

COPING MECHANISMS USED BY  
MOTHERS WHEN CARING FOR THEIR  
ADOLESCENT CHILD WITH  
CEREBRAL PALSY

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## **DECLARATION**

This research dissertation is the result of my own work/investigation, except where otherwise stated.

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## ABSTRACT

This study explores the coping mechanisms of mothers caring for adolescent children with cerebral palsy. This study attempted to address a gap in the literature pertaining to understanding negative and positive ways of coping related to mothers and the specific problems they have to deal with when caring for adolescents with cerebral palsy. The qualitative study focuses on experiences and feelings directly obtained from mothers and it looked at what coping mechanisms benefit mothers whilst they are caring for their adolescent child with cerebral palsy, what factors could compromise the mother's coping style and how adolescence impacts on the mother's ways of coping. The research revealed that mothers tended to use either emotion-focused ways of coping which was more maladaptive, or problem-focused ways of coping which were more adaptive ways of coping. A number of coping mechanisms were identified which appeared to benefit mothers, some of these include obtaining support from the medical profession as well as obtaining social support. The findings illustrated that there were particular 'poor' facilitative factors that could compromise the mothers coping style. Facilitative factors either influenced mothers to use more problem-focused ways of coping or more emotion-focused ways of coping. It was found that both these ways of coping were linked to different defence mechanisms.

This study found that adolescence placed more stress on the mother since new issues relating to adolescence emerged and had to be managed. The implications of these findings for management and care of mothers in these situations are discussed. It is hoped that the present findings will contribute to assisting clinicians in being able to focus on the important areas when working in this field.

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## **CHAPTER ONE**

### **1.1 Introduction**

Cerebral Palsy is a nonprogressive disorder that is acquired early in life (Cogher, Savage & Smith, 1992). The term describes a disorder of posture and movement which is caused by a brain lesion (McCarthy et al. 1992). This lesion often occurs before, during or after birth (Goodman & Katz, 2001). The brain lesion is permanent and the condition is lifelong (McCarthy et al. 1992). There are various types of cerebral palsy, these include diplegia, quadriplegia, hemiplegia, athetoid cerebral palsy, ataxic cerebral palsy and mixed type (Goodman & Katz, 2001). Depending on the location of the brain injury, these children can experience sensory and communicative difficulties, cognitive impairment, hearing and vision problems, sensory deficits and seizures. In addition, they may experience learning difficulties and behavioural problems (McCubbin & Huang, 1989). No two children with cerebral palsy are the same, due to the varying degrees of severity (Newey, 2008).

There are many responsibilities and difficulties involved in being a mother to a child. These difficulties are magnified when the child is disabled (McCarthy et al. 1992). The mother's role has to expand to that of nurse and caregiver since most of her time is spent caring for her child. It is assumed that the pressure put onto mothers with children with cerebral palsy increases even more as the child starts going through adolescence. Adolescence often includes mood swings, emerging sexuality and anxiety about the adolescent's future (Louw, Van Ede & Louw, 1998).

This investigation focuses on adolescent children with cerebral palsy as there may be many aspects to cerebral palsy that cause a considerable amount of frustration and stress for the child as well as the mother. The difficulty in speech and motor functioning has a huge impact on stress levels of mothers (McCarthy et al. 1992) and added to this could be the issues the adolescent faces, which could further call for robust coping mechanisms on the mother's part. Coping is a stabilizing factor that benefits people when they are in stressful situations. Cerebral Palsy can combine motor impairment with cognitive and lingual impairment and often children with cerebral palsy are multiply disabled.

Ultimately it is hoped that the findings from the study will provide a valuable understanding of the factors that contribute towards the way mothers cope with this specific situation.

## **1.2 Rationale**

There is a gap in the literature regarding obtaining information from a qualitative perspective, as well as focusing on mother's ways of coping with adolescent children with cerebral palsy. Limited studies focusing on the coping mechanisms the mother uses when caring for her adolescent child with cerebral palsy were found which motivated the need for this research (Eker & Tüzün, 2004; Ones, Yilmaz, Cetinkaya, & Caglar, 2005; Raina et al. 2005).

This study hopes to bridge this gap by exploring how mothers cope with their adolescent child with cerebral palsy as well as focusing on behaviour problems that could emerge during the adolescent phase of the child and how this added stress impacts on the mother's life. This qualitative study will focus on experiences and feelings directly obtained from mothers. For this to be fulfilled, the study will use in-depth interviews that allow for a better understanding of coping mechanisms amongst mothers. The research hopes to discover ways mothers cope with the stressors and pressure of having an adolescent child with cerebral palsy. The identification and understanding of coping mechanisms used would enhance our understanding of the way mothers cope and could be beneficial to clinicians and people seeking help.

## **1.3 Aims**

The study focused on the following research questions:

1. What kinds of coping mechanisms did mothers use and how were they utilized.
2. What factors might compromise the mother's coping style.
3. How do issues of adolescence impact on the mother's ways of coping.

## **CHAPTER TWO**

### **2. Literature Review: Coping with disability**

#### **2.1 Introduction**

The broad theoretical framework this study used is the ecology of human development by Bronfenbrenner (Bronfenbrenner, 1979). This theory looks at how people develop within an environment and the interaction between the two. Development in people is seen as the way a person deals with and perceives his environment. The ecological system consists of the immediate setting which in this study is the home or classroom and the interaction that takes place between the individual, family and society (Bronfenbrenner, 1979).

The ecology of human development is the study of mutual accommodation between a human being and the changing aspects of the immediate setting in which the person lives. This process is affected by the relationships between these settings and by the settings within larger contexts. A microsystem incorporates roles, interpersonal relations and activities that are experienced by a person within the setting. A mesosystem consists of two or more settings in which the person participates and the interrelation between these two settings. An exosystem exists when one or more settings do not involve the person as an active participant, but rather it becomes a setting in which events occur that affect, or are affected by what happens in the setting containing the person. A macrosystem looks at the consistencies that exist at the cultural level, along with belief systems underlying these consistencies. When a person's position in the environment is changed due to the change in the person's role or due to the change in the setting, an ecological transition occurs. Human development occurs when the person acquires a differentiated and valid notion of the ecological environment and becomes motivated to engage in the activities of that environment (Bronfenbrenner, 1979).

This model emphasizes that what is important for behaviour and development is how the environment is perceived as opposed to how it may exist in a reality that is more objective (Bronfenbrenner, 1979). The ecology of human development theory is useful

for this research since the mother is seen as the center of the ecological system. The way the adolescent behaves in his/her microsystem has a direct affect on the mother who cares for her adolescent. This creates a mesosystem since there are two settings the adolescent participates in. This in turn affects the way the mother copes with her adolescent.

As an extension of the ecology of human development theory, I will make use of the theories of coping to understand how coping and defence mechanisms can be psychological mediating factors in determining how people deal with stress. Ways of coping relate to the broad behavioural understanding of the way someone adapts. Moos and Schaefer's (1993) theory of coping will be used since this theory refers to the general conceptual framework which emphasizes that personal and situational factors shape efforts of coping (Zeidner & Endler, 1996). People use psychological defences as a buffer and a mediating factor in their response to stress. The psychological defences and coping mechanisms people adopt will determine how adaptive the person is in coping (Taylor, 1992).

## **2.2 Disability and the media**

A report from the "Monitoring media project" found that people with disabilities make up a considerable part of the population of South Africa. Although this is true, media coverage about people with disabilities is very low and limited. From a 2001 population figure of 44,819,778, 5% were reportedly disabled (Sibanda & Roberts, 2003).

