of the specific details (i.e., the frequency and prevalence) of a situation, social setting or relationship (De Vos, 2005; Neuman, 2006; Rosnow

& Rosenthal, 1993). Descriptive research describes and reports on variables without an intention of explaining them (Cozby, 2004; Harris, 1998). In this research, resilience in families living with a child with CP is explored and described.

Various descriptive methods can be used (Elmes, Kantowitz, & Roedifer III, 2003, Goodwin, 2005; Graziano & Raulin, 2000). These include observational methods, case studies, meta analysis or archival research, and survey research (Cozby, 2004; Graziano & Raulin, 2000). The present study used a cross-sectional survey research design as a means of gathering both quantitative and qualitative data, since a biographical questionnaire and structured paper-and-pencil measures were utilised. A survey technique is a method of gathering information by questioning individuals who are the object of research (Cozby, 2004; Salkind, 2003). There are various advantages to using the survey method. Some of the advantages of survey research are that it allows the researcher to gain a broad picture of the topic under study. Data can be gathered in one sitting and minimal facilities are required (Salkind, 2003) resulting in significant savings in terms of time and expenses (Cozby, 2004). In addition, the survey method provides opportunity for greater privacy for the participants (Cozby, 2004) and it is relatively easy to establish validity and generalisation of the results, depending on the effectiveness of the sampling technique used (Cozby, 2004; Neuman, 2006; Salkind, 2003). Furthermore, interview bias is reduced by participants completing identically worded self-report measures (Strydom, Fouche, & Delport, 2002).

Survey research also has potential challenges such as that of ensuring a sufficient response rate (Salkind, 2003). There are various reasons for low response rates, such as participants with literacy problems, low educational background or simply too many time demands and constraints. People may not understand questions, or are too busy or not interested enough to

complete the survey (Cozby, 2004). Low response rates inadvertently produce a smaller sample than the researcher intended. The implications of this are that the findings based on those who do respond will be different from if the entire group had been considered and as a result the external validity of the study decreases (Gravetter & Forzano, 2003; Salkind, 2003; Whitley, 2002). Other disadvantages of the survey method include biased sampling, risk of misunderstood and unanswered questions, lack of spontaneous responses and susceptibility to faking, as well as a lack of control over the environment (Neuman, 2006).

The researcher attempted to control some of these disadvantages by encouraging the participants to answer the questions as honestly as possible. In order to reduce unanswered and misunderstood questions, the researcher provided a contact number. Furthermore, stamped addressed envelopes were provided to increase the poor response rate usually associated with the survey method. In light of some of the limitations related to survey research, the researcher attempted to manage the possibility of a low response rate by identifying more families than the study intended. In addition, the researcher made brief contact with the potential research participants in the form of a telephonic or face-to-face conversation, where the aim of the study as well as the possible benefits thereof, were explained to the family. Regular follow-up attempts were also made with families during which they were encouraged to complete and return the sets of questionnaires.

In order to increase the families' level of understanding, each family was provided with sufficient information about the study as well as the contact details of the researcher in the event that any questions or concerns related to the study arose. An inclusion criterion of the study was that the research participants had to have at least a Grade 10 language proficiency in either English or Afrikaans. Families were also provided with sets of questionnaires and an

instructional letter in their language of preference. This criterion restricted limitations related to literacy and low educational background. Furthermore, the research participants were encouraged to answer the questions as honestly as possible, ensuring that spontaneous and honest perceptions of their experience would facilitate better management of the child's disorder and would create insight regarding the development of healthier family relations.

It can be concluded that it is important to guard against potential pitfalls when designing survey research and to be cautious about generalising from the results (Corbetta, 2003; Neuman, 2006). The sampling procedure and issues related to the research participants for the present study are now discussed.

4.4 PARTICIPANTS AND SAMPLING

The sampling procedure often results in sampling bias (Cozby, 2004; Goodwin, 2005) and is therefore a critical issue to consider when identifying the research sample. The sampling procedure and the issues related to the research participants are discussed in the following section.

4.4.1 Sampling

In view of the aim of this study, non-probability, purposive sampling was used to gather participants. Non-probability sampling implies that the probability of a person being chosen as a research participant is unknown since the researcher is unfamiliar with the size or the members of the population (Gravetter & Forenzo, 2003; Neuman, 2006). Non-probability sampling is more cost effective than other methods and the cluster of the population included is easily accessible to the researcher (Cozby, 2004). However, one limitation of this type of sampling is

that the participants are not randomly selected and therefore the results of the study cannot be generalised beyond the scope of the research sample. In light of the exploratory descriptive nature of the research, the above-mentioned limitations related to the sampling procedures were considered, but not seen as significant problems (Cozby, 2004).

In purposive sampling, the researcher is able to use her judgment to select the sample based on the specific goals of the research and the inclusion criteria of the sample (Whitley, 2002). This implies that participants are selected on the basis of certain characteristics such as specific knowledge or experiences related to the purpose of the study (Shaughnessy, Zechmeister, & Zechmeister, 2000). In this type of sampling, the risks of selection bias are high and therefore the results of the study cannot be generalised to the larger population (Graziano & Raulin, 2000). However, advantages of this method include the fact that the researcher does not have to have a sampling frame available and the researcher can control the applicability of the participants to the research population, i.e. that the participants have to meet the inclusion criteria (Cozby, 2004; Shaughnessy et al., 2000).

The discussed sampling methods were used to identify families who met the inclusion criteria for the present study. The goal was to involve a minimum of 60 families as research participants. The inclusion criteria of the study are stipulated in the section to follow:

For the purpose of this study, a family was defined as two or more people that live together for the benefit and the development of each member, and the group as a whole (Greeff, 2004). The family unit had to include a child that had been diagnosed with CP by a neurologist or paediatrician for a minimum period of six months. The child with CP had to form part of the family where the caregivers reside within the same house, regardless of the nature of their relationship (e.g., co-habiting or married). The initial goal was to enlist the help of two

caregivers of the child living with CP as representatives for the family, both of which were to complete questionnaires individually, and which had to be over the age of 18 years. However, following a poor response rate of two caregivers per family unit, the goal was amended to enlist the help of at least one female caregiver of the child living with CP as a representative for the family. Additional inclusion criteria were that the family had to include a child with CP aged between 24 months and 18 years of age. A Grade 10 proficiency level in English or Afrikaans was recommended to understand the questionnaires however previous family resilience research projects that were published had been successfully conducted with participants with only a Grade 8 language proficiency level (Der Kinderen & Greeff, 2003; Greeff & Human, 2004; Greeff & van der Merwe, 2004).

The non-probability purposive sampling technique was suitable for study as the researcher approached several pre-determined special needs schools within the Nelson Mandela Bay Metropolitan area and requested their participation in the research. Furthermore, the Cerebral Palsy Association (Eastern Cape) in the Nelson Mandela Bay Metropolitan was approached to enlist their help in obtaining participants for the study.

A total of 138 families who met the inclusion criteria for the study were identified using the techniques described. A total of 44 sets of questionnaires were returned, of which 30 sets of questionnaires met the inclusion criteria of the study. Fourteen sets of questionnaires could not be used for the purpose of this study, since the research participants did not meet one or more of the inclusion criteria of the study. A total of 27 families met the inclusion criteria of the study, of which three had two female caregiver participants. An outline of the information that was obtained from the sample of participants is discussed in the next section.

4.4.2 Research Participants

A total of 27 families from the Nelson Mandela Bay Metropolitan participated in this study. The majority of research participants lived in Port Elizabeth (24 families), while the remaining three families were from Uitenhage. The participants were all female caregivers of the child living with CP. Three families that participated in this study involved two female caregivers (i.e., one consisting of the mother and domestic helper of the child living with CP and two consisting of the mother and the grandmother of the child living with CP). The ages of the participants ranged from 26 years to 67 years. The mean age of the caregivers that participated was 43.90 years.

In terms of marital status, the majority of the participants were married ($n=16$). There were eight participants who were single, four that were widowed, one that was divorced and one that was separated. The duration of the married caregivers' relationship with their spouses ranged from 6 years to 36 years, with an average of 15.79 years.

A limitation of this study is that research participants were not asked to indicate the relationship of all of the people living in the family home. The implication was that it was unclear as to which members of the household were additional people living in their home with them. The family composition ranged from two to ten family members living in the home, with an average of 4.59 family members per household.

Although in this study the questionnaires were only made available in English and Afrikaans, research participants were provided an opportunity to indicate their home language as being English, Afrikaans or isiXhosa. The sample shows a relatively even distribution of English ($n=10$), Afrikaans ($n=9$) and isiXhosa-speaking ($n=11$) research participants. The research participants whose home language was neither English nor Afrikaans (i.e., isiXhosa) were able to

choose to complete the questionnaires in either English or Afrikaans based on their language proficiency. The results indicated that the education level of the research participants varied from high school to tertiary education. The majority of research participants had obtained high school education level ($n=16$), while six obtained a degree, and eight had obtained a diploma. The majority of the research participants were employed in some capacity, whether permanent or temporary in nature ($n=21$). The remaining nine participants indicated unemployment at the time of the research.

One of the inclusion criteria of this study was that the family had to include a child between the ages of 24 months and 18 years who had been diagnosed with CP by a neurologist or paediatrician for a minimum period of six months. The rationale behind the inclusion criteria is that family resilience literature (McCubbin et al., 2001; Walsh, 2002) suggested that adjustment and adaptation involves processes that occur over time. The rationale for the age range preference was to homogenise the life cycle stage of the family. The ages of the children diagnosed with CP in this study ranged from 4 years to 17 years with the average age of 4.92 years. The specifics of their ages are as follows: 1 four-year-old, 3 five-year-olds, 6 six-year-olds, 2 seven-year-olds, 3 eight year olds, 2 ten year olds, 1 eleven year old, 2 twelve year olds, 2 thirteen-year-olds, 1 fourteen-year-old, 2 fifteen-year-olds, 1 sixteen-year-old and 4 seventeen-year-old children. The biographical data further indicated that the gender of the children on which information was provided were majority male ($n=16$), with twelve of the children being female. One set of twins was included in the sample. The majority of the children had been diagnosed with CP between the ages of seven to twelve months ($n=9$). Six of the children were diagnosed with CP at birth, another six were diagnosed between the ages of two to six months. Two of the children were diagnosed with CP between the ages of 13 and 18 months, while one

was diagnosed at the age of 24 months. Two of the children were diagnosed with CP between the ages of 25 and 30 months, and the remaining two children were diagnosed at the age of five years. The various methods that were used to obtain the data are discussed in the section to follow.

4.5 RESEARCH MEASURES

Various measures were used to gather data for the study. These included a biographical questionnaire with two open-ended questions as well as seven brief structured paper-and-pencil questionnaires. The following structured questionnaires were employed for the purposes of this study:

1. Family Attachment and Changeability Index (FACI8)
2. Social Support Index (SSI)
3. Relative and Friend Support (RFS)
4. Family Problem-Solving Communication (FPSC)
5. Family Hardiness Index (FHI)
6. Family Crisis-Oriented Personal Evaluation Scales (F-COPES) and the
7. Family Time and Routine Index (FTRI)

The FACI8 represented the dependent variable, namely the extent to which the family has adapted, while the other measures represented the independent variables. These questionnaires were made available in English and Afrikaans. The biographical questionnaire and the seven structured questionnaires took the participants approximately one hour to complete. Since the measures have not been standardised for the South African population, scores are in the form of raw scores as opposed to standardised scores. In addition, these measures have been used in

South African studies that have been published (Der Kinderen & Greeff, 2003; Greeff & Human, 2004; Greeff & van der Merwe, 2004). Furthermore, a study is currently being conducted at the University of Stellenbosch that is investigating the reliability, validity and the relevance of these measures for the South African population (Brown-Baatjies, 2006). The measures that were used for the aim of this study are now described.

4.5.1 Biographical Questionnaire

A brief biographical questionnaire consisting of twelve items (see Appendix D) was compiled to obtain relevant information from the research participants such as area of residence, economic status, marital status, family composition (e.g., number of family members), relationship to the family member as well as language. The participant was requested to indicate the child's age and gender, the time period of the diagnosis and to describe, in an open-ended manner, the limitations of the child with CP. Furthermore, the educational levels as well as employment of family members were also requested. An opportunity to request generalised feedback regarding the results of the study was provided as the final item on the biographical questionnaire.

The biographical questionnaire was compiled with the goal of gathering important demographic and background information pertaining to research participants, which enabled the researcher to contextualise the findings of the open-ended question and the paper-and-pencil measures. The open-ended question of the biographical questionnaire requested the participants' opinions on which factors or strengths they believed helped their family through their crisis period. This provided the research participants with an opportunity to comment on strengths that they possessed but which were not listed in the other questionnaires. The additional seven

questionnaires attempted to measure the components of the Resiliency Model of Family Stress, Adjustment and Adaptation as depicted in Chapter Two.

4.5.2 Family Attachment and Changeability Index 8 (FACI8)

The Family Attachment and Changeability Index 8 (FACI8) was adapted from the Family Adaptability and Cohesion Evaluation Scales II (Olson, Portner, & Bell, 1989) by McCubbin, Thompson, and Elver (1995) as a measure of family functioning. In accordance with the theoretical model underlying this research, the FACI8 was used as the dependent variable and determined the level of family adaptation (XX).

This index is designed to evaluate family functioning by measuring attachment and changeability. The Attachment subscale measures how attached family members are to each other by analysing the time they spend together and the nature of their communication. Families who engage in activities as a unit and confide in each other as opposed to confiding in people outside of the home are more attached. An example of an Attachment subscale item is 'It is easier to discuss problems with people outside the family than with other family members'. The Changeability subscale measures the level of flexibility in the relationships between family members by examining factors, such as whether the family is prepared to compromise when problems arise, or whether rules can be changed, for example: 'Our family tries new ways of dealing with problems'.

This measure consists of 16 statements about the family for which the participant has to indicate on a 5-point Likert scale (never, sometimes, half the time, more than half, always) how applicable each statement is to the family at that time. Each subscale consists of eight items and may be used together or separately.

The internal reliability (Cronbach's alpha) of the subscales varies between .75 and .80, whilst the validity was established by determining the FACI8's relationship to successful outcomes of a treatment programme (McCubbin et al., 2001). The overall internal reliability for the FACI8 in this study was .81 (Cronbach alpha), while the internal reliability of the subscales was .84 (Cronbach alpha) for Attachment and .66 (Cronbach alpha) for Changeability.

4.5.3 Social Support Index (SSI)

The Social Support Index (SSI), developed by McCubbin, Patterson and Glynn (1982), measures the extent to which families are integrated into their community; the degree to which families find support in their community; and the level of network and emotional support that families perceive that the community provides. This questionnaire also taps into the family and community resources component (BBB) of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin et al., 1997). Community-based social support is viewed as an important contributing factor in resilience. Sources of support include emotional support (such as recognition and affirmation), esteem support (affection) and network support (relationships with relatives) (McCubbin et al., 1997). Social support acts as a buffer against family crisis factors, promotes family recovery and acts as a mediator of family distress (McCubbin et al., 2001).

The SSI consists of 17 items that the participant responds to (with specific reference to their family) on a 5-point Likert scale ranging from strongly disagree, disagree, neutral, agree to strongly agree, for example: 'People can depend on each other in this community'. The internal reliability of the SSI is .82 (Cronbach alpha) and the test-retest reliability is .83. The validity

coefficient of .40 correlated with the criterion of family well-being (McCubbin et al., 2001). In the present study, the SSI was found to have an internal reliability of .87 (Cronbach alpha).

4.5.4 Relative and Friend Support (RFS)

The Relative and Friend Support Index (RFS), developed by McCubbin, Larson and Olson (1982), measures the extent to which family members use the support of friends and relatives as a coping strategy when dealing with stressors. The instrument attempts to measure the family resources (BB) component of the Resiliency Model (McCubbin et al., 2001). The RFS consists of eight items rated on a 5-point Likert scale ranging from strongly disagree, disagree, neutral, agree to strongly agree, for example: 'We cope with problems by seeking advice from relatives'. This measure has an internal reliability of .82 (Cronbach alpha) and a validity coefficient of .99 (McCubbin et al., 2001). In the present study, the RFS was found to have an internal reliability of .72 (Cronbach alpha).

4.5.5 Family Problem-Solving Communication (FPSC)

The Family Problem Solving and Communication Scale (FPSC), developed by McCubbin, McCubbin and Thompson (1988), evaluates the positive and negative patterns of family communication when dealing with stressful situations. In particular, the FPSC was essentially developed for research into family stress and resiliency with the goal of measuring the problem-solving and coping component (PSC) of the Resiliency Model. It is assumed that the quality of communication indicates to what extent family functioning, adjustment and adaptation are experienced as satisfactory. This measure consists of 10 items on a 4-point Likert scale, which ranges from false, mostly false, mostly true, to true. These items are divided into two subscales,

one for evaluating positive communication and one for evaluating negative communication in the family during conflict situations.

The positive communication subscale, referred to as 'Affirming Communication', measures the type of communication that diffuses a situation by conveying caring. For example: 'When our family struggles with a conflict which upsets us, we try to stay calm and talk things through'.

The negative communication subscale, referred to as 'Incendiary Communication', focuses on communication that exacerbates a conflict situation. For example: 'When our family struggles with a conflict which upsets us we scream at each other'.

The internal reliability for the whole measure is .78 (Cronbach alpha), while the test-retest reliability is reported to be .86 (McCubbin et al, 2001). The overall internal reliability for the FPSC in this study was .72, while the internal reliability of the subscales was .55 (Cronbach alpha) for Affirming Communication and .75 (Cronbach alpha) for Incendiary Communication. The validity of the FPSC is supported by multiple studies conducted by McCubbin et al. (2001), including studies of ethnic families.

4.5.6 Family Hardiness Index (FHI)

The Family Hardiness Index (FHI) measures the fortitude and durability of the family unit by evaluating its characteristics of hardiness. This measure was developed by McCubbin et al. (1986) and taps into the family's existing resources (BB) and family schemas (CCCCC), which is a dimension that is closely linked to hardiness as conceptualised in the Resiliency Model. Hardiness refers to a sense of control that the family experiences in terms of the outcomes of life events (CC) and hardships (AA) and facilitates family adjustment and adaptation over time.

Moreover, it refers to whether the family takes an active rather than passive stand with regard to adjustment and adaptation to stressful situations (McCubbin et al., 2001)

The instrument consists of 20 items that are divided into three subscales, namely commitment, challenges and control, which the participants respond to on a 5-point Likert scale (false, mostly false, mostly true, true, not applicable). Focussing on the collective 'we', rather than an individualistic 'I' perspective, items were constructed to slot in with one of three subscales:

The Commitment subscale measures the family's ability to work together, their internal strengths and their dependability with statements such as 'We believe that things will work out for the better if we work together as a family'. The Challenge subscale measures their ability to be innovative, to positively reframe crises as challenges and to seek out new experiences as challenges using statements such as 'We seem to encourage each other to try new things and experiences'. The Control subscale measures the extent to which the family have an internal locus of control and feel that they are in control of their circumstances as opposed to being the victims of fate with items such as 'We realise our lives are controlled by accidents and luck'.

The internal reliability of this measure is .82 (Cronbach alpha), and the test-retest reliability is .86. The validity coefficients range from .20 to .23 for family satisfaction, time routines and adaptability (McCubbin et al., 2001). In this study, the overall internal reliability of the instrument was -0.83 (Cronbach alpha) and was not able to be analysed due to a problem with one of the items. The internal reliability of the subscales for this study were .77 (Cronbach alpha) for the Challenge subscale, .52 (Cronbach alpha) for the Control subscale, and .80 (Cronbach alpha) for the Commitment subscale.

4.5.7 Family Crisis-Oriented Personal Evaluation Scales (F-COPES)

The F-COPES, developed by McCubbin et al. (1982), is designed to identify the problem-solving and behaviour strategies used by the family during a crisis. This instrument examines the interaction of the cumulative effect of demands (AA); family resources (BB); family problem-solving and coping ability (PSC) and meaning (CC) of the Resiliency Model. The measure focuses on two levels of interaction as illustrated in the Resiliency Model. Firstly, it observes the internal coping strategies within the family system (i.e., it looks at how the family manages problems and crises internally amongst themselves); and secondly, it concentrates on the external coping strategies between the family and the social environment (i.e., it focuses on how the family measures problems outside their boundaries, but which have an influence on the family unit). This instrument consists of 30 items rated on a 5-point Likert scale (strongly disagree, disagree, neutral, agree, strongly agree). Higher scores indicate effective and positive coping behaviour. The 30 items are divided into 5 subscales, namely (a) Acquiring social support subscale which measures whether the family is able to actively seek support from their social network consisting of relatives, neighbours and friends, (b) Reframing subscale which measures whether the family is capable of positively redefining stressful situations to make these more manageable, (c) Seeking social support subscale which measures the family's ability to seek out spiritual support, (d) Mobilising family to acquire and accept help subscale which measures the extent to which the family is able to seek out resources in the community and accept help from others, and (e) Passive appraisal subscale which measures the ability of the family to simply accept problematic issues, without actively trying to solve them, thereby minimising reactivity. Examples of items that participants were requested to respond to, include: 'When we face problems or difficulties in our family, we respond by seeking encouragement and

support from friends' and 'We define the family problem in a more positive way so that we do not become too discouraged'.

The F-COPES has a test-retest reliability of .71 (Cronbach alpha) and an internal reliability coefficient of .77 (Cronbach alpha) for the total scale (McCubbin et al., 2001). The construct validity of the questionnaire was proved with a factor analysis and a varimax rotation of the axes (Greeff & Aspeling, 2004). The Acquiring social support subscale has an internal reliability (Cronbach alpha) of .83 on the original version (McCubbin, Thompson, & McCubbin, 1996), and in the present study, an internal reliability of .74 (Cronbach alpha). The Reframing subscale has an internal reliability (Cronbach alpha) of .82 on the original version (McCubbin et al., 1996), and in the present study, an internal reliability of .71 (Cronbach alpha). The Seeking spiritual support subscale has an internal reliability (Cronbach alpha) of .80 on the original version (McCubbin et al., 1996), and in the present study, an internal reliability of .79 (Cronbach alpha). The Mobilising family to acquire and accept help subscale has an internal reliability (Cronbach alpha) of .71 on the original version (McCubbin et al., 1996), and in the present study, an internal reliability of .78 (Cronbach alpha). The Passive appraisal subscale has an internal reliability (Cronbach alpha) of .63 in the original version (McCubbin et al., 1996) and in the present study, an internal reliability of .40 (Cronbach alpha).

4.5.8 Family Time and Routine Index (FTRI)

The Family Time and Routine Index (FTRI), developed by McCubbin et al. (1986), evaluates the types of activities and routines used and maintained by the family and the importance of these to the family. These activities and routines contribute to the family's range of new and existing resources (BB). The specific activities and routines that a family engages in offer

relatively reliable indices of family integration and stability, which contribute to family resiliency. This instrument taps into the family type (T) component of the Resiliency Model (McCubbin et al., 2001).

The FTRI scale is comprised of 30 Likert-type items divided into eight subscales, namely parent-child togetherness, couple togetherness, child routines, meals together, family time together, family chores routines, relative's connection routines and family management routines. The participant responds to each item on two scales, the first being the degree to which each statement applies to their family behaviour (false, mostly false, mostly true, true) and the second being the level of importance that the family places on each routine (not important, somewhat important, very important or not applicable).

The FTRI has an overall internal reliability of .88 (Cronbach alpha) and the validity was confirmed by significant correlations with multiple criterion indices of family strengths (McCubbin et al., 2001). In this study, the overall internal reliability of the instrument was .90 (Cronbach alpha). Examples of items that participants were requested to respond to, include: 'Parents have some time each day for just talking with their children' and 'Family has a certain family time each week when they do things together at home'. The research procedure that was followed in the study is discussed next.

4.6 RESEARCH PROCEDURE

Researchers should constantly be concerned with ethical considerations when planning, conducting, and evaluating research (Cozby 2004). In consideration of ethical research procedures, a copy of the research proposal for this study was submitted to the Faculty Research, Technology and Innovations Committee and Ethics Committee (Human) at the Nelson Mandela

Metropolitan University to obtain permission for commencement of the study. Once permission was granted, the researcher approached the Department of Education to obtain consent to approach several schools in the Nelson Mandela Bay Metropolitan to participate in the study. Thereafter the researcher contacted the pre-determined schools to seek the principals' permission to access participants for the study. The researcher also approached the Cerebral Palsy Association (Eastern Cape) in an attempt to access participants for the study. A detailed description of the value of the study, either telephonically or in person and in written document form, was provided to the principals at the schools and the Cerebral Palsy Association (Eastern Cape).