A disability survey presented in a report "We also count" from the Department of Health (1997) provided information regarding the extent of reported disabilities and the nature of the disabilities experienced in South Africa. The prevalence rate of disability in South Africa showed that the majority of people who have disabilities were found in the Eastern Cape (8.9%) and Kwa-Zulu Natal (6.7%). Illness (26%) was found to be the main cause of disability. The results from this survey showed that many of the participants were not aware of what caused their disability, with 21% saying they "did not know" what caused their disability (Disability survey for the Department of Health, 1997, p. 18).

### **2.3 Coping with a disabled child**

Nelson (2002), cited in McGuire, Crowe, Law and Van Leit (2004), did a metasynthesis of studies examining a four-step process of coping that mothers with children with disabilities follow. The first step characterizes fear, anxiety, grief, shock, disappointment, guilt and despair about the child's disability. The second step involves the redefinition of the mother's maternal image to reflect her role as a mother of a child with special needs. This calls for her to become the expert caregiver to her disabled child. In the third step, mothers "make personal sacrifices and alter their lifestyle to accommodate their new role" (McGuire et al. 2004, p. 55). The fourth step looks at mothers redefining "normal" to affirm their own identity and their child's sense of worth (McGuire et al. 2004).

#### **2.3.1 Stressors that impact on mothers**

As McDonald and Chance (1965) state: "It is quite easy for a therapist to become so concerned about the Cerebral Palsied child's difficulties that the problems of the child's parents are overlooked" (McDonald & Chance, 1965, p. 48). There appear to be a number of important factors to consider here.

##### 2.3.1.1 Experience with the health profession

According to McKenzie and Müller (2006), assistance to parents of disabled children by the medical profession is often perceived as a disempowering experience for the parents. The medical profession tends to undermine parents' confidence in their ability to help their children. Also, rehabilitation therapists often tend to rely on the mother – instead of both parents – to ensure that techniques they provide are implemented.

A study by McDougall, Swartz and van der Merwe (2006) found that many mothers experience the process of trying to obtain a diagnosis for their child from medical professionals difficult and emotional. Since society sees women as having the bigger role in producing children, mothers in particular feel under societal pressure to produce a 'perfect child'. Disappointment and anger is usually felt afterwards when they feel they have produced a deficient child. Some mothers felt there was a lack of information from the medical professionals regarding how the disability would have an impact on parents.

They also felt the clinical context focused on the disabled child's impairments and ways they would not cope instead of the ways they would cope. It was found that this could be a reason why medical professionals did not always provide information on how to cope with a child's disability when the diagnosis was disclosed to parents (McDougall et al. 2006).

#### 2.3.1.2 Parents blame each other

According to McDougall et al. (2006), parents often blame the medical professionals and also blame each other. Mothers in this study found that extended family members would look down on them and speculate about what the mother must have done to have a disabled child. Mothers often felt shame as a result. Parents felt their child's disability must have come from their partner's side of the family. Mothers also expressed their concern with regard to the inability to produce 'perfect' children as having an impact on their and their family's social status.

#### 2.3.1.3 Psycho-social stressors

A study by Ones, Yilmaz, Cetinkaya and Caglar (2005) focused on how mothers may experience severe psycho-social stressors. This study found that mostly mothers when compared with both parents experienced depressive symptoms. They further discussed the finding that mothers who have children with cerebral palsy attempt to overcome complications that develop from their child's condition but are often unable to satisfy their own needs (Ones et al. 2005). In this study, there was a comparison between mothers' stressors and the severity of their child's cerebral palsy. The severity was measured on a Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997). This system classifies children with cerebral palsy into five groups according to gross motor movement, where the lower the score in the GMFCS, the better the functioning of the child. The authors found that poorer motor functionality did not add a detrimental effect to the quality of life of the mothers. They did mention however that this finding could be due to the fact that most of the children in their sample were diagnosed with 3<sup>rd</sup> and 4<sup>th</sup> levels of functioning, therefore there was not an equal distribution of levels of functioning (Ones et al. 2005).

Interestingly, McCubbin & Huang (1989) reported contrary findings. These findings suggested that the stressors and demands the families reported in their study increased when the child with cerebral palsy's disability was more severe. This severity included their physical functioning. Although they emphasized the importance of assessing stressors and strains in families who are caring for a disabled child, they felt that the focus should be on families who were caring for a child with a severe disability. This is because these families would be at greater risk for becoming overburdened by the multiple demands placed on them due to the severity of the disability.

Ones et al. (2005) conducted a study in Turkey and found that major stressors placed on mothers of cerebral palsied children were: (1) financial strains, (2) physical effects due to picking their child up and getting things for their child, (3) time-consuming demands of in-home care, (4) medical, educational and therapy appointments which require family members' time, (5) inability to change jobs due to the need for uninterrupted service provision and medical insurance, (6) an inability to change residence or a need to move as a result of convenient accessibility of education or medical services, and (7) a lack of information and resources, including transportation and legal services.

In the discussion below, there is some overlap with Ones et al. However a review of the literature also suggests that a lack of social support and parent individual activities (Taylor, 1992; Imms, Reilly, Carlin & Dodd, 2008); geographical accessibility (McKenzie & Müller, 2006); behavioural problems (Carlsson, Olsson, Hagberg & Beckung, 2008) and developmental changes (Floyd & Gallagher, 1997) are also important factors which can cause psycho-social stressors that can impact on mothers.

#### 2.3.1.3.1 Time consuming demands

Mothers may find themselves so busy caring for their child that they have no other time to do things at their leisure. Hintermair (2000) found children with disabilities including an auditory impairment may have difficulty adapting to their environment and constantly need and demand attention from their caregivers. These children often become clingy

towards their parents which leaves “very little room to breathe” (Hintermair 2000, p. 329).

McGuire et al. (2004) focused on the multiple challenges a mother with a disabled child faces. They designed a program to increase the satisfaction, time use and occupational performance of mothers of school-aged children (ages 3 to 14 years) with disabilities. They found that mothers of children with disabilities spend so much of their time on caring for their disabled child that they had little time for sleep and other necessary and meaningful occupations. Mothers may experience pressure to take on time-consuming activities like advocating for their child or assuming responsibility for performing therapy and other interventions at home for their disabled child. With these demands, some mothers find themselves unable to fulfill other aspects of their life such as spending time with their friends or husband.

As Jones, Howard, O’ Leary, Thurgood, (1992) explained:

“There are frequent appointments to be kept with different specialists; there is the constant need to stimulate the child with exercises provided by the physiotherapist and portage worker, as well as working out their own scheme to stimulate the child. Often household chores go unheeded. There is a danger that brothers and sisters may feel left out, or that one parent may take on all the work with the child” (Jones et al. 1992, p. 5).

According to McKenzie and Müller (2006), mothers often take their children from one therapist to the next which reduces time for themselves as well as for the child to engage in social activities.

As a consequence, mothers often tend to feel guilty because of lack of time or energy for doing things other than caring for the child. It is as though there is this constant feeling of never doing enough (Taylor, 1992).

#### 2.3.1.3.2 Financial difficulties

In South Africa, McKenzie and Müller (2006) found that there were added stressors to mothers regarding the amount of money needed to provide therapeutic interventions for their disabled adolescents. They found that the mothers had to choose which therapy to focus on because they were unable to afford all the suggested therapies and had to determine the number of therapy sessions they could afford.

#### 2.3.1.3.3 Physical stressors and illness

Difficulties that were identified by McGuire et al. (2004) were the mother's burden of responsibility, feeling physically drained, feelings of disorganization and having to deal with their confusion about their self-identity which made it difficult to adjust to new roles in adult environments like work and coping with isolation. Other difficulties many mothers mentioned were feeling exhausted, unmotivated and depressed (McGuire et al. 2004).