Once permission had been granted, the researcher contacted families identified by the schools to request their participation. A covering letter (see Appendix B) was sent to all potential participants informing them about the researcher, the nature and purpose of the study, and issues of confidentiality. The voluntary nature of the research was addressed and, at the same time, the covering letter indicated the value and benefit of the research to the participants. The researcher's contact number was included in the covering letter for any questions that may have arisen regarding the information provided. Interested participants who met the inclusion criteria were asked to contact the researcher directly in order to ensure that confidentiality was maintained. Once research participants conveyed their interest to participate, the researcher created research packages comprising of two sets of pre-designed consent forms (see Appendix C), biographical questionnaires (see Appendix D) as well as the seven structured paper-and-pencil questionnaires (one set for each caregiver/guardian or parent), written in either English or Afrikaans. Where possible, the researcher made physical contact with the participants and provided them with the research packages and, where this was not possible, the research

packages were mailed to the participants. Participants were asked to sign the consent forms and return them directly to the researcher, along with the completed biographical forms and questionnaires in the stamped, addressed envelope provided thereby confirming their agreement to participate voluntarily in the study.

In order to increase the families' response rate, regular follow-ups and reminders were done with families to encourage them to complete the questionnaires and also to provide the researcher an opportunity to answer any questions relating to the present study that the families may have had. These follow-ups also provided an opportunity for the participants to withdraw from the study, if they so wished. As a result of the poor response rate, the inclusion criteria were adjusted to include only one female caregiver per family unit. A total of 138 sets of questionnaires were sent out and 44 sets were returned. An independent coder assisted in scoring and re-checking the questionnaires. The following section addresses the analysis of the data.

4.7 DATA ANALYSIS

Both qualitative and quantitative data were analysed in terms of the aim of the study. These are discussed below.

4.7.1 Qualitative Data Analysis

Thematic content analysis was used to analyse the qualitative data obtained from the open-ended questions in the biographical questionnaire. Content analysis refers to the analytical classification process that a researcher follows in order to organise data into relevant themes and categories (Henwood & Pedgeon, 1997). Coding is a fundamental part of qualitative research.

Rather than simply being a clerical task, it enables the researcher to organise raw data into themes and concepts that may then be used to analyse the data (Babbie, 2004; Neuman, 2006).

An independent coder was employed in order to counter potential researcher bias. The content analysis process followed Tesch's (1990) Model of Content Analysis, which is an eight-step model used to categorise the data meaningfully. Tesch's model (1990) was followed in the following manner:

The researcher first gained a general impression of the data by reading through the material as the data was gathered, so as to gain an understanding of the data and begin formulating ideas around recurrent themes in the data.

The next step was to select any one data document and begin to identify common topics from the material. The researcher then captured these topics in writing, the ultimate goal being to establish what the document was about and its underlying meaning. This procedure was then repeated for all data documents.

During the third step, the researcher made a list of all the topics and themes that emerged from the data documents. Themes were clustered together in terms of major themes, unique themes and leftovers for each data document.

Once the themes were identified, they were abbreviated into codes, which were then written next to the appropriate sections of the text. The value of this phase was that it allowed the researcher to detect new themes and codes that could be integrated into the text.

The researcher then assigned descriptive names to the themes and created categories for them. From the lists of categories, related themes were grouped together, reducing the overall list of themes. Once the researcher had made a final decision regarding the abbreviation for each category, the codes were arranged in alphabetical order.

Data material related to specific categories was assembled in one place and a preliminary analysis was performed. The goal of this procedure was to identify and summarise the content for each category so as to identify information that was pertinent to the study. After extensive analysis, the researcher decided whether the categories were inclusive or exclusive enough and recoded the data accordingly.

As with all research, it was important to establish the accuracy of the information or its internal validity. The researcher employed Guba's Model of Trustworthiness (De Vos, Strydom, Fouché, & Delpont, 2002) to ensure objectivity and to counter researcher bias throughout the qualitative data analysis process. This model is invaluable in that it enables the researcher to determine the internal and external validity, reliability and objectivity of the qualitative data and poses questions to the researcher regarding whether or not the results of the qualitative data adhered to the four constructs, namely credibility, transferability, dependability and conformability (Guba & Lincoln, 1985). These constructs are similar to the more conventional terms of the positivist paradigm, namely internal and external validity, reliability and objectivity. A brief explanation of these constructs is now provided (De Vos, 2005).

Credibility refers to the inferences made about the data. It is the alternative to internal validity, where the goal was to demonstrate that the study was conducted in a manner that ensured that the research participants were identified and described in an accurate way. The researcher ensured that data was vigilantly and accurately communicated.

Transferability, as a criterion of trustworthiness, is similar to external validity. This, however, was not considered for the purposes of this study, since it refers to the degree to which the findings can be transferred to a context outside the study. The present study is exploratory-

descriptive in nature and therefore the ultimate goal was not to generalise the findings to larger populations.

Dependability is viewed as the alternative to reliability, where the possibility of replicating the study and achieving similar results is considered. However, qualitative researchers suggest a change from the positivist assumptions surrounding reliability, where it is assumed that we live in an unchanging social world where results can easily be replicated, as these assumptions are in contrast to the qualitative/interpretive view that the world is dynamic and that replication of results is problematic (De Vos, 2005; Guba & Lincoln, 1985). Nevertheless, it is necessary to be meticulous when describing the setting and conditions in which the qualitative research is conducted, as well as that of the participants, the research design and procedure (Coolican, 1999).

Conformability captures the traditional concept of objectivity. Guba and Lincoln (1985) emphasised that others should be able to confirm the findings of a study. The goal is to remove the subjective influence of some of the characteristics that are inherent to the researcher and rather focus on the data themselves (De Vos, 2005). An independent coder was employed in an attempt to counter potential researcher bias.

4.7.2 Quantitative Data Analysis

Descriptive statistics was employed to analyse the biographical information, while correlation and regression analysis was employed to analyse the quantitative data. In this study, the FACI8 represented the dependent variable, while all the remaining measures, including the biographical questionnaire, represented the independent variables. The independent variables form part of the

process which ultimately leads to *bonadaptation* or *maladaptation*. The FACI8 indicated the family's resilience by measuring the degree of their adaptation (XX) after a hardship or crisis.

Correlation and regression are closely related (Harris, 1998), as regression analysis cannot be performed without there being several independent variables (Coolican, 1999). Correlation analysis measures the strength and significance of the relationship between two or more variables and illustrates the degree to which values on one could predict values on another (Bordens & Abbott, 2002). These variables are not manipulated in any way, but are rather merely observed for any relationship that might exist (Bordens & Abbott, 2002). Furthermore it measures and describes the direction and degree of the relationship between variables (Gravetter & Forzano, 2003; Jackson, 2003; Mertens, 1998). Regression analysis allows the researcher to examine the relationships that exist between multiple independent variables and a single dependent variable and to determine the extent to which the independent variables can predict the dependent variable (Strydom et al., 2002).

The Spearman's rank correlation coefficient (Spearman r) was calculated to determine the relationship between the research participants' level of family adaptation and potential resiliency variables. The correlation value provides information regarding the strength and direction of the relationship between two variables, which permits prediction (Elmes et al., 2003; Harris, 2003; Rosnow & Rosenthal, 1993). This value can range from -1.00 to +1.00, with zero indicating no relationship at all (Cozby, 2007; Spata, 2003). A bigger numerical value of Spearman's r indicates a stronger relationship between the correlated variables, regardless of the positive or negative sign (Spata, 2003). The sign of the Spearman's r indicates the direction of the relationship between the variables. A positive correlation suggests that an increase in one value is associated with a corresponding increase in the value of the other variable. A negative

correlation indicates that a decrease in the value of one variable is associated with a corresponding increase in the value of the other variable (Coolican, 1999; Cozby, 2004; Graziano & Raulin, 2000; Russell & Roberts, 2001; Spata, 2003). When there is no trend between variables and it appears that there is no relationship between them, there is no correlation. A limitation of the Spearman's correlation coefficient is that it is limited to establishing the significance of relationships between variables, and that no inferences regarding causality can be established (Coolican, 1999; Cozby, 2004; Graziano & Raulin, 2000; Harris, 1998; Spata, 2003).

In order to assess this significance, p values were employed. Harris (2003) stated that most psychological reports make use of a p value of 0.05 to assess the significance of the correlation. Although a correlation that reaches a p value of 0.05 is considered to be significant, an r that reaches a p value of 0.01 or 0.001 is considered a more stringent and rigorous significance level (Harris, 2003). The strength of the relationships between variables was interpreted using the well-established guidelines of Guilford (1946). These guidelines are as follows:

Less than 0.20	slight; almost negligible relationship
0.20 – 0.40	low correlation; definite but small relationship
0.40 – 0.70	moderate correlation; substantial relationship
0.70 – 0.90	high correlation; marked relationship
0.90 – 1.00	very high correlation; very dependable relationship

In addition to calculating Spearman's correlation coefficients and determining significant relationships between variables, a regression analysis was conducted. Regression analysis was used to establish whether a combination of independent variables, as opposed to a single independent variable, could predict scores on the dependent variable (FACI8). The motivation

behind this procedure was that an independent variable on its own may not correlate significantly with the dependent variable. However, when combined with other independent variables, this combination may predict the dependent variable (Harris, 2003). The mean was used to measure central tendency and standard deviations were used to measure variability. The mean describes the group's performance by providing the "typical" score in the group (Zechmeister, Zechmeister, & Shaugnessy, 2001). The standard deviation measures how much the scores deviate from the mean (Cozby, 2004).

Throughout the data analysis process and research procedure, rigorous ethical guidelines were adhered to. These ethical considerations are now briefly discussed.

4.8 ETHICAL CONSIDERATIONS

Struwig and Stead (2001) emphasised the importance of researchers respecting the rights and dignity of research participants. The ethical procedures considered throughout this study are now discussed.

4.8.1 Informed Consent and Voluntary Participation

Informed consent provides research participants with sufficient information to assess for themselves whether or not they would like to partake in the proposed study (Foxcroft & Roodt, 2001). The principals of the identified schools and the Cerebral Palsy Association (Eastern Cape) that agreed to support the study were provided with an introductory letter (see Appendix A) that outlined the nature and purpose and the inclusion criteria of the study. Principals of identified schools and the Cerebral Palsy Association (Eastern Cape) also assisted in identifying participants for the study. Once permission was obtained from these individuals, a covering

letter was sent to all potential participants, informing them about the researcher, the nature and purpose of the study, the possible value and benefit of the research, and addressing issues of confidentiality and the voluntary nature of the research. The researcher's contact number was provided in the covering letter for any queries regarding the information provided.

Interested participants who met the inclusion criteria were requested to contact the researcher directly in order to ensure that confidentiality was maintained. The researcher provided the interested participants with a pre-designed consent form, authorised by the Ethics Committee (Human) of the Nelson Mandela Metropolitan University, to confirm their voluntary willingness to participate in the research. The researcher respected the participants' right to decline participation or withdraw from the research at any time.

4.8.2 Privacy and Confidentiality

The general principle in dealing with confidential personal information is that such information should be used with great care and only disclosed where necessary (Louw & Edwards, 1997). The covering letter sent to all participants emphasised the importance of confidentiality in the study, reassuring participants that their privacy would be protected and ensuring that their personal identities would not be revealed in the reporting of the research.

Confidentiality was also maintained through the process of coding the questionnaires. The participants' particulars with the corresponding questionnaire codes were only made available to the researcher. Anonymity was ensured by only requesting the participants' personal details should they request generalised feedback of the results and findings of the study. The privacy of the research participants and the confidentiality of their personal details were further maintained

when the researcher provided stamped addressed envelopes for the return of the completed forms to the researcher.

4.8.3 Minimising Psychological Risk and Harm

When conducting research, the researcher has an ethical responsibility to minimise risk and protect participants from any physical or psychological harm that might be incurred during participation in such a study (Leedy & Ormrod, 2005; Strydom, 1998). In order to minimise psychological risk or harm towards the research participants, this study was strictly evaluated by the Faculty Research, Technology and Innovations Committee at the Nelson Mandela Metropolitan University before receiving approval for commencement of the research. This study was considered to be of minimal risk since the study explored activities related to the daily lives of the research participants (Shaughnessy et al., 2000) within a positive psychology framework that explored the adjustment and adaptation processes of the family. In the event of the participants feeling any discomfort while completing the different measures, they had the option of contacting the researcher or withdrawing from the research at any time, having been informed that they were not obligated to fulfil their commitment as a result of the signed consent form.

4.8.4 Dissemination of Results

Imparting knowledge obtained in this study was considered to be of importance. The research participants were invited to provide their contact details on the biographical questionnaire should they wish to receive a brief summary report of the general findings of the study. Each of the participating schools and the Cerebral Palsy Association (Eastern Cape) will be provided with a brief summary report of the general findings of the study upon completion of the study, as part of

sharing the knowledge gained through this research study. Upon completion of the study, a copy of the final treatise will be given to the District Office, Educational Support Programmes, as requested as well as to the library of the Nelson Mandela Metropolitan University. The results of the study will also be outlined in the form of a draft manuscript that will be submitted for review for article publication purposes. Furthermore the researcher will present the findings of this study at a research conference or congress.