Eker and Tüzün (2004) found that mothers of children with cerebral palsy had inadequate sleep patterns and avoided seeing a doctor when they needed one. This neglect of their own needs could have caused the development of physical problems. Some of the tasks a mother had to do for their child with cerebral palsy included heavy lifting, turning, bathing, helping the child use the toilet, getting the child to sleep, getting the child dressed and helping the child to move. All of these tasks put physical strain on mothers. This research also found that added stress was placed on the mother due to her being the main caregiver and a belief many of the mothers held was that if they failed, the child would suffer.

#### 2.3.1.3.4 Lack of social support and individual activities

Much of the research illustrated how much time is taken up caring for a physically disabled child. Many parents tended to make frequent sacrifices for their disabled child (Taylor, 1992). A study by Imms, Reilly, Carlin and Dodd (2008) identified the importance of children with cerebral palsy participating in activities outside of their school environment. The authors emphasized how participation in activities provided

opportunities for socialization and skill development which would contribute to the development of children, especially those with disabilities. However, these extra activities could also put further pressure on parents' limited time available to them. Taylor (1992) found that parents gave up their own interests and hobbies to spend the maximum amount of time working with their child.

The study by McGuire et al. (2004) found a main theme to be the lack of adult support which contributed to feeling isolated. The mothers came to identify the lack of adult support with a lack of the adult's understanding about the disabled child, making them feel as though they were fighting their battle alone.

It is important to understand that parents are also affected by the problems of managing the day-to-day demands of the disability. The child's disability often results in reduced opportunities to go out, and therefore many parents could have a restricted social life which could lead to difficulties of social integration (Taylor, 1992).

The program designed by McGuire et al. (2004) focused on the importance of mothers rebalancing their lives to improve their sense of well-being. The mothers in this program examined the negative influences in their lives and found that having a positive outlook was an important aspect for personal well-being. By establishing priorities throughout the day, the mothers felt more effective in managing the tasks they had to do. The program also established that support groups were felt to be beneficial as the mothers no longer felt alone as they listened to other people who experienced similar frustrations, problems and joys of parenting a disabled child.

#### 2.3.1.3.5 Geographical accessibility

Geographical accessibility in South Africa also seemed to cause problems for mothers when they had to take their adolescents to several therapists for their input. Many of the therapists appeared to work in different areas; therefore shared goals for the adolescent were not set and worked towards. McKenzie and Müller (2006) found that mothers in this

predicament found themselves “overstretched” by having to take their adolescent from one therapist to the next (McKenzie & Müller, 2006, p. 312).

#### 2.3.1.3.6 Behaviour problems

In a study by Carlsson et al. (2008) behavioural problems were found to be common in children with cerebral palsy. Behavioural problems appeared to be exacerbated when other neurological impairments such as epilepsy were present.

In a study by Floyd and Gallagher (1997) the presence of child behaviour problems was generally found to be one of the most important determinants of parental stress and care demands. The severity of these behaviour problems for children with disabilities can be predictive of poor family adjustment. Stress was increased due to the presence of child behaviour problems and problems in managing the child. Disruption of activities and opportunities for other family members also added to the stress. Behaviour problems limited access to normalized experiences for disabled children by keeping them in more restricted school placements and also by limiting family activities.

Important predictors of the well-being of caregivers were found to be determined by the child’s behaviour, demands of the caregiver and the functioning of the family. Research has shown that a higher level of behaviour problems were related to lower levels of psychological and physical health of the primary caregiver. Better family functioning, higher self-esteem, and sense of mastery was associated with better psychological health as parents tried to deal with the vicissitudes of stress (Raina et al. 2005).

#### 2.3.1.3.7 Developmental changes

In families coping with a disabled child stress recurs throughout childhood and into adulthood when the child faces new developmental changes and challenges, or when the child fails to reach age-related gains in development. The parent-child struggle often increases during adolescence which may cause increases in stress for parents (Floyd & Gallagher, 1997).

## **2.4 Developmental issues in adolescence**

There are a number of particular developmental issues that occur in adolescence that need to be considered in exploring the impact these may have on the caregivers of disabled children. It is important to keep in mind the complexity of the adolescent's physical and sexual development, the development of their thinking, their feelings, their relationships with peers and their identity. Some developmental tasks adolescents need to master are "development of an own identity, development of independence from parents and other adults, development of socially responsible behaviour, establishment of heterosexual relationships and preparation for marriage and family responsibilities" (Louw, Van Ede & Louw, 1998, p. 388).

### 2.4.1 Individuation conflicts

Adolescence is a challenging time for those who are involved. Challenging as it is for young people who do not have a disability it is often even more difficult for those who have. Parents need to allow the adolescent to develop their own autonomy as well as be available to help them whenever their dependence on parents arises (Taylor, 1992).

It can be very difficult for an adolescent with cerebral palsy to develop their own independence away from their parents and other adults (Taylor, 1992). Parents may have adopted a way of caring that does not easily adjust to the increased demands for independence. The young disabled person may become used to everything being done for him/her. Whilst different disabilities have different severities and stabilities, a level of protectiveness and special caring is likely to be appropriate in adulthood as well as childhood, but there is a danger of this becoming the inappropriate standard response. As Madden (1992) states: "Too many people with disability still say that they feel condemned to permanent childhood" (Madden, 1992, p. 538).

### 2.4.2 Sexuality

Sexual maturation is one of the most important events in development. Adolescents increasingly become aware of their sexuality which starts to form a part of their interpersonal relationships and identity (Louw, Van Ede & Louw, 1998).

Experimentation and bodily self-examination might be restricted by a disability since the adolescent with cerebral palsy may have little privacy since they are likely to be closely supervised. Young people with disabilities therefore sometimes have few opportunities for sexual encounters due to their dependency on their parents (Cogher, Savage & Smith, 1992).

#### 2.4.3 Emotional turmoil and behavioural issues

Many disabled adolescents experience developmental difficulties and limitations that impact experiences and have the effect of constraining their identity development (Taylor, 1992).

Some adolescents experience emotional changes due to their physical, cognitive, social and personality development which have a connection with adolescents having emotional outbursts and mood swings (Louw, Van Ede & Louw, 1998). The fact that adolescents have more emotional outbursts and mood swings could have an impact on the limited expression of affect that some of the adolescents with cerebral palsy have. Some adolescents with cerebral palsy may have difficulty expressing their inner frustration due to their restricted mobility and their poor communication skills. They may be unable to slam doors, walk out of the room and possibly experience difficulty arguing. If adolescents with cerebral palsy experience difficulty in this way, then any attempt at rebelling against their parents would possibly have to be in a non-verbal way. Another point to mention is that adolescents with cerebral palsy are unlikely to be able to challenge their parent's values as this could threaten their own security since they are dependent on their parents for physical care (Cogher et al. 1992).

### **2.5 Coping with Cerebral Palsy**

#### **2.5.1 Theories of coping**

Coping is seen to be a stabilizing and mediating factor that can benefit individuals during stressful periods (Lazarus & Folkman, 1984, as cited in Zeidner & Endler, 1996). Problem solving and emotion regulation are understood to be functions of coping (Lazarus, 1991, as cited in Schwarzer & Schwarzer, 1996). Coping includes cognitive

and behavioural aspects to reduce stressful conditions (Lazarus & Folkman, 1984, as cited in Zeidner et al. 1996). Zeidner et al. (1996) looked at categorizing the conceptualization of coping into assumptions about primary determinants of responses to coping. The dispositional approach, used in the ego-psychoanalytic model, emphasises that stable person-based factors are used in the ‘choice’ of coping behaviours. The contextual approach is emphasized in the appraisal-based model by Lazarus where situation-based factors are seen as shaping people’s selection of coping responses (Lazarus & Folkman, 1984, as cited in Zeidner et al. 1996). Problem-focused coping is seen as being action-oriented since the person-environment relationship is changed by instrumental actions. Emotion-focused coping, on the other hand, includes cognitive coping mechanisms that do not directly change the situation but they rather help attach a new meaning to the situation (Lazarus & Folkman, 1984, as cited in Schwarzer & Schwarzer, 1996).