4.9 CONCLUSION

Chapter Four provided an overview of the research methodology followed in this study. The present study aimed to identify resilience factors that facilitate adaptation in families living with and caring for a child diagnosed with CP, which was best met through a combination of quantitative and qualitative research techniques. Data was gathered in the form of structured questionnaires and from two open-ended questions in the biographical questionnaire. Participants were identified through the employment of non-probability, purposive sampling techniques.

Quantitative data was analysed through correlation and regression analyses, while Tesch's thematic content analysis was used to identify themes from qualitative data. Throughout the research, the researcher carefully considered the ethical procedures and practices in an attempt to secure the well-being of research participants. The results obtained from the content and statistical analysis are presented and discussed in the following chapter.

CHAPTER FIVE

RESULTS AND DISCUSSION

5.1 INTRODUCTION

The results of this study are presented and discussed according to the primary aim of the study, which was to identify, explore and describe the resiliency factors that facilitate adjustment and adaptation in a family with a child that has CP. Chapter Five provides a description of the quantitative and qualitative results that were obtained from the seven questionnaires.

The biographical details of the sample are initially presented in order to obtain a comprehensive picture of the sample. Thereafter, the results of the open-ended question that was included in the biographical questionnaire are discussed. Finally, a description of the quantitative results that were obtained from the quantitative measures is provided and discussed in terms of the study and the literature. The following section unpacks the biographical questionnaire.

5.2 THE BIOGRAPHICAL QUESTIONNAIRE

As discussed in Chapter Four, the biographical variables that were mentioned relate specifically to the information obtained from the biographical questionnaires that the female caregivers of the child diagnosed with CP completed. As the variables obtained from the biographical questionnaire have been discussed previously, the qualitative findings of the open-ended question specific to each child's limitations as a result of the CP are presented.

5.2.1 Limitations of the Children as a Result of Cerebral Palsy

From the 30 research participants (i.e. 27 families) that participated in this study, 29 participants responded to an open-ended question in which they were asked to describe the specific limitations of the child with CP as a result of the CP. This qualitative data was analysed using Tesch's model of content analysis and a researcher was employed as an independent coder to ensure that the process of analysis was trustworthy. The rationale for such an open-ended question was to provide an indication of each family's specific challenges as a result of the CP and in order to gain a greater understanding of the research population. A limitation of this population group is that CP varies considerably with regard to the child's functional impairment and degree of disability (Murphy & Such-Neibar, 2003), making it difficult to homogenise the population group. The range of severity varies from complete immobility and dependency on others to functional abilities of talking, self-care, walking, running and other skills, although with some clumsiness (Levitt, 2010). The functional limitations of each child as reported by the caregivers are presented in Table 1.

Table 1: Limitations of the Child as a Result of Cerebral Palsy (n=29)

LIMITATIONS AS A RESULT OF CEREBRAL PALSY	FREQUENCY (n=29)
Motor Deficits	
Cannot walk independently	7
Cannot stand or walk / Uses a wheelchair	8
Cannot run	2
Delayed walking and milestones	5
Poor balance	3
Weak muscle strength / Low muscle tone	8
Impaired walking	3
Poor hand functioning, hand co-ordination and fine motor skills	6
Spasticity	2
Mild CP	2
Visual Deficits	
Impaired eye-sight	3
Speech and Communication Deficits	
Poor speech / communication skills	8
Non-verbal	3
Activities of Daily Living	
Dependent on others	8
Difficulty in completing independently	4
Other Associated Problems	
Attention Deficit/Hyperactivity Disorder	1
Scholastic difficulties	3
Drooling	1
Epilepsy	1
Emotional difficulties	2

5.2.1.1 Motor Deficits

CP is primarily associated with motor impairments (Badawi et al., 1998) of various forms (Kolb & Whishaw, 1999). The participants of the study reported a broad range of motor limitations that their children with CP experience. The extent of the physical limitations ranged from complete inability to stand or walk and dependent on the use of a wheelchair ($n=8$) to unable to walk independently (i.e., without the use of an aid) ($n=7$). Examples of statements were:

- “Cannot walk without a walking frame” (i.e., cannot walk independently)
- “Can’t walk alone yet” (i.e., cannot walk independently)
- “She is using a wheelchair”
- “Unable to sit or stand...wheelchair bound” (i.e., cannot stand or walk)
- “He is not able to walk” (i.e., cannot stand or walk).

Other participants indicated that although their children could walk, they were unable to run ($n=2$). An example of a statement was:

- “Can walk but can’t run”.

A number of the participants reported that their children with CP experienced delays in their developmental milestones and in walking ($n=5$). Examples of statements included:

- “She never crawled”
- “She only started walking at the age of 5”
- “He didn’t [sit] till the age of 4”.

Poor balance impacts on smooth walking skills. Three participants reported their children to have poor balance ($n=3$), while five participants referred to their children as having impairment in their walking ($n=5$). Examples of the statements include:

- “He has a poor balance” (i.e., poor balance)
- “... se balans is nie 100% nie” [...’s balance is not 100%]¹ (i.e., poor balance)
- “My child finds it difficult to bend the knees” (i.e., impaired walking)
- “He is limping a little bit” (i.e., impaired walking)
- “Linkerbeen sleep” [left leg drags] (i.e., impaired walking).

The impaired control of motor functions of people living with CP has the potential to impact negatively on the child’s overall development (Jan, 2006; Jones et al, 2007). Muscle weakness, fatigue, and poor co-ordination are associated with these motor deficits (Jan, 2006). Participants reported weak muscle strength and low muscle tone ($n=8$) and poor hand functioning, poor hand co-ordination and poor fine-motor skills ($n=6$). Examples of the statements were:

- “The right side of her body is weak” (i.e., weak muscle strength)
- “She is a low tone muscle” (i.e., low muscle tone)
- “She can’t hold heavy things with her hand” (i.e., weak muscle strength)
- “Can’t button his shirts” (i.e., poor fine-motor skills)
- “Hand co-ordination is limited”
- “Struggles with fine motor skills”
- “Minimum hand function”.

The degree of disability and functional impairment varies greatly within the subtypes (Murphy & Such-Neibar, 2003). Although participants were not specifically requested to indicate the CP subtype of their children, a number of participants indicated spasticity ($n=2$) and mild CP ($n=2$) in the open-ended question.

¹ [English translation]

5.2.1.2 Visual Deficits

It was found that many of the children diagnosed with CP experience low visual acuity (Odding et al., 2006). Visual impairments are common in children with CP, affecting approximately 28 percent of children with CP (Ashwal et al., 2004). Three participants ($n=3$) in this study reported that their children experienced problems with their eye-sight and vision. Examples of the statements were:

- “Eye-sight”
- “Het net sig in een oog” [only has vision in one eye].

5.2.1.3 Speech and Communication Deficits

Dysarthria and other speech related impairments associated with oral-motor dysfunction are common in children with CP (Ashwal et al., 2004; Pennington & McConachie, 2001a, 2001b). The degree of speech and communication impairment varied from reports of poor speech ($n=8$) to non-verbal expression of speech ($n=3$). Examples of the statements were:

- “Can’t talk properly” (i.e., poor speech)
- “Speech deficit, more a slur”
- “He cannot talk” (i.e., non-verbal)
- “Kan nie terug praat nie” [can’t talk back] (i.e., non-verbal).

5.2.1.4 Activities of Daily Living

The degree of disability as a result of CP impacts on the child’s level of independence. As CP is diverse with regard to the degree of severity (Cruickshank, 1976), the levels of dependency for activities of daily living ranged from completely dependent on others ($n=8$) to some level of

independence with difficulty in completing activities of daily living independently ($n=4$).

Examples of the statements included:

- “Can’t do anything for himself...needs to be fed, wash and care for...he is dependent on his close family” (i.e., dependent on others)
- “He can do nothing for himself. Help is needed when dressing, feeding and bathing him” (i.e., dependent on others)
- “Hy vind dit moeilik om homself in die bad te help, sy rug te was en hare te borsel” [he finds it difficult to help himself in the bath, to wash his back and brush his hair] (i.e., difficulty in completing activities independently)
- “We constantly have to help her with certain things like dressing herself because she does everything slowly” (i.e., difficulty in completing activities independently).

5.2.1.5 Other Associated Problems

CP is often accompanied by other disturbances such as perception, cognition, behaviours, epilepsy (O’Shea, 2008), poor co-ordination of chewing and swallowing, urinary incontinence, constipation, sleep disturbances and drooling (Jan, 2006). Some of the associated problems that participants reported included Attention Deficit/Hyperactivity Disorder ($n=1$) and scholastic difficulties ($n=3$). Examples of the statements were:

- “She struggles with Maths”
- “He is a very slow learner”

Furthermore participants identified drooling ($n=1$), epilepsy ($n=1$) and emotional difficulties ($n=2$) as accompanying difficulties. Examples of the statements included:

- “He is always wet in the chest because of drooling” (i.e., drooling)

- “Hy is epilepsie” [He is epileptic] (i.e., epilepsy)
- “Little bit shy when meeting children” (i.e., emotional difficulties)
- “Hy is vol moods” [He is moody] (i.e., emotional difficulties).

Now that the specific challenges related to living with a child with CP with regard to this sample have been outlined, the results of the measures are presented and discussed in the following section.

5.3 RESULTS AND DISCUSSION

This section focuses specifically on the aim of the study, namely the identification, exploration and description of resiliency factors that facilitate adjustment and adaptation in a family with a child that has Cerebral Palsy. The qualitative findings are presented first and discussed, followed by the quantitative results and then the integration of the two.

5.3.1 Qualitative Analysis

From the 30 research participants (i.e., 27 families) that participated in the study, 26 participants responded to an open-ended question in which they were asked to report the most important factors or strengths which they felt had helped their family to adapt after their child was diagnosed with CP. The qualitative data was analysed using Tesch’s model of content analysis, and an independent coder was employed to ensure the trustworthiness of the process of analysis. The question that was posed to the participants was, “In your own words, what are the most important factors, or strengths, which have helped your family lately?” The common themes that emerged from the analysis support existing literature and previous research on resilience (McCubbin et al., 2001; McCubbin et al., 1997), as well as research on strengths that

families use to cope with the challenges related to life with a child living with CP. Factors that aided families to bounce back were identified. The common themes that emerged from the participants' responses are presented in Table 2, followed by a discussion of the common themes and sub-themes.

Table 2: Themes that Emerged from the Content Analysis (n=27)

RESOURCES	FREQUENCY
Family support	19
Family Togetherness	6
Marital Relationship	1
Social Support	11
Emotional	9
Instrumental	4
Religion and Spirituality	
Belief	13
Behaviour	4
Support	3
Acceptance and Understanding of the Disability	8
Tolerance and Patience	2
Normalisation of family life	2
Communication	8
Problem-Solving and Conflict Resolution	6
Sense of Humour	1
Family Time and Routine	3
Child's Characteristics	4
Financial Support and Resources	2

5.3.1.1 Family Support

The main theme that research participants indicated as important to the family's adaptation was that they had a supportive family, which included spouses and children (n=19). Some made specific reference to the supportive role of the child's siblings. Examples of statements included:

- "Her older sister helps a lot – she's very protective and cares for her sister!"
- "Everyone has a part to play and we all help each other"

- “Support each other in difficult times”
- “I have a fantastic family bond with my parents and sisters and they help me so much, not just financially, but also just lending a ear and with babysitting when I need it during school holidays”
- “I know that I can go to any family member... for help and support”
- “Ek glo met die hulp van my ouers sou ek dit nie alleen kan doen nie” [I do not believe that could have done it without the help of my parents]
- “Dank ek die Here dat ek ‘n familie het soos hierdie wat my teenvolig bystaan” [I thank God that I have a family that fully supports me].

Since the whole family unit is impacted by crises such as the diagnosis of a child with CP (Walsh, 2003a), the whole family’s involvement in the adjustment and adaptation to the crisis is important (McCubbin et al., 2001). The findings correlate with existing literature on families living with children with CP which highlights the importance of the family’s positive appraisal of the crisis and the support that the members offer each other (Lin, 2000). In addition, the supportive role of the parents (King et al., 1999; Mobarak et al., 2000; Wanamaker & Glenwick, 1998) and the role of the sibling(s) in the adjustment and adaptation to a crisis such as the diagnosis of CP were also supported in existing literature (Russell, 1978).

Specific reference was made to family togetherness (n=6) as an important factor in successfully dealing with adverse situations. Examples of the statements were:

- “Being able to stand together in testing times”
- “We stand together and talk things through”
- “Stick to each other and believe in one another”
- “We have worked together as a family unit – sharing the load at all times”.

Resilience literature highlights that the families that obtain bonadaptation will be high in family coherence as these families are secure in their purpose together and their ability to make future plans. A number of participants responded in ways indicating that they are part of such families (McCubbin et al., 2001). The family's sense of coherence (CCCC) forms the motivational and appraisal basis for transforming the family's potential resources into actual resources, which in turn reduces the family dysfunction by mobilising family resources (Hawley, 2000; McCubbin et al., 2001). When parents are supportive of each other, a more secure and nurturing family environment for the rest of the family is created, which facilitates greater adaptation for the child with CP as well as the rest of the family.

One of the research participants also indicated the importance of their marital relationship as a factor that contributed to the family's bonadaptation ($n=1$). As one of the research participants stated:

- “My husband and I have a good strong marriage”.

This finding correlates with the finding that marital functioning can potentially serve as a buffer to parenting stress (Saddler et al., 1993). The literature documenting the impact of the diagnosis of CP on a child, however, highlights the negative effects of the diagnosis on the parents and the marriage (Friedrich & Friedrich, 1981; Vijesh & Sukumaran, 2007) [see Chapter Three].

5.3.1.2 Social Support

Participants' answers to the open-ended question indicated that sources of social support were a primary resource that helped families adjust and adapt to living with a child diagnosed with CP ($n=11$). Research participants also indicated a variety of people that provided support (e.g.,

grandparents, health practitioners, schools and friends) and indicated different types of social support divided into two subthemes, namely emotional support ($n=9$) and instrumental support ($n=6$). Emotional support refers to the availability of a person with whom one can discuss problems, share feelings and disclose worries when necessary, whereas health practitioners provide instrumental support that includes helping behaviours such as advice, guidance, information about community resources and offering time and skills. Examples of statements were:

- “Surrounding ourselves with friends and family makes our lives wonderful” (i.e., emotional support)
- “I have very understanding friends that I work with and they treat my child like any other child” (i.e., emotional support)
- “My work is quite flexible and understanding” (i.e., emotional support)
- “Loving and caring for each other in the family is very important” (i.e., emotional support)
- “Liefde en baie daarvan” [love and lots of it] (i.e., emotional support)
- “My daughter went to a new school...makes her part of a group” (i.e., instrumental support)
- “The school help me a lot” (i.e., instrumental support)
- “Daughter has her own classroom assistant” (i.e., instrumental support).

Literature has highlighted social support as an important resiliency variable (McCubbin et al., 1997; Walsh, 1996; 2003a; Wills, Blechman, & McNamara, 1996). Social support (BBB) is important to the family since this resource can help the family give meaning to the crisis situation, develop coping strategies, and foster the family’s ability to change (McCubbin et al.,

1997). Unfortunately, CP tends to have an isolating effect on the family (Friedrich & Friedrich, 1981). Social support groups can serve as a buffer in caregiver stress and the family is better able to function when they are able to rely on social support networks. The fact that the participants indicated use of such support highlights their abilities to use social support in order to overcome the day-to-day challenge of having a child living with CP.

5.3.1.3 Religion and Spirituality

Research participants in this study indicated that spirituality and/or religion, and the activities which came with belonging to a Church, were strength factors that contributed to adaptation in their family units ($n=12$). Spirituality is an umbrella term under which one finds religion (Kaye & Raghavan, 2002). Some of the participants made specific reference to aspects of religion such as religious belief ($n=13$), religious behaviour ($n=4$) and the support ($n=3$) that they received from their congregation. Examples of statements included:

- “Being Christian and believing that whatever we do God helps us to carry on with life” (i.e., belief)
- “It is to have faith and believing that God will conquer everything” (i.e., belief)
- “A spiritual pillar in life is definitely the anchor midst the storm” (i.e., belief)
- “Having the faith to face the realities of life” (i.e., belief)
- “Our faith has played an important role in staying strong” (i.e., belief)
- “Prayer also helped” (i.e., behaviour)
- “Godsdiens en gebied” [religion and prayer] (i.e., behaviour)
- “Even at Church I receive a lot of support” (i.e., support)
- “Support of the Church” (i.e., support).

When individuals encounter situations which they view as being beyond their control, the hope of divine intervention through placing their trust and faith in God increases the family's belief that God is in control of an otherwise unmanageable situation (Paragament, 1995). Hope is a future-orientated belief that enables the family to see beyond their problem-saturated present and fuels energy and efforts to rise above adversity, which is a vital resilience factor in the process of adaptation (McCubbin et al., 1997).

Spirituality has been highlighted in literature as a resiliency variable (McCubbin et al., 1997; Patterson, 2002a; Walsh, 1998a; 1999; Werner & Smith, 1992; Yates & Masten, 2004). Research has proven that spiritual beliefs and practices are significant contributors to healthy family functioning (Walsh, 1999). Participants' responses are therefore in agreement with literature in that religion and spirituality are important resources that they are able to depend on within the family context where a child has been diagnosed with CP.

Families might struggle to find meaning when a young child is diagnosed with a condition such as CP and could search for meaning through their spiritual beliefs and practices (McCubbin et al., 1997; Walsh, 2003b). Religion appears to be important in that it provides families with an interpretive framework, enhances personal coping resources, and provides a source of social support (Siegal, Anderman, & Schrimshaw, 2001). When families are faced with illness, religious activities and affiliation with religious organisations can help psychological adjustment (Siegal et al., 2001).

5.3.1.4 Acceptance and Understanding of the Disability

Participants' answers to the open-ended question indicated that within the boundaries of the immediate family, the parents' acceptance of the condition was found to be a key source that

helped families adjust and adapt to living with a child diagnosed with CP ($n=8$). As part of this acceptance, research participants specifically indicated acceptance of their child for who they are ($n=8$) as a strength factor for their families. Furthermore, they described tolerance and patience in caring for their children with CP ($n=2$) as well as making efforts to treat all the family members equally and normalising family life ($n=2$) despite having a disabled child, as strength factors. Tolerance and appreciation of each individual's differences are important factors in acceptance. Examples of participants' statements included:

- “to accept the problem of your child” (i.e., acceptance and tolerance)
- “Acceptance of him as he is and a readiness to encourage independence and personal development” (i.e., acceptance and patience)
- “Accepted our child for who he is” (i.e., acceptance)
- “Respect each other and elders from outside and tolerance” (i.e., tolerance and patience)
- “Family life is as normal as possible” (i.e., normalisation of family life).

These responses correlate with resilience literature which highlights the importance of family members showing respect, appreciation, and understanding of the individuality and uniqueness of each person within the family unit (Cohen et al., 2002; Silberberg, 2001; Walsh, 2003a). Furthermore, acceptance is regarded as a strength when family members acknowledge, value and tolerate each other's differences (Silberberg, 2001).

5.3.1.5 Communication

Research participants also viewed open and honest communication ($n=8$) as a strength factor that they employed to solve problems and resolve conflicts ($n=6$). In addition, one participant referred to the use of humour ($n=1$) as a strength factor. Examples of statements included:

- “Positive communication” (i.e., communication)
- “[We] talk things through” (i.e., communication)
- “Understanding each other’s problems and be able to solve them amicably” (i.e., problem-solving)
- “When there is conflict or misunderstanding it is resolved immediately” (i.e., conflict resolution)
- “Working together to solve problems” (i.e., problem-solving)
- “Om ‘n sin vir humor te hê” [to have a sense of humour] (i.e., humour).

As was discussed in preceding chapters, communication has been highlighted in literature as an important resiliency variable (McCubbin et al., 1997; Patterson, 2002a; Walsh, 2003a; 2003c). The type of communication that research participants described may be seen as affirming communication which was identified as an important variable within the Resiliency Model (McCubbin et al., 2001). Affirming communication affirms the members of the family and brings solidarity to the family unit. McCubbin et al., (1997) also identified communication as a general resiliency factor. Furthermore, Walsh (2002) identified clear communication processes as a key resource found in family adaptation.

5.3.1.6 Family Time and Routine

Another theme that research participants identified as an important variable was family time and routine ($n=3$). The participants’ responses indicated that families considered family time and routine as important in establishing a sense of stability and predictability in the family unit. Examples of statements were:

- “Spending quality time at our holiday house on our own” (i.e., family time)

- “Spending time alone is also important” (i.e., family time)
- “I keep structure so the children all know where they stand and whats happening and when” (i.e., structure due to boundaries)
- “... boundaries and rules to be respected” (i.e., structure due to boundaries).

All of the above statements are in agreement with literature on resilience, which suggests that the specific activities and routines in which a family engages can help that family create a sense of predictability (McCubbin et al., 1997). Research on resilience further suggests that family time and routine may have a direct influence on the well-being of the family unit and its members. Families who engage in activities that promote togetherness among family members appear to develop and benefit from other family strengths such as coherence, bonding, flexibility and hardiness (McCubbin et al., 2001).

5.3.1.7 The Child’s Characteristics

Research participants indicated that their child’s acceptance of his/her condition was also important ($n=4$). Examples of statements included:

- “The fact that[child] is very positive and out going and that Cerebral Palsy does not get her down”
- “... she’s also very determined”
- “Daughter’s personality has helped – she’s very accommodating and accepting”.

According to the Resiliency Model, the family’s appraisal of the stressor has a great impact on the family’s ability to adapt to the crisis (McCubbin et al., 2001). The responses of the participants support literature on individual resilience which highlights an easy temperament

(Garmezy, 1993), self-efficacy, self-mastery (Rutter, 1985) and independence (Wolin & Wolin, 1993) as some of the protective characteristics of resilient people.

5.3.1.8 Financial Support and Resources

Research participants indicated the importance of financial resources such as a stable income and financial support ($n=2$). Examples of statements were:

- “Economical stability through testing times”
- “If one of us is having financial problems we try to help each other and deal with the situation”.

The finding in the present study supports the view that adequate financial resources assist the families’ adjustment and adaptation processes (Walsh, 1998b). As mentioned in Chapter Three, the management and care of CP often involves extra interventions such as special needs schooling, various therapy interventions (physical therapy, occupational therapy, speech therapy), orthotic devices, and surgery. An increased financial concern can contribute towards a pile-up of stressors and place an additional strain on the family’s ability to adjust. However, according to the Resiliency Model, having adequate financial stability is a resistance resource (B) that facilitates adjustment (McCubbin et al., 2001). The following section provides a summary of the qualitative results of the present study.

5.3.1.9 Summary of the Qualitative Results

Various themes emerged from the verbatim responses of the research participants. The themes that emerged highlight the importance of resilience factors that are related to individual family members, the family as a whole and the larger community. The most important theme that

emerged was the importance of family support such as family togetherness and a strong marital relationship. Research participants also indicated the importance of social support, such as emotional and instrumental support. In addition, the research participants indicated that religion and spirituality, their acceptance and understanding of their child's disability, open communication and problem-solving skills, family time and routine, their child's positive characteristics, as well as financial support and resources all contributed to their family's ability to cope. The following section provides a description of the quantitative results.

5.3.2 Quantitative Analysis

The structured questionnaires were analysed using Spearman's rank correlation coefficients (Spearman r) and best-subset regression analysis. Correlation analysis is used to measure the association between two or more variables and the extent to which the change in the values of one variable could be associated with the change of values of another variable. Furthermore, it can be used to describe the direction and degree of relationship between certain variables (Sapsford & Jupp, 2006). The results of these analyses are discussed in the following section.

5.3.2.1 Correlation Analysis

Spearman's rank correlation coefficients (Spearman r) were calculated to determine the interrelationship between family adaptation (as measured by the FACI8) and potential resilience factors. While a Spearman's rank correlation does not indicate a causal or explanatory link, it does indicate relationships between variables. These correlation coefficients are presented in Table 3. To assess the significance of these correlations, p values were used. As discussed in Chapter Four, a p value of 0.05 is the standard value that is used for most psychological reports,

although a p value of 0.01 or 0.001 is considered to be more significant. This is due to the latter p values being representative of more stringent and rigorous significance levels (Harris, 1998). While p values were used to indicate the significance of correlations, Guilford's guidelines (1946) were used to interpret the magnitude of these correlations. According to these guidelines, correlations that range between 0.40 and 0.70 are considered to be moderate, indicating a fairly substantial relationship. The guidelines as proposed by Guilford are outlined as follows:

- Less than 0.20 slight; almost negligible relationship
- 0.20 – 0.40 low correlation; definite but small relationship
- 0.40 – 0.70 moderate correlation; substantial relationship
- 0.70 – 0.90 high correlation; marked relationship
- 0.90 – 1.00 very high correlation; very dependable relationship

The correlation results for the research participants are represented in Table 3.