An integrative conceptual framework understands the strengths of dispositional and contextual theories of coping (Zeidner et al. 1996). This model also looks at the reciprocal relationship between environmental factors such as the person’s socio-economic status and quality of life, and individual factors such as self-confidence. These influences, when combined, shape the health and well-being of the person through cognitive appraisals of the situation and ways of coping (Zeidner et al. 1996).

Coping can be defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, as cited in Judge, 1998 p. 263).

When conceptualizing coping, one should be aware that coping does not necessarily have an endpoint or reach completion. Rather, coping comprises ongoing strategies to deal with ongoing stressors. The effort to cope can be expressed in behaviour, emotion and cognition. One should also be aware that understanding the cognitive appraisal of the

situation that is causing the need to cope is a prerequisite to begin the process of coping (Schwarzer & Schwarzer, 1996).

There are problems that arise since cognitive coping and cognitive appraisal can be confounded. A way of separating this can be seen when "...coping refers to what a person thinks or does to try manage an emotional encounter; and appraisal is an evaluation of what might be thought or done in that encounter" (Lazarus, 1991, as cited in Schwarzer & Schwarzer, 1996 p. 1). It is important to be aware of problems that could appear when coping is to be disentangled from coping resources. Resources are static antecedents that can include personal or social aspects of coping. Coping proper, however, is a process that depends on the resources the person has. It is imperative to understand why the person is coping in a certain way, in other words, a person could make a positive statement due to their personality trait (dispositional) or it could be due to situational aspects such as a product of stress management (situational) (Schwarzer & Schwarzer, 1996).

It is important to note that people often go through stages when dealing with a demand that is stressful. A coping mechanism that an individual uses in the first stage might not be useful in the second stage. If stages can be identified, the coping mechanisms used should be assessed within each stage the person goes through (Schwarzer & Schwarzer, 1996). A further distinction in terms of episode, domain and stage should be discussed. An episode is a stressful encounter that has a beginning and an ending. A domain includes the area in which the problem arises. A stage is a subdivision of an episode and is important since individuals do not necessarily cope in the same way through each stage (Schwarzer & Schwarzer, 1996).

Judge (1998) reported that coping strategies that involve ways to change the cause of the stress can be referred to as problem-focused coping. Efforts to maintain emotional responses to the stressors can be seen as emotion-focused coping. Problem-focused ways of coping can include active problem-solving as well as seeking social support and interpersonal efforts to alter the situation. Emotion-focused forms of coping include

detaching from the situation, controlling one's feelings, wishing the problem would disappear, and blaming oneself for the actual situation. This form of coping includes denial, avoidance or wishful thinking which could be positively related to depressed moods (Judge, 1998).

According to Krohne's (1993) coping theory, two basic dimensions have been devised that group possible responses people use when coping. The first dimension includes instrumental, vigilant, confrontative coping which incorporates strategies that are characterized by processing the threatening information. The second dimension includes avoidant, emotional and palliative coping which is made up of strategies that are characterized by turning away from the cues that are related to the threat (Schwarzer & Schwarzer, 1996). This can be related to emotion-focused and problem-focused ways of coping (Judge, 1998) since problem-focused ways of coping can be seen in the first dimension where the information is processed and emotion-focused ways of coping are similar to the avoidant dimension described in Krohne's theory of coping (Schwarzer & Schwarzer, 1996).

#### **2.5.1.1 Coping, Mothers and Cerebral Palsy**

Much of the literature (Ones et al. 2005; Eker & Tüzün, 2004; Judge, 1998; McGuire et al. 2004; Taanila et al. 2001) focused on how parents cope with the difficulties of having a child with cerebral palsy within the average age range of two years to twelve years. Not many have focused on adolescents with cerebral palsy (Ones et al. 2005).

Coping is generally affected by a number of factors. Particular issues with mothers coping with their child with cerebral palsy are described below. In exploring this, the assumption is made that appropriate coping strategies make use of existing resources available to the individual. Using coping strategies is seen as an active process that includes behaviours the family employs to help manage difficulties (Taanila, Syrjälä, Kokkonen & Järvelin, 2002). A study on parental stress and the use of support systems found that the families' service utilization was highly dependent on the parents' motivation to obtain assistance (Floyd & Gallagher, 1997). In addition to available

support systems, the best system was found to be meetings with parents who are in a similar situation since this allows for the parents to share experiences (Hintermair, 2000).

McCubbin and Huang (1989) focused on moderator variables which mitigate stress in mothers. Significant variables were found to be marital satisfaction resources like spousal, financial and emotional support as well as physical help with child care. These variables can play a buffering role to stress.

According to the Western Cape Cerebral Palsy Association, there are Social workers who have support groups for mothers who have children with cerebral palsy on a monthly basis. There are three support groups around the Cape Town Peninsula area (J. Singleton, personal communication, 5 January 2009). According to the Natal Cerebral Palsy Association, there are no support groups for parents who have adolescents with cerebral palsy in the Durban area, however there is one support group in Pietermaritzburg (P. Van Eeden, personal communication, 8 January 2009). Other than these the researcher is not aware of any other support services in South Africa specifically targeting cerebral palsy.

Much of the literature reviewed (Eker & Tüzün, 2004; Judge, 1998; Ones et al. 2005; McGuire et al. 2004) focused on quantitative studies where parents with children with cerebral palsy were compared with either a sample group who did not have a disability (Ones et al. 2005), or a group of parents with children who had minor health problems (Eker & Tüzün, 2004). Taanila et al., (2002) focused on parents with physically and/or intellectually disabled children and discovered different coping strategies used between families that coped well and families that did not cope as well. Factors that emerged from families that coped well were: acceptance, obtaining new information, optimistic attitudes, good family cohesion, open communication, good social support, self-confidence, flexibility. Factors emerging from the low-coping families were: serious disagreements in accepting the child's disability between parents, all coping strategies were used by the mother only, social support was received only by the mother, marital relationship was not very good, negative feelings were shown, serious problems with other siblings, denial.

The five domains in which the high- and low- coping families differed most from each other were: (1) parents' initial experiences, (2) personal characteristics; (3) effects on family life; (4) behaviour in everyday life; and (5) social support. In the high coping group, parents had an optimistic attitude towards their family life and their child. The parents accepted their child's disability quite quickly after the initial shock and were confident that their child would cope within the available support systems. Although family cohesion had increased, parents still kept their individual activities. The parents equally shared the housework and childcare tasks or they had made arrangements about which tasks they would each do. These parents also had a broad social support network (Taanila et al. 2002).

The parents in the low-coping group had experienced shock at their child's diagnosis. They were uncertain about their child's future and they thought they had to give up their work and personal activities because of their child. The parents had a small and informal support network. Relatives and friends who were considered to be part of the informal support network were perceived as being an annoying hindrance when they were around. The mothers in this group did all the work by themselves (Taanila et al. 2002).

The tasks involved in caring for a child can often go unrewarded within the partnership, family and also intrinsically if the child does not appear to progress. There is also the "continuity of stigma, the second glances, quizzical looks, the attempts to give sympathetic smiles, the gaze avoidance and the looks of frank distaste to be coped with daily" (Taylor, 1992 p. 57).