Table 3: Spearman's Correlations between Adaptation (FACI8) and Potential Resilience Variables

VARIABLES	CAREGIVERS (n=30)	
	<i>r</i>	<i>p</i>
Relative and Friend Support (RFS)		
Total RFS Score – family's use of friends & relatives as a coping mechanism during crises	0.37	0.05*
Social Support Index (SSI)		
Total SSI Score – degree to which family finds support in their community	0.35	0.06
Family Crisis Oriented Personal Evaluation Scales (F-COPES)		
– Problem solving behaviour used during crises		
Reframing – redefining negative situations in a positive way	0.03	0.87
Passive Appraisal – passive acceptance of problematic issues to minimise reactivity	0.19	0.33
Social Support – ability to actively seek social support	0.19	0.33
Spiritual and Religious Support – ability to actively seek spiritual support	0.36	0.06
Family Mobilisation – ability to seek out community resources and accept help from the community	0.06	0.75
Family Hardiness Index (FHI) – fortitude and durability of family unit		
Commitment – ability to work together and internal strengths	0.29	0.12
Challenges – positive reframing, ability to learn	0.49	0.01*
Control – internal locus of control	0.34	0.08
Family Time and Routine Index (FTRI)		
Behaviour Total Score – extent to which family engages in routines	0.59	0.01*
Value Total Score – degree to which family values their routines	0.13	0.49
Child Routines – routines to promote autonomy and order in children and teens	0.01	0.98
Couple Togetherness – routines to promote communication between couples	0.51	0.01*

Table 3 (Continued)

Meals Together – routines to promote togetherness through family mealtimes	0.36	0.05*
Parent-Child Togetherness – routines to promote communication patterns between parents and children	0.22	0.26
Family Time Togetherness – special events, family time	0.65	0.01**
Relatives Connection Routines – routines to promote meaningful connection with relatives	0.45	0.01**
Family Chores Routines – routines to promote teen and child responsibility in the home	0.65	0.01**
Family Management Routines – routines to maintain order in the home	0.30	0.11
Family Problem-Solving Communication (FPSC)		
Affirming Communication – positive, supportive communication patterns	0.18	0.35
Incendiary Communication – negative, inflammatory communication patterns	-0.16	0.40
Total FPSC Score – style of family communication during crises	0.17	0.37

* $p < 0.05$, ** $p < 0.01$

In this study, the FACI8 is used as a measure to determine the level of family adaptation. In the Resiliency Model, family adaptation is indicated as XX and used as an indication of adaptation. Family adaptation ranges from positive bonadaptation, implying that the family has accepted and is able to function congruently with new patterns of functioning, to negative maladaptation, which propels the family back into a crisis situation (McCubbin & McCubbin, 2001). There were a number of resiliency variables that showed significant positive correlations with the FACI8. The unique resiliency factors associated with family adaptation (as indicated by FACI8 total scores) in this study are now outlined. These factors are discussed in the context of

the literature pertaining to resilience as provided in Chapter Two, as well as the literature on CP as provided in Chapter Three.

5.3.2.1.1 *Relative and Friend Support*

The Relative and Friend Support (RFS) scale measures the degree to which family members use the support of friends and relatives as a coping strategy when dealing with stressors. This instrument taps into the family resources component (BB) of the Resiliency Model (McCubbin et al., 2001). The results of the RFS indicated a low positive correlation ($r = 0.37, p = 0.05$), with a small but definite relationship existing between relative and friend support and adaptation. The findings are supported by literature which states that social and family support serves as a buffer against family crises and promotes family recovery (Lin, 2000; McCubbin et al., 1997).

5.3.2.1.2 *Family Hardiness Index*

The Family Hardiness Index (FHI) (Challenges subscale) showed a positive correlation with the FACI8. The Challenges subscale forms part of three subscales of the FHI. The remaining two subscales are the Commitment and Control subscales. The FHI was used to measure internal strengths and durability of the family unit (McCubbin et al., 2001). It assesses how hardiness is used as a resource to mediate the effects of stress in families and in turn, facilitate family adjustment and adaptation. Family hardiness refers to an active stance in managing stress, as well as maintaining a sense of control over life and having a positive perception of change (McCubbin et al., 2001). Kobasa (1979) suggested that a commitment to various areas of one's life, having a sense of control and viewing change as a challenge allows a hardy person to

develop. Various authors have noted that family hardiness aids family adaptation (McCubbin et al., 1997; Svavarsdottir, McCubbin, & Kane, 2000).

In terms of the measure's applicability to the Resiliency Model, the FHI taps into the family's existing resources (BB) and the family's appraisal of the situation (CC). Situational appraisal (CC) can be described as the family's ability to weigh up their resources against new demands on their established patterns of functioning which is created by the crisis (McCubbin & McCubbin, 2001). It consists of five processes, namely the family's schema, coherence, paradigms, situational appraisal and stressor appraisal. The family's resources (BB) include their strengths and capabilities.

The significant positive correlation between the FACI8 and the Challenges subscale score of the Family Hardiness Index (FHI) indicates that these families' ability to positively reframe and learn from their crisis is a resource that aids family adjustment and adaptation in this sample. In terms of the strength of the correlation, the correlation between the FHI Challenges subscale and the FACI8 can be viewed as moderate ($r = 0.49, p = <0.01$). According to Guilford's (1946) guidelines outlined in Chapter Four, a moderate correlation indicates a fairly substantial relationship. This indicates that the families are able to reframe and define their hardships as challenges rather than problems, allowing them to develop hardiness. When the family is able to innovatively reframe and redefine their hardships together as challenges from which they can learn and when they have a sense of control and influence in the outcome, the family is more able to adjust and adapt to the crisis they are facing.

While the Challenges subscale of the FHI showed a significant positive correlation with the FACI8 ($r = 0.49, p = <0.01$), the other two subscales showed a definite, but small, correlation with the FACI8. Although no literature was found to further explain this correlation, it may be

speculated that having a child diagnosed with a lifelong condition such as CP presents continuous challenges. As the child with CP develops through the developmental stages and as the family's resources change, so the family will need to find new solutions that best meet the needs of the child and the family as a unit, while at the same time maintaining a resilient stance in the face of their adversity (Hirose & Ueda, 1990).

On the whole, the correlations of this study corroborate results of other studies in South Africa which have shown that family hardiness characteristics, such as internal strengths and durability of the family unit, play a significant role in the family's resilience (Greeff & Human, 2004; Greeff & van der Merwe, 2004). Consequently, a strong sense of managing stress, maintaining a sense of control over life, and having a positive perception of change has been proven to play a considerable role in these participants' lives.

5.3.2.1.3 *Family Time and Routine Index*

The Behaviour subscale of the Family Time and Routine Index (FTRI) also showed a positive correlation with the FACI8. The results indicated a moderate positive correlation between activities and routines that help the family spend quality time together in order to create togetherness, and to adapt more easily.

The FTRI was used to measure both the types of activities and routines that the families engage in and maintain (i.e., the Behaviour subscale) as well as the value that they attribute to these activities and routines (i.e., the Value subscale) (McCubbin et al., 2001). In terms of the Resiliency Model, these activities and routines contribute to the family's range of new and existing resources (BB) and tap into the family type (T) component of the model. A family's typology describes how the family unit usually behaves (i.e., their established patterns of functioning).

Resilience literature indicates that time spent together provides a family with a sense of predictability and stability that fosters harmony and balance. The specific activities and routines that a family engages in offer relatively reliable indices of family integration and stability, which contribute to family resilience (McCubbin et al., 2001). During times of crisis, family time and routine may be set aside or disrupted and replaced by a complete devotion to the family crisis. However, in times of crisis, family routines and time together can help the family create a sense of predictability (McCubbin et al., 1997).

While resilience literature reiterates the importance of family time and routine, literature on families living with a child with CP indicates that the challenges related to CP lead to changes in the day-to-day life of all family members (Patterson, 2002a; Sen & Yurtsever, 2007; Vijesh & Sukumaran, 2007). In order to adjust and adapt, the family needs to adopt new routines and rituals to incorporate the special requirements of the disability and integrate these with the old routines and rituals of the family (Patterson, 2002b).

The positive correlation between the FACI8 and the Family Time and Routine Index Behaviour subscale (FTRI) indicates that family time and routine are resources that aid family adjustment and adaptation for this sample. There is a significant correlation between the FTRI Behaviour subscale and the FACI8. The magnitude of this correlation was moderate ($r = 0.59, p = <0.01$).

While the Behaviour subscale showed a positive correlation with the FACI8, no substantial correlation was obtained for the Value subscale. This subscale measures the importance (i.e., value) that the family places on routines. A possible explanation for the fact that there was no significant relationship obtained for the Value subscale could be related to the questionnaire. The FTRI consists of eight subscales and some of the questions contained in these subscales may

not have been relevant to the research participants. The majority of research participants' children fell in the middle child age range (i.e., from 4 to 12 years of age) and some of the questions were related to family times and routines relevant to adolescents. An example of one such statement is "Teenagers do regular household chores." The fact that some of these statements were not applicable to some families would have lowered the scores on both the Behaviour and Value subscales and in turn affected the magnitude of the relationship for the research participants. Four of the eight subscales, however, indicated significant correlations with the FACI8. These included the Couple togetherness subscale ($r = 0.51, p = 0.01$), Family time togetherness subscale ($r = 0.65, p = 0.01$), Relatives connection routines subscale ($r = 0.45, p = 0.01$) and Family chores routines subscale ($r = 0.65, p = 0.01$). According to Guilford's (1946) guidelines, all four of these subscales have a moderate correlation with the FACI8, indicating a fairly substantial relationship. These routines include activities which promote communication between couples (Couple togetherness), family togetherness through special events and family occasions (Family time togetherness), routines and events that promote meaningful connection with relatives (Relatives connection routines) and routines that promote teen and child responsibility in the family (Family chores routines).

5.3.2.1.4 *Summary of the Correlation Results*

In conclusion, two measures showed significant positive correlations with the FACI8 for the research participants. These measures were the Family Hardiness Index and the Family Time and Routine Index. This suggests that family hardiness as well as family routines and time together are resilience factors that facilitate adjustment and adaptation for the research participants. The Relative and Friend Support showed a low positive correlation with the

FACI8. This result is consistent with literature on resilience that indicates the importance of a social support network (McCubbin et al., 1997; McCubbin et al., 2001). Literature on families living with a child diagnosed with CP also highlights the importance of building a social support network (Lin, 2000). Now that the correlations have been discussed, the results of the regression analysis are presented and explained.

5.3.2.2 Regression Analysis

A best-subset regression analysis was conducted for the caregivers of the child living with CP. The motivation behind this procedure was that an independent variable on its own might not have correlated significantly with the dependent variable. However, when combined with other independent variables, this combination might have predicted the dependent variable. It is important to note, before interpreting the analysis, that the sample size was small, which may have impacted the results. The results of this regression analysis are shown in Table 4.

Table 4: Regression Analysis for Family Adaptation (FACI8) as Dependent Variable versus Potential Resiliency Variables ($n = 30$)

VARIABLES	B	p-value
Family Time and Routine Index (FTRI)		
Total	0.444	0.004
Family Hardiness Index (FHI)		
Challenge subscale	0.470	0.002

The identified variables explained 57.12% ($R^2 = 0.571$) of the variance of the FACI8 scores. The following variables are, according to the results of the data analysis, the best predictors for family adaptation (as measured by the FACI8):

- Activities and routines that help the family in spending time together and creating a sense of integration (Family Time and Routine Index: Total score);
- The ability to positively reframe crises as challenges and to seek out new experiences as challenges (Family Hardiness Index: Challenges subscale).

5.4 INTEGRATING QUALITATIVE AND QUANTITATIVE RESULTS

The value of the open-ended question was that it allowed the researcher to enrich the quantitative data provided through the biographical questionnaire and the seven structured questionnaires. As the results of the quantitative and qualitative data have been illustrated, certain noteworthy observations were made when integrating both the quantitative and qualitative results. The first observation was that there was a correlation between certain quantitative and qualitative results. The second observation was that there were new themes that emerged in the qualitative data that were not reflected in the results of the quantitative data (i.e., communication). The third and final observation was that there were themes that emerged in the qualitative data that were not tapped into by the structured questionnaires, despite measures

tapping into this theme. An integration of the qualitative and quantitative results, illustrating the three noteworthy aspects of the results, is presented in Table 5. This is followed by the conclusion to the chapter.