McGuire et al. (2004) looked at solutions to the issues that mothers felt added to their stress levels. Some important solutions were to create positive feelings and experiences, to maintain their own identity and to assert their own needs as well as taking the time to do things for themselves. Environmental factors that contributed to the mothers wellbeing were physical and emotional support, spending quality time with friends, exercising, as well as being aware of available resources.

Floyd and Gallagher (1997) found that the type of disability and the presence of child behaviour problems were the most important determinants of parental stress. They further explain that the impact of disabilities on parents depends on the characteristics of the particular disability as well as characteristics of the family that influence stress and the types of coping resources that families use. This could be explained by determining whether the family uses emotion-focused or problem-focused ways of coping.

According to Dovey and Graffam (1983) as cited in McKenzie and Müller (2006), parents experienced intense periods of stress which were associated with daily living problems that occurred with their disabled child. The implications were that the impact of their child's disability fluctuated over time as did the nature of the parental concerns. This illustrated that parents go through stages of accepting their child's condition and caring for their disabled child.

There are also cultural determinants that possibly mediate the mothers' ability to cope with disability. The author of a study on mental disorders and disability across cultures (Pretorius, 1995) identified how people with different cultural backgrounds perceived disability differently. From a traditional African point of view, illness was sometimes seen as the sign of a lack of harmony between the person and his/her ancestors and social environment. The spirits of ancestors are often believed to cause forms of illness including disabilities. This usually occurs if people fail to perform rituals or fail to observe instructions from the ancestors (Mokhosi & Grieve, 2004). According to these authors, misfortune and suffering is usually interpreted as resulting from the anger of the ancestors.

In South Africa, 80% of African patients preferred to seek help from a traditional healer before they consulted other doctors. The traditional African healing concept is intertwined with cultural beliefs as well as with religion, and any healing process that does not include these beliefs is thought to be unsatisfactory. According to Pretorius

(1995), western views of disability should therefore not be applied to a culture that has a different perception of disability and a different view of life.

Masasa, Irwin-Carruthers and Faure (2005) noticed the importance of being sensitive to differences when living in a multicultural, multiracial and multilingual society, especially when providing a service to people with disabilities. The authors identified the importance of how a lack of awareness of cultural beliefs could hinder the service provided to people from differing cultural backgrounds. The authors concluded that health professionals should be trained to become more culture-sensitive when working with people from a cultural background that differs from their own. The authors also recommended that health professionals and traditional healers work more closely together in order to provide a more multicultural service.

#### **2.5.1.2 Grief stages**

The factors mentioned earlier show a particular impact on mothers. The process of coping with these emotional factors can be understood in terms of particular phases. These phases can be compared to the stages of grief (Taylor, 1992). The grief stages by Kübler-Ross (1970) would be applicable here. According to Kübler-Ross (1970), these stages are seen as coping mechanisms to deal with extremely difficult situations. These stages can last for different periods of time and can replace each other or exist side by side.

According to Kübler-Ross (1970), the first stage of grief is denial and isolation. The parent's first reaction is that of shock. It is usually temporary and will soon be replaced by partial acceptance (Kübler-Ross, 1970). In terms of disability, parents experience shock when they receive the news of their child having a disability. In this first stage of shock, parents need to be supported by each other as they receive the information. This is so they can discuss it between themselves and to confirm what they heard (Taylor, 1992). Once this feeling has disappeared, denial acts as a buffer after unexpected shocking news. Parents of children with cerebral palsy are usually unable to believe the news and fail to accept the information given to them. Denial for parents is a defense as well as a stage in grief (Taylor, 1992).

When the first stage of denial cannot be maintained any longer, the second stage which incorporates feelings of anger, rage, envy and resentment replace denial. This second stage is very difficult to cope with from the family's point of view. This is because this anger is displaced in all directions and is often projected onto the environment at almost random times (Kübler-Ross, 1970). The anger parents go through can sometimes be directed at the actual handicap. Anger can also help shield against helplessness, guilt and depression (Taylor, 1992).

The third stage of grief is the bargaining stage (Kübler-Ross, 1970). Parents of children with cerebral palsy do not necessarily go through this stage. This stage in grief includes a deadline and prize that is offered "for good behaviour". It also includes a promise that the person will not ask for anything more if this one postponement is granted. Most bargains are usually made with God (Kübler-Ross, 1970, p. 72).

Depression can occur in the fourth stage. This stage occurs when there is a realization that this is real and can no longer be denied (Kübler-Ross, 1970). In this stage, once anger has receded, opportunities arise where one considers "the self, one's potential share in the blame, the sense of helplessness and hopelessness about the future. Self-blame can reach delusional proportions" (Taylor, 1992, p. 56).

According to Taylor (1992), parents of children with cerebral palsy could also develop enormous feelings of guilt which could arise when thinking about their child's disability. These thoughts can include ideas about injuring their child or wishing their child would die soon. Some parents also perceive the disabled child to be a form of punishment. For instance, some would see it as punishment for former pregnancies that were terminated, thoughts of feeling ambivalent about having children are also linked to feelings of punishment (Taylor, 1992).

Loss is recognized as an absence of something from the outer world. A death creates different degrees of loss within different people, often determined by what the lost person

meant to the individual. If one looks at the loss of “the child we hoped he would have been” it shows that the degrees of loss will vary greatly even within a caring, close-knit family (Taylor, 1992, p. 57).

Taylor (1992) explored loss related to parental expectations. What is felt to be lost is the child who could have realized the parent’s expectations. Mourning is complicated by the fact that the child cannot be mourned as a ‘lost object’ since the child’s presence precludes this kind of grief process. However, it would seem as though parents dealing with having a child with a disability would follow similar stages of grief. It seems as though the grieving process is of a particular kind best captured by the following quote by Taylor (1992):

“The pain of loss follows the course of ordinary grief with these exceptions. The continuity of the handicapped child gives a sense of guilt to grief, and it will repeatedly provide powerful reminiscence of that original pain when they discovered the difference between their child to others” (Taylor, 1992, p.54).

Taylor (1992) found that parents use a variety of defence mechanisms while they move through the grief stages.

“Parents will be encountered in various stages of their grief, a grief which is easily acutely rekindled by the professional activity itself. The grief will be countered by various defense mechanisms so that the combination of the stage of grief reached and the modes of defenses used will produce a variety of presentations of distress within parents” (Taylor, 1992, p. 54).

If these stages of grief have been worked through, the fifth stage which is acceptance will be reached. In this stage, depression or anger would have dissipated (Kübler-Ross, 1970).

Carter (2004) described the emotions that occur whilst moving through the various phases of the grief model:

“As we move through the phases of the cycle ...we mourn the loss of the child we anticipated...the child who slipped through our hands...the one who quietly disappeared into the crowd, never to be found. This mourning process...is a necessary step before we can move on and begin to accept our disabled children into our lives” (Carter, 2004, p. 181).

Contrary to the idea of there being particular stages, Kleinman (1988) identified the importance of acknowledging each patient as an individual and that suffering is an individual process that cannot be categorized into phases that each person would experience. The author felt that each patient had their own personal illness narrative. These narratives included ways the individual patient structured his/her illness and experiences from cultural and personal ways. The author felt that each story a patient brought could only be made sense of in the context of that person's life. In order to understand it, health professionals should relate illness and life to each person's cultural context. The author found that many medical professionals saw patients as a “case” (Kleinman, 1988, p. 131). From this perspective, the patient changed from being a subject and became an object.

As one of Kleinman's research participants mentioned, “All that nonsense that's written about stages of dying, as if there were complete transitions – rooms you enter...the anger, the shock...they are part of each day. And in no particular order, either” (Kleinman, 1988, p. 147). Kleinman recommended practitioners to not push the patient into a model of dying that could be invalid in that particular patient's life, he stressed the importance of individuality and allowing the patient to go through whatever he/she needed to. He found that the patients he interviewed went through a process of making and re-making meaning in their own context. The author felt it was important to not focus on general ideas of the meaning of illness but to rather attend to the manner in which individual

patients find meaning, the way they created meaning and the social and psychological reactions that determined the meanings (Kleinman, 1988).

Although some of the literature suggests that mothers go through stages, other literature identifies the importance of acknowledging each person as an individual. Suffering is seen as an individual process that cannot be categorized into phases. These are interesting findings which will be important to keep in mind when analysing the themes that emerge from the interview sample.

### **2.5.1.3 Defences mothers use**

People use psychological defences as a buffer and mediating factor to their response to stress. Psychological defences people adopt have an impact on the way they will cope. Defence mechanisms (or coping styles) are unconscious psychological mechanisms that attempt to shield the individual against stressors or to avoid pain (American Psychological Association, 2000). Coping is a conscious cognitive and behavioural response to manage internal or external demands (Schwarzer & Schwarzer, 1996).

Examples of defences parents of disabled children use are, sublimation, repression, denial and projection. Sublimation is usually a positive defence mechanism that is used and can occur when parents repress an unconscious conflict that is denied gratification into a more acceptable form of expression. Sublimation can channel personal needs in an adaptive way. The original hurt and pain can be developed into more useful activities that can either concern the handicap or be directed elsewhere (Taylor, 1992).

Although defences can be adaptive, rigidly held defences can have a negative impact on psychological development. It is well known that some of the maladaptive defences are repression, denial and projection. It is important to note that coping mechanisms employed by mothers may not necessarily benefit their children. These defences can be counterproductive if parents use them excessively. Firstly, repression or suppression occur when one does not think about something that is difficult and painful to deal with.

Parents and children who 'forget' their appointments, programmes and diets are often suppressing which suggests a more conscious process (Taylor, 1992).

Denial may be a factor in parents' inability to accept their child has a disability. "Denial is the repudiation of fact" (Taylor, 1992, p.60). This defence mechanism can interfere with treatment and may be related to only some aspects of the diagnosis, for example its chronic nature and persistence. However, denial can in some instances be very necessary in coping with chronic disability since this could be a protective factor for the mothers if they are unable to deal with their child's disability at that time.

Projection occurs when a person ascribes to others actions or wishes in one's own self that one would not dare talk about. This can occur when a parent fears for the safety of their child in the care of others which might arise from unexpressed personal wishes that the child will be harmed (Taylor, 1992).

## **2.6 Conclusion**

The literature suggests that there are many stressors that have an impact on mother's ability to cope when they care for their disabled child. Issues during adolescence such as their physical and sexual development appear to exacerbate mother's stress. Some literature (Kübler-Ross, 1970; Carter, 2004; Taylor, 1992) suggested that people move through different phases that can be seen to be similar to the stages of grief. Kleinman (1988) on the other hand emphasized the importance of seeing each person as an individual who should be allowed to experience grief and death in their own way, without having a model imposed on them. This was explored with the participants of this study. The issue of whether mothers dealt with issues of mourning in a linear fashion will be discussed below (Chapter six).

It appears that most of the literature isolates support as an important factor when coping with caring for a disabled child. Although this is the case, how they experience such support and the difficulties that the mothers encounter, specifically with adolescents with cerebral palsy, has yet to be explored.

## **CHAPTER THREE: METHODOLOGY**

### **3.1. Design**

An Ideographic research design was used. This design was used as it studies individuals as individuals rather than individuals as members of a population. Developing case studies was useful for this research as case studies are descriptive and can provide rich information about individuals (Lindegger, 2002). The information and observations obtained from the interviews assisted in providing a thorough understanding of the mothers' perceptions of coping. Interview methodologies are also useful in potentially generating new insights that emerge from the interview (Terre Blanche & Kelly, 2002).

A qualitative, interpretive method was used because it helped to describe and interpret people's experiences and feelings expressed in human terms rather than through the quantification of data. Interpretive research assumes the subjective experiences of people are real and should be taken seriously. This kind of research takes the view that it is important to understand others' experiences by listening to them and by interacting with them (Terre Blanche & Kelly, 2002). The participants' answers to the questions in the interview were clearly subjective in nature. The interpretive method was therefore applicable in this research as the data was analysed with the mothers' feelings and experiences in mind. Thematic content analysis (Krippendorff, 2004) was used to organise and make sense of material gathered in the interviews and focus groups. Content analysis is used when the researcher is interested in analysing the meanings found within texts. The researcher views data as representations of texts that have been created to be read for their meaning (Krippendorff, 2004). Details of which will be discussed below (section 3.5).

### **3.2 Procedure**

A Special Needs School was approached to investigate their interest in this research study. Purposive sampling as described by Strauss and Corbin, (1990) was used as the sample in this research had been chosen specifically to investigate coping mechanisms of mothers of adolescents with Cerebral Palsy at the Special Needs School. Ethical

clearance was obtained from the parents who participated in the interviews as well as from the University of KwaZulu-Natal.

### **3.2.1 Phases of research**

Research was carried out in two different phases with two different samples.

#### **3.2.1.1 Phase 1: Interviews with the focus group**

This phase consisted of a focus group interview (Questions are provided in Appendix I). The Principal of a Special Needs School asked mothers who have adolescents with cerebral palsy at the school if they were willing to participate in the study. The names of the mothers interested in participating were given to the researcher and they were telephoned to arrange a meeting. They were informed of the following: (1) The content of the interview, (2) that participation would be voluntary, (3) that the information obtained would remain confidential, (4) that they would remain anonymous and (5) that they would be able to withdraw from the interview at any time.

An interview was conducted with this focus group and the duration was 60 minutes. Themes were elicited from this meeting in order to gain more of an understanding regarding the difficulties and coping strategies evident in mothers faced with such challenges. The information obtained from these mothers and from the literature review was organized into themes which facilitated the development of the questions (Questions are provided in Appendix II) that were investigated in phase two which involved individual interviews with mothers with adolescent children with cerebral palsy at a separate Special Needs School.

#### **3.2.1.2 Phase 2: Interviews with the mothers of adolescents with Cerebral Palsy**

With the school's permission, letters were sent out to mothers who had adolescents with cerebral palsy at the Special Needs School. The letter informed mothers that participation would be voluntary, information obtained during the interview would remain confidential and that they could decide to withdraw from participation in the research at any time.

Once the names and telephone numbers of the mothers were obtained, they were contacted to make an appointment and were informed of the structure of the interviews. The interviews were conducted at the participant's home in order to put them at ease and to observe them in their own natural setting. The researcher asked the participants for their permission for the researcher to take notes for the duration of the interview in addition to the interview being audio-taped. Before the interviews were audio-taped, the surrounding setting was made free from noise and interruption. Each interview was recorded in a separate file and each file was labelled, for example "Participant 1" with the date it was recorded. The recorded interview was then transcribed. The interviews were 60 minutes long each.

Due to the sensitive nature of the content of this study, the participants were prepared for the type of questions that would be asked prior to the interview. They were prepared by being informed of the general content of the questions (Terre Blanche & Kelly, 2002). Similar to the mothers in the focus group, mothers were reminded that their participation was voluntary, the information obtained from the interview would remain confidential and that they were able to withdraw from the research at any time. They were informed of their anonymity and during the interview only their first names were used when it was necessary. If a mother felt she could no longer continue with the interview due to the sensitive nature of the content, the interview would have been terminated. When sensitive issues were addressed in the interview, the researcher behaved in a sensitive and professional manner. The researcher informed the mothers that a referral for counselling would be provided if it was necessary.