Table 5: Integration of Qualitative and Quantitative Results

Qualitative Findings	Quantitative Results					
	RFS	SSI	F-COPES	FHI	FTRI	FPSC
Family Support	†	†				
Social Support	†	†	‡			
Religion and Spirituality			†			
Acceptance and understanding			†	†		
Communication						‡
Family Time and Routine					†	
Child's Characteristics *						
Financial Support and Resources *						
Key						
Themes that emerged that were not tapped into via questionnaires						*
Correlations between qualitative and quantitative results						†
Themes that emerged in qualitative results but not in quantitative results (even though measures tapped into this theme)						‡

5.5 CONCLUSION

The results of this study, in relation to the aim of the study, were presented in this chapter. Triangulation of methods, incorporating both qualitative and quantitative methods of analysis, was employed. The themes that emerged from the qualitative component of the study were

illustrated and, where possible, linked to previously discussed literature on resilience and CP. The qualitative data was valuable in providing greater depth to the data and exposing possible future research questions. As the sample size of this study was small, the results of the quantitative measures were interpreted with caution. The results of the correlation and regression analyses were discussed and, where possible, these were explored and explained in relation to literature cited in earlier chapters. In addition, the results were conceptualised according to the Resiliency Model, which was the conceptual model utilised for the purpose of this study. Following this, the qualitative and quantitative themes were weighed and compared with one another. Now that the results of the study have been outlined, certain conclusions can be made. The conclusions based on the results of this study, the value of the research, the limitations of the study, as well as recommendations for future research are outlined in Chapter Six.

CHAPTER SIX

CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

6.1 INTRODUCTION

Chapter Six provides a summary of the conclusions that were drawn from the key findings of the current study. The limitations encountered during the study as well as the contributions of the study to the body of knowledge are also discussed. The chapter is concluded with an outline of recommendations for future research areas.

6.2 CONCLUSIONS OF THE STUDY

When drawing valid conclusions based on the results of the study, it is imperative to return to the main aim of the study as a starting point. This study aimed to identify, explore and describe the resiliency factors that enable families to adjust and adapt as a result of living with a child diagnosed with CP.

The research was based on the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin et al., 2001), which suggests that certain factors and processes enable families to bounce back from a crisis (i.e., resilience). The results of this study highlight a range of resilience factors that families living with a child diagnosed with CP use during the process of adjustment and adaptation.

The qualitative results contributed significantly towards helping the researcher identify, explore and describe those factors. This information is particularly important and significant as it provided the views and opinions of participants regarding those strengths or factors that helped them on a day-to-day basis. The resiliency factors identified through the content analysis were

consistent with findings from literature and research (Garmezy, 1984; McCubbin et al., 1997) which indicates three domains responsible for the emergence of resilience: individual personality, the family (in terms of cohesion and lack of discord) and the community (or social support). The themes that were identified through the open-ended question suggest that the most important resilience factors included family support, social support, religion and spirituality, acceptance and understanding of the disability, communication, as well as hope, love and faith. Other themes that emerged were family time and routine, the child's characteristics and financial support and resources. The results of the qualitative analysis supported and enriched the quantitative data.

Structured questionnaires were used to obtain results for the quantitative analysis of the sample. There were a number of resiliency variables showing a significant positive correlation with the FACI8. The variables that were found to facilitate family adjustment and adaptation in this study included the family's ability to be innovative and motivated to experience new things; activities and routines that facilitate family integration and stability, allowing them to spend more time together helping to create a sense of togetherness, as well as couple togetherness; family integration into the community and experiencing the community as a source of support; the support and utilisation of members of the immediate family, extended family and family friends; and the family's ability to seek out spiritual support.

In summary, the qualitative data in this study served to support the quantitative data and also provided new themes. Now that the conclusions based on the results of the study have been discussed, it is important to discuss the value of the research.

6.3 VALUE OF THE RESEARCH

The field of human sciences has experienced a paradigm shift from the traditionally pathogenic based perspective, which focused primarily on illness and deficits, to a salutogenic perspective which emphasises strengths and resources (Antonovsky, 1987). This perspective holds great value for the field of family psychology (De Haan et al., 2002; Hawley & De Haan, 1996; Patterson, 2002b; Walsh, 2002, 2003a). When this approach is applied to a family system, it encourages the perception of a family as challenged rather than damaged, and as successful as opposed to deficient (Hawley & De Haan, 1996; Walsh, 1996). This study was therefore able to investigate the factors and processes that allow families to move towards health.

The value of a proactive, health-focused orientation should not be underestimated in a developing country such as South Africa where resources are limited (Greeff & Aspeling, 2004). The value of this research is then that it contributed towards describing what variables families living with a child diagnosed with CP employ in helping them manage their day-to-day living. By using resilience-related concepts such as ‘adjusting’ and ‘adapting’, ‘protective and recovery factors’, the reparative potential of the family was highlighted rather than viewing the family system as dysfunctional or damaged in some way. In addition to this, the current study is the first South African study exploring the adjustment and adaptation processes of families living with a child diagnosed with CP.

The study also contributed to the Clinical Health Psychology discipline by viewing CP as a manageable condition to which a family can adjust and adapt. The variables that were identified through this study are valuable in that they hold the potential for the creation of family interventions (Hawley, 2000; Hawley & De Haan, 1996; Walsh, 2002, 2003a). This could be used to help families cope with the stress related to caring for a child with CP.

A further contribution that this study has made is from its qualitative component. It has been noted that qualitative investigations are needed to compliment the study of resilient families (McCubbin & McCubbin, 2001; Patterson, 2002b). The value then of this study is that the qualitative component gave the caregivers the opportunity to convey their experiences and contributions as a result of living with a child diagnosed with CP. While this study holds numerous valuable contributions to research, there are also limitations to this study that have been noted by the researcher. A discussion of these limitations follows.

6.4 LIMITATIONS OF THE STUDY

It is important to consider the various limitations associated with this research. No research project is without its limitations as there is no such thing as a perfectly designed study (Marshall & Rossman, 1999). A major limitation of this study was the fact that only one family representative from each family completed the questionnaires given to them. In addition to the problem of subjectivity in only using one representative, this methodology allowed the assessment of the perceptions of only one individual family member as opposed to an assessment of the entire family unit. As explained by De Haan et al. (2002), data is gathered at an individual level and extrapolated to a family level. While such data can be useful and appropriate for a number of research questions, they are limited in their usefulness for the operationalisation of resilience on a family level.

Another limitation related to the methodology of the study is the exploratory nature of the study. Exploratory research implies studying a new and unstudied area in the hope of formulating future research questions (Neuman, 2006). The concept of family resilience is new and relatively unstudied in the South African context and therefore an exploratory methodology

suited the aim of the study. However, there were limited South African studies completed in this field from which information could be drawn. The researcher, however, could not find any research exploring the resiliency factors specifically relating to families living with a child diagnosed with CP, either locally or internationally. As mentioned previously, the predominant literature on CP focused mostly on the management of the disorder as well as on the stress and coping strategies of the families involved with little information being provided regarding the strengths inherent within these family systems. This meant that the researcher had to refer to many international resources related to the field of family resilience as well as literature on CP.

Ideally, random probability sampling should be used, but the present study employed non-probability sampling. Although the primary advantage of this sampling technique was that it was convenient for the researcher, the results of the study are not completely representative of the general population of families living with a child with CP.

An additional reason as to why the findings cannot be generalised, relates to the sample itself. Firstly, the sample was very heterogeneous in terms of family structure, position of the child in the family, the degree of disability in the child, as well as the age of the child. In addition, the focus of the present study was on resilience in families that are living with a child diagnosed with CP, but no comparison group was available to compare the way that they may differ from families without a physically disabled child. A second limitation was that the sample was very small, which is important, since an inappropriately low sample size is likely to produce non-significant findings (Cozby, 2007). Despite the fact that 199 sets of questionnaires (61 sets contained two sets of questionnaires for two caregivers) were mailed and delivered to potential participants, only 44 of these responded and of those 44 participants, only 30 of the questionnaires were usable as the remainder of the participants did not meet the inclusion criteria

of the study. In addition, some of the participants did not complete the open-ended question on the biographical questionnaire, further reducing the number of participants for the qualitative component of the study. The researcher made every attempt to collect the remainder of the questionnaires. The greatest problem was that the low response rate typically suggests response bias (Shaughnessy et al., 2000). This has serious implications as the people who did not respond might represent a qualitatively different group from those who did respond (Salkind, 2003). As a result, the external validity of the study is affected. Furthermore, the small sample size also contributed to the questionability of the result of the regression analysis.

The small sample size also contributes to another limitation of this study, namely the non-representative nature of the various ethnicities in the Eastern Cape. The researcher made every attempt to include all ethnic groups in the study through the various data gathering techniques, including approaching various special-needs schools around the Nelson Mandela Bay Metropolitan as well as the Cerebral Palsy Association for the Eastern Cape area. However, despite these attempts to include an ethnically representative sample, this small sample does not adequately represent the diverse ethnicities within the Eastern Cape.

A further limitation of this research links specifically to the measures that were used to collect the data. The biographical questionnaire could have asked the research participants to indicate which of their children had CP as well as which members of the family were additional people living with the family in order to further enrich the data.

There were several questionnaires used in this study which were self-report, structured paper-and-pencil questionnaires. Although the use of self-report questionnaires allowed for participant anonymity, there are certain disadvantages related to anonymity. Firstly, research participants have less incentive to respond, some may not understand the questionnaires and the

questionnaires may be interpreted differently by different individuals. As participation was voluntary, it is impossible to find out why some families did not respond and thus no information is available regarding the resilience variables in those families. The number of questions in the quantitative questionnaires and the response categories changing from measure to measure may however have caused some participants to become fatigued, frustrated and even a little confused. The researcher observed that many of the last two questionnaires of the sets of questionnaires were either incomplete or missing responses altogether.

The standard consent form used for research at the Nelson Mandela Metropolitan University is only available in English. As a result of this, research participants had to be conversant with English as a first or second language. A large number of families that were identified were Afrikaans and isiXhosa first-language-speaking and they may, therefore, not have understood the consent form and have chosen, on this basis, not to participate.

A limitation of the Family Time and Routine Index (FTRI) is related to the nature of some of the questions. One of the inclusion criteria of the study was to include families living with a child with CP between the ages of 2 and 18 years. The rationale for the age range preference was to homogenise the life cycle stage of the family. Some of the questions on the FTRI however tapped into activities that were related specifically to activities of adolescents and parents, which may not have been applicable to families with younger children, thus further impacting the results of this measure.

Despite the various limitations of this study, recommendations for future research are offered. A discussion of these recommendations is now presented.

6.5 RECOMMENDATIONS

In light of the low response rate of this study, the following is suggested. Firstly, it is recommended that future researchers make use of a larger and more representative sample (both in terms of age as well as ethnicity, for example by doing a country-wide study) so that the results could be made more applicable to larger populations of families living with a child diagnosed with CP. This could also contribute towards a greater understanding of the lives of families from the diverse ethnic backgrounds within South Africa in general. A significant amount of the literature cited in this study originates from international sources. This supports the researcher's recommendation for further South African research relevant to families living with a child diagnosed with CP. Furthermore, an exploration of the differences in resilience factors cross-culturally would be of value to the South African population.

In order to manage the possibility of a low response rate, it is suggested that families be interviewed or questionnaires be administered in person, where possible. For example when enlisting the support of schools, an evening could be arranged at the school where interested parents are given an opportunity to complete the questionnaires with the researcher present. The same could be done at specific CP clinics within communities (e.g., hospitals, physical therapy clinics, occupational therapy clinics, orthopaedic clinics etc.) while the parents are waiting to consult with the health care professionals. If the researcher is not able to attend such meetings or clinics in person, it is recommended that the researcher employ the help of research assistants and orientate them to the criteria of the study as well as the instructions for the questionnaires thereby eliminating any potential confusion or misunderstanding of the items on the questionnaires and in so doing, decreasing the time period for the return of questionnaires and

increasing the response rate dramatically. It is also recommended that the families be offered an incentive for their time and co-operation.

Another recommendation would be to involve the siblings of children living with CP as research participants since they also have to adjust and adapt to life with a sibling with CP and face the same or similar challenges within the family unit (Burton, 1975; Russell, 1978). It is also recommended that two caregivers participate in the study rather than just one, and that the two caregivers' scores on the measures be compared to explore and identify differences in the resiliency factors utilised in these families. In light of the feedback received from some of the research participants, it is recommended that fewer questionnaires be utilised in future studies.

Furthermore, it is recommended that the open-ended question on the Biographical Questionnaire that tapped into the factors or strengths that the participants' believed helped their family through their crisis be phrased more directly to avoid ambiguity. Although the word "lately" in the current phrased question does ensure some focus on the adaptation rather than adjustment phase of the resiliency model, the question may exclude earlier aspects of this phase and include confounding patterns. An alternative question could be, "In your own experience what are the most important family strengths needed in living with children diagnosed with cerebral palsy?"