### 3.3 Sample

Two samples were used in this study:

<b>Focus group sample</b>	<b>Age of adolescent</b>	<b>Culture of adolescent and mother</b>	<b>Gender of adolescent</b>	<b>Severity of disability</b>
Participant 1	13	Indian	Female	Quadriplegic
Participant 2	17	Indian	Male	Quadriplegic
Participant 3	13	Coloured	Female	Quadriplegic
Participant 4	19	White	Female	Quadriplegic
<b>Individual interview sample</b>				
Participant 1	13	White	Female	Quadriplegic
Participant 2	16	White	Female	Hemiplegic
Participant 3	15	White	Male	Hemiplegic
Participant 4	17	White	Male	Quadriplegic
Participant 5	17	White	Male	Quadriplegic

Table 1: Demographics of participants and their adolescent children

#### 3.3.1 Focus group sample

This explorative study obtained information from four mothers who had adolescent children with cerebral palsy who agreed to participate in a focus group. Three of the mothers who participated in the focus group were mothers who worked at the school. It is possible that this could have created bias as the mothers could have felt compelled to answer in a particular way and not truthfully.

The researcher felt a focus group would be useful as a guide to help identify and understand themes that could be useful in the development of the questions for the interviews. The principal of a Special Needs School was contacted and informed of the study. An e-mail discussing the study was sent to the principal. The principal was asked whether he knew of mothers who would be interested in discussing their experiences

caring for their adolescent child with cerebral palsy. The principal identified five mothers who fitted the criteria. These mothers were contacted by the researcher, informed of the study and obtained their permission to have the focus group audio-taped. A date and time to meet at the school was set. The focus group was conducted in the school board room. All five mothers felt it would be best to meet at the school and they were all happy to meet in the board room. The time of the meeting was set one hour and a half before the mothers had to pick their children up from the school. Only four of the mothers arrived. All of the mothers signed an informed consent form before the focus group commenced.

### **3.3.2 Individual interview sample**

Information was then obtained from five individual semi-structured interviews with mothers of adolescent children with cerebral palsy. The mothers all had adolescents that attended a Special Needs School. The criteria for the selection of mothers was that their child needed to be within the age range of 12 to 19 years and the child needed to have a moderate to severe level of disability. Moderate to severe disability can be defined as disability falling within the level III to V category on the Gross Motor Function Classification System (GMFCS) for cerebral palsy. The GMFCS is based on self-initiated movement. Distinctions between the five levels are based on the levels of mobility the person has (Palisano et al. 1997). Although the focus group consisted of a mixed race group, only White mothers responded to the letter and were willing to participate in this study. This has important implications for the study given historical, cultural, political and economic factors that still affect different race groups in South Africa. For this reason it is important to review possible reasons why this occurred.

### **3.3.3 Possible reasons for demographics of individual interview sample**

There are a number of possible reasons why only white mothers participated in the individual interviews:

1. Alienation due to an individualistic perspective and Access problems
2. Cultural belief systems
3. Internalized discrimination
4. Inequalities between Black and White people under the Apartheid regime

## 5. Language barrier

### 3.3.3.1 Alienation due to an individualistic perspective and access problems

According to Schneider (2006) the history of disability in South Africa has been seen to be a problem of the individual. This view was associated with an individualistic perspective or the medical model of disability. This individualistic perspective may have had alienating effects which could possibly have made it more difficult for African mothers to deal with and to obtain support. The individualistic perspective changed over the years and the current view is no longer seen as a problem of the individual but is understood to be a problem of the environment (Schneider, 2006). The environment is seen as a restricting and limiting place for people who are disabled. Schneider (2006) defines disability as including external environmental factors as well as internal personal factors. Many of the African students were residing at the boarding facility at the school and therefore access to their mothers would have been difficult as they lived in rural areas that were far away from the city. The mother's perceived inaccessibility possibly contributed to them not responding to the invitation to participate in this study.

### 3.3.3.2 Cultural belief systems

A possible reason for African families not participating in this study could be due to their reluctance in wanting to discuss their feelings about their child's disability. Mokhosi and Grieve (2004) found that many African people have cultural belief systems that play an important role in their perception of adversity. According to these authors, a cultural belief they have is that any illness, accident or misfortune is caused by the mystical power held by a sorcerer or their ancestors. In the African culture, nothing harmful happens by chance; everything is caused by someone directly living or dead. If these beliefs were held it may explain why African parents were reluctant to discuss ways they cope since it could be a reminder that they did something to upset their ancestors.

### 3.3.3.3. Internalized discrimination

Eptein (1984) as cited in John (2004) found that mothers tend to hide their shame of having a child with a disability which could be linked to a form of avoidance-coping.

According to Braatvedt (1949) as cited in John (2004), the idea of the shamed mother is quite pertinent in the Zulu culture since it is believed that if a woman has a child that is born with a disability, the mother must have done something wrong to have displeased her ancestors. This shows how much pressure is placed on the mother since she is blamed for her child's disability. This could further explain possible reasons for the African mothers invited to participate in this study declining. According to John (2004) many participants in her sample were cast out or abandoned by their families since they believed the mothers were cursed. Another mother in this sample asked her husband to build a high wall around their house so that people would not ask her about her child's disability (John, 2004). It may be possible that similar forms of 'internalized discrimination' operate in other non-western groups because they lack access to information to work against such discrimination.

#### 3.3.3.4. Inequalities between Black and White people under the Apartheid regime

Howell, Chalklen and Alberts (2006) found that although Black and White disabled people were both discriminated against, the experiences of Black and White disabled people and their families were very different when compared to one another under the Apartheid regime. This reflected the inequalities between Black and White people in South Africa in general. In South Africa, the apartheid regime segregated groups of people of different colour to certain areas. Black people were sent out of the city to more rural areas. These areas did not cater for people with disabilities. White disabled people in South Africa had a relatively privileged position in relation to Black disabled people since they were given support by organizations and the state. Although this occurred under the apartheid regime, all grants are currently of the same value for all people in South Africa. The lives of the majority of Black disabled people consisted of struggling on a daily basis to cope with violence, neglect, poverty and deprivation due to the lack of state support.

Many positive changes have taken place regarding the history of disability in South Africa, but many parents of disabled children still experience difficulties in accessing appropriate health care and educational services for their children. This is due to the high

levels of poverty and the distance from services that is still evident in South Africa (Howell, Chalklen & Alberts, 2006). Hence, many of the students at the Special Needs School in this study were staying at the boarding facility in order to get the appropriate education and facilities needed for their disability. Therefore a sense of discrimination, living at a distance from the school as well as costs involved may have also explained why Black mothers did not attend.

#### 3.3.3.5. Language barrier

Language could also be a barrier since many of the African mothers lived in rural areas where English is not used. The letters sent to the mothers were written in English only. This was done as the researcher intended for the mothers to speak English during the interviews. The researcher felt if English was not spoken by the mothers that the use of interpreters could have made the interviewing more complex since much of the tone and nuances could have been lost. This may be a shortcoming to the study.

#### 3.3.3.6. Conclusion

Fortunately, the rise of the disability rights movement changed the perspective that disability was seen to be a problem of the individual and the problem was thought of as being situated in the environment (Schneider, 2006). Although this is the case, many African mothers' cultural beliefs (such as them believing their child has cerebral palsy due to a curse) could have caused them to still feel alienated. This could possibly provide some insight into why no African mothers responded to the study. The experience and support provided from other people (or lack thereof) for the African mothers could have impacted negatively on their views of obtaining help and therefore could have influenced them in opting out of participating in this study.