Another recommendation for future studies regarding families of this nature, is to include a longitudinal component. As resilience may be seen as a process which occurs over time (De Haan et al., 2002; Walsh, 2002), the experience that a family has may change. There would be value in designing a research study that examines the level of resilience within families at different stages after a child has been diagnosed with CP. This would provide information about how and when resilience resources develop in families and to what extent. It is suggested that future researchers attempt to obtain three measurements of resilience, i.e., (a) at the time of

diagnosis, (b) six months after the diagnosis and (c) 12 months after the diagnosis. The field of family resiliency research will at that stage no longer be so new, with sufficient time having lapsed for longitudinal studies to be successfully conducted (De Haan et al., 2002).

Furthermore, future studies related to families living with a child diagnosed with CP should be more homogenised, for example studies should focus on families with children at a specific category of CP (i.e., quadriplegia or diplegia) or specific degree of severity (i.e., mild, moderate, severe). In addition, specific age groups should be considered (i.e., 2-5 years; 16-18 years or 20+ years) as challenges faced by the families change as the child develops and matures.

6.6 CONCLUSION

This study aimed to identify, explore and describe the resiliency factors that enable families to adjust and adapt to having a child diagnosed with CP. With this aim in mind, the researcher made use of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 2001) to provide a framework for the interpretation of the findings. Results were obtained through a combination of quantitative and qualitative measures. Although the results of this study cannot be generalised to the broader population of families where a child has been diagnosed with CP, the study nevertheless made contributions to the field of family resilience, especially in the South African context. Although it is important to acknowledge the limitations of this study, the contributions made by this study cannot be ignored. The resilience factors that were identified as well as the factors that could contribute to a family's level of vulnerability, offered important information regarding the sample under investigation. The study could also provide guidance for future research on the adjustment and adaptation processes of families living with a child with a disability.

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APPENDIX A:
Covering Letter to Principals

Contact Person: Renée Small

20 July 2009

The Principal
PORT ELIZABETH
6000

Dear

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

In line with the requirements for a Master's degree in Clinical Psychology, it is necessary to complete a research treatise as part of my course work. The title of my research is, "Resilience in families living with a child diagnosed with Cerebral Palsy". The aim of the research is to explore and describe the factors that facilitate adjustment and adaptation in families after a child has been diagnosed with Cerebral Palsy. I am therefore writing to you in order to request permission to access relevant participants from your school.

To date, the vast majority of research on Cerebral Palsy has been on the epidemiology, treatment and management of the disorder as well as some research on the stress responses and coping strategies used in these families. Further studies in this field reflect that even though there is considerable stress, pain and difficulty encountered by parents raising children with Cerebral Palsy, it would be incorrect to view these families as pathological. It would be more correct and beneficial to focus on the strong and positive relationships which parents and families develop and that bolster them. Consequently, the main objective of the proposed research is to examine family resilience and those factors which help parents to manage in these daunting circumstances. The concept of resilience in family life indicates that ability to cope effectively with challenges and hardships, to function in crisis situations and to demonstrate resourcefulness, as well as the ability to adjust to new and changing situations and to resume constructive functioning. Any measure of success will bring improved prospects for their child's adjustment and a more fulfilled life for the whole family. The benefit and value for participants in this research is considerable, as further understanding of how to cope with day-to-day life for both the parent and child, through understanding what 'resiliency' areas could be improved upon, will be gained. This in turn will allow for better management of the child's disorder and will facilitate healthier family relations.

Each participant will receive an envelope with a number on it. This number will appear on each questionnaire and will enable the researcher to keep track of the questionnaires to ensure that all

information remains together. The envelope will contain a consent form, a biographical questionnaire in addition to seven other brief questionnaires pertaining to the adjustment and adaptation of a family with a child who has been diagnosed with Cerebral Palsy. All documents will be provided in the participant's home language (English / Afrikaans). The researcher will provide instructions for completing the questionnaires. The questionnaires will take approximately one hour to complete.

The participant will be asked to complete and sign a consent form and provide his/her surname and initials. His/her identity and that of his/her family will at all times be kept confidential, and only the researcher and you will be aware of this information. In order for the research to be valid, I am requiring the participation of 60 families, with two members per family participating. The criteria for participants are as follows:

- (a) Participants should be part of a family unit where a child has been diagnosed with Cerebral Palsy by a neurologist or paediatrician for a minimum period of 6 months,
- (b) The participants should live in the same residence as the dependent, and should be involved in caring for him/her,
- (c) The child should be between 24 months and 18 years of age,
- (d) Participants should have a Grade 10 proficiency level in English or Afrikaans in order to fully understand the questionnaires, and
- (e) Participants should be over 18 years of age.

Participation in this research is completely voluntary, and each participant has the right to withdraw at any given time. Once participants have completed the consent form and all the questionnaires, these will be mailed to the researcher using the stamped, addressed envelope provided.

In consideration of granting access, please note that this study undergoes strict evaluation by the Faculty of Research and Technology Institute at the NMMU. You are welcome to contact the Faculty Officer on 041-504 2121 or me at any time on 084 667 5174. In addition, permission to contact participants via your school was granted by the Department of Education.

Your assistance will be greatly appreciated.

Yours sincerely,

Mrs Renée Small
Researcher

Ms Otilia Brown
Supervisor

Dr Diane Elkonin
Co-Supervisor

Prof. Mark B. Watson
Head of Department

APPENDIX B:
Covering Letter to Research Participants



**Nelson Mandela
Metropolitan
University**

f o r t o m o r r o w

**South Campus
Psychology Clinic**

Tel +27 (0)41 504 2330 Fax. +27 (0)41 583 5324
uclin@nmmu.ac.za

13 April 2010

Contact Person: Renée Small

Dear Research Participant

As part of my course work for the Masters degree in Clinical Psychology, I am required to complete a research treatise. The title of my treatise is: “Resilience in families living with a child with Cerebral Palsy”. The proposed study aims to explore and describe the factors that facilitate adjustment and adaptation in families with a child with Cerebral Palsy. It is with this goal in mind that I wish to enlist your family’s assistance and participation.

Should you agree to participate in this study you will receive an envelope with a number on it. In the envelope you will find a set of questionnaires. A number will appear on each questionnaire and will enable the researcher to keep track of the questionnaires to ensure that all your information remains together. For the purpose of record keeping, a list of the participants’ names with the corresponding number to their questionnaires will be available to me.

In the envelope you will find a consent form and biographical questionnaire in addition to seven other brief questionnaires with regard to adjustment and adaptation as a family with a child diagnosed with Cerebral Palsy. The researcher will provide instructions for completing the questionnaires, which will be available in Afrikaans and English. Completion of all the questionnaires should take approximately an hour. As all responses to the questionnaires will be regarded as confidential, you are therefore requested to answer the questions as honestly as possible.

It is essential that you complete all the questionnaires to provide extensive data for the study. Once all the questionnaires are completed, you are requested to place the questionnaires in the envelope and hand them back to the researcher.

Should you wish, the researcher will gladly provide generalised feedback of the results and findings of the study in the form of a report. Please indicate if you would like to receive general feedback in the relevant section on the biographical questionnaire. Should you at any point not want to continue with the study, you may withdraw from the study without any recourse.

Your participation will be valued and truly appreciated. In the event that you should require any additional information, I can be contacted via the following number and email address:

Cellphone: [REDACTED] or

Email: [REDACTED]

Yours sincerely

Mrs Renée Small
Researcher

Ms Otilia Brown
Supervisor

Dr Diane Elkonin
Co-Supervisor

Prof. Louise Stroud
Head of Department

APPENDIX C:

Consent Form

NELSON MANDELA METROPOLITAN UNIVERSITY**INFORMATION AND INFORMED CONSENT FORM**

Title of the research project	Resilience in families living with a child diagnosed with Cerebral Palsy.
Reference number	
Principal investigator	Mrs Renée Small
Address	NMMU Department of Psychology PO Box 77000, Port Elizabeth
Postal Code	6031
Contact telephone number	██████████

A. DECLARATION BY OR ON BEHALF OF PARTICIPANT (Person legally competent to give consent on behalf of the participant)		<i>Initial</i>
I, the participant and the undersigned	<input type="text" value="(full names)"/>	
I.D. number	<input type="text"/>	
Address (of participant)	<input type="text"/>	
A.1 I HEREBY CONFIRM AS FOLLOWS:		
1.	I, the participant, was invited to participate in the above-mentioned research project that is being undertaken by <input type="text" value="Mrs Renée Small"/> of the Department of <input type="text" value="Psychology"/> In the Faculty of <input type="text" value="Health Sciences"/> of the Nelson Mandela Metropolitan University.	
2.	The following aspects have been explained to me, the participant:	
2.1	Aim: The researcher is studying resilience in families who have a child diagnosed with Cerebral Palsy The information will be used to gain an understanding of the factors that contribute to the families' ability to overcome a diagnosis of Cerebral Palsy.	

2.2	Procedures: I understand that I will be provided with questionnaires that will take approximately one hour to complete. Generalised feedback regarding the study's outcomes will be made available should I be interested.	
2.3	Risks: I will not remain anonymous to the researcher and supervisors should I request feedback.	
2.4	Possible benefits: As a result of my participation in this study, more insight can be gained into the factors that make families living with a child diagnosed with Cerebral Palsy resilient. This information can be used in intervention programmes to offer families information and support.	
2.5	Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigators.	
2.6	Access to findings: A copy of the research will be placed in the library of the Nelson Mandela Metropolitan University. An article may be published in a journal aligned to the profession of psychology. Generalised feedback regarding the findings of the study will be provided to participants.	
2.7	<p>Voluntary participation/refusal/discontinuation:</p> <p>My participation is voluntary <input type="checkbox"/> YES <input type="checkbox"/> NO</p> <p>My decision whether or not to participate will in no way affect my present or future employment/lifestyle <input type="checkbox"/> TRUE <input type="checkbox"/> FALSE</p>	
3.	<p>The information above was explained to me by</p> <p><input type="text" value="Mrs Renée Small"/></p> <p>in <input type="checkbox"/> English <input type="checkbox"/> Afrikaans</p> <p>and I am in command of this language.</p> <p>I was given the opportunity to ask questions and all these questions were answered satisfactorily.</p>	
4.	No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.	
5.	Participation in this study will not result in any additional cost to myself.	

A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT

Signed/confirmed at

	on		2010
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Signature or right thumb print of participant

Signature of witness

Full name of witness

B. STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I, Renée Small declare that

- I have explained the information given in this document to

(name of participant)

- he/she was encouraged and given ample time to ask me any questions;
- this conversation was conducted in

	English		Afrikaans
--	---------	--	-----------

and no translator was used.

- I have detached Section D and handed it to the participant

	YES		NO
--	-----	--	----

Signed/confirmed at

PORT ELIZABETH	on	13 APRIL	2010
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Signature of interviewer

Signature of witness

Full name of witness

C. IMPORTANT MESSAGE TO PARTICIPANT

Dear participant

Thank you for your participation in this study. Should, at any time during the study:

- an emergency arise as a result of the research, or
- you require any further information with regard to the study, or
- the following occur

You are unsure about how to complete the questionnaires.
You have lost your questionnaires.

Kindly contact

Renée Small

at telephone number

[REDACTED]

APPENDIX D:
Biographical Questionnaire

Questionnaire no.:

BIOGRAPHICAL INFORMATION

All information in this questionnaire will be treated as strictly confidential and your information will be anonymously processed. Please cross the box most appropriate to you, or complete the statement in the space provided:

1. **Area of residence** (town or city or suburb)

2. **Economic status**

a) What is your family's estimated gross income per year?

<input type="checkbox"/> Less than R20 000	<input type="checkbox"/> R21 000 – R40 000	<input type="checkbox"/> R41 000 – R60 000
<input type="checkbox"/> R61 000 – R80 000	<input type="checkbox"/> R81 000 – R100 000	<input type="checkbox"/> R101 000 – R120 000
<input type="checkbox"/> R121 000 – R140 000	<input type="checkbox"/> R141 000 – R160 000	<input type="checkbox"/> R 160 000 or more

3. **Current Marital Status**

Married Co-Habiting If other, please specify: _____

How long have you been living with your partner? (completed years)

4. **Family composition**

a) How many people live in your home?

For each of the person in your home, including you, please try and answer the following:

Member	Gender	Age	Residing permanently with you
1	M / F		Yes / No
2	M / F		Yes / No
3	M / F		Yes / No
4	M / F		Yes / No
5	M / F		Yes / No
6	M / F		Yes / No
7	M / F		Yes / No
8	M / F		Yes / No
9	M / F		Yes / No
10	M / F		Yes / No

b) Relationship of family member diagnosed with Cerebral Palsy to you

c) Current age of child diagnosed with Cerebral Palsy

d) Age at which child was diagnosed with Cerebral Palsy

e) Please describe the child's limitations as a result of Cerebral Palsy

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Thank you for your co-operation!