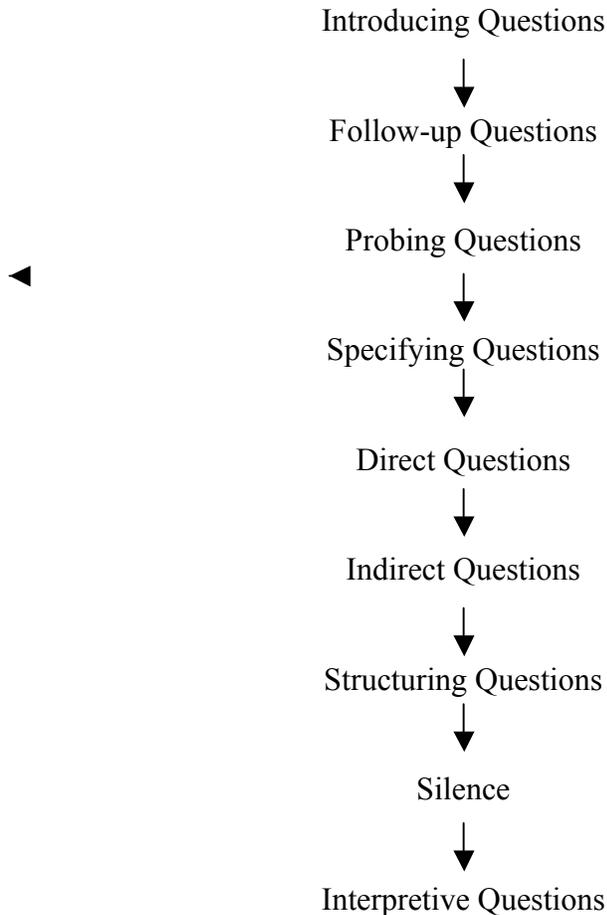
### **3.4 Instruments / Data collection**

Qualitative research interviews (Kvale, 1996) were used. Semi-structured interviews instead of questionnaires were used since an observation of the participants can take place, which also allows for an in-depth inquiry. Interviews were used since they help the

researcher establish rapport and it allows the researcher to probe vague responses (Judd, Smith & Kidder, 1991).

Semi-structured interviews allow for some questions to be planned in advance as well as allowing for questions to be spontaneously developed due to the discourse that emerges from the participant during the interview. Semi-structured interviews also allow for the participant to produce a narrative of their life or sections of their life that concern the subject of inquiry (Wengraf, 2001).

Kvale's (1996) typology of interviewing was used. This type of interviewing seemed appropriate since the interviews were semi-structured. Apart from this, the interviews were intended to obtain the mothers' particular experiences of how they cope when caring for their adolescent child with cerebral palsy. Kvale (1996) uses a number of different types of questions during the interview. He suggests the following sequence in semi-structured, open-ended interviews:



This sequence was useful as a guide during the interviews however the researcher did not always use this specific sequence. Since the interviews were semi-structured, the researcher used some of these questions more often than the others and posed them in a different order depending on the style of answering of the participant. This helped to gain more of an understanding of each of the participant's lives.

### **3.5 Analysis**

Thematic content analysis (Krippendorff, 2004) was employed to understand the common coping mechanisms and the defences used by mothers. A five step process was used as suggested by Terre Blanche and Kelly (2002).

#### Step 1: Familiarisation and immersion

In this first step, the data obtained from the interviews was read over and over so as to immerse oneself in the texts (Terre Blanche & Kelly, 2002).

### Step 2: Theme induction

In this step, the content was thought about in terms of processes and functions. It was important to find an optimal level of complexity within the main themes of the content. Themes and subthemes were extracted from the interviews. The themes were worked with before deciding on a specific system such as the coding system. During these processes the focus of the research was not lost (Terre Blanche & Kelly, 2002).

### Step 3: Coding

Coding incorporates marking sections of the data to make themes. The themes were highlighted with coloured ink on the computer and the computer function of cut-and-paste was used (Terre Blanche & Kelly, 2002). The coded themes that emerged from the data were compared and contrasted with the current theory of coping and defenses as well as with themselves to shed light on the way mothers cope.

### Step 4: Elaboration

This step included exploring the themes more closely. The purpose was to find nuances of meaning that were not captured in the original coding system. It was important to experiment with the different ways of structuring the data until a good account of the content of the data is understood (Terre Blanche & Kelly, 2002).

### Step 5: Interpretation and checking

This contains a written account of the phenomenon that was studied. It was important to go through the interpretation looking for any contradictions or areas that were over emphasized. This was done by checking the interpretation for any contradictions. It was important to include a reflection on how the researcher's personal involvement could have influenced the researcher's way of collecting or analyzing the data (Terre Blanche & Kelly, 2002).

## **CHAPTER FOUR: EMERGING THEMES FROM THE FOCUS GROUP**

### **4.1 Introduction**

This chapter provides a summary of the findings collected. First the data collected from the focus group will be discussed. The data collected from the focus group was used to develop the questions that were investigated with the mothers who had adolescent children with Cerebral Palsy at the Special Needs School.

### **4.2 Phase 1: Interviews with the focus group**

A focus group was used to allow the researcher to be immersed in the content. This was useful for providing content to the semi-structured questions.

### **4.3 Difficulty in obtaining the focus group**

The first focus group was formed after the researcher had telephoned a Cerebral Palsy Association. A meeting was held with the social worker and the principal of this school to discuss the possibility of forming a focus group of mothers. Five mothers were identified and contacted. The mothers who were contacted were informed of the research study. They were informed of the following: (1) The content of the interview, (2) that participation should be voluntary, (3) that the information obtained would remain confidential, (4) that they would remain anonymous and (5) that they would be able to withdraw from the interview at any time. The mothers had planned to meet at the Cerebral Palsy Association, however of the five members that were supposed to meet only one mother arrived. This mother was interviewed briefly and thanked for her time.

The researcher looked for another school where there was a possibility of identifying mothers who would participate in the research study. The principal from a special needs school was contacted and the focus group was formed and interviewed.

### **4.4 Findings of the focus group**

It appears that many of the mothers in this group found support through talking as most of the quotes indicate. This appeared to instill a sense of hope in the mothers since they could see how other mothers have managed with their disabled child.

#### **4.4.1 Factors contributing to better ways of coping:**

##### **4.4.1.1 Acceptance of the disability**

*“I looked at it as a special child and I said ok, you gave me a task to do and I must get on with it and that’s what I did.” – Participant 1.*

*“...you eventually stop looking at what they can’t do and you start seeing them for what they are.” – Participant 4.*

Many of the mothers felt they accepted their child’s disability quite early on by focusing on the task at hand and on what the child could do rather than what he/she could not do.

##### **4.4.1.2 Good support system**

*“I get a lot of support here at the school, I must say I get a lot of support here.” – Participant 1.*

*“You get more out of just talking to other parents I think.” – Participant 3.*

*“That’s how I kept going, the therapist and the teachers.” – Participant 2.*

Although none of the mothers attended support groups, the mothers felt that they had a good support system at the school as three of the mothers worked at the school. What helped some of them come to terms with their child’s disability was to speak to other mothers who have children with Cerebral Palsy. It appears that many of the mothers felt they had support through talking as most of the quotes indicate. It would seem that talking to other mothers could have instilled a sense of hope; to know that other mothers have been through a similar experience and managed through it.

#### **4.4.1.3 No guilt feelings**

*“I didn’t do anything wrong, I couldn’t help that my child was premature. I also feel the medical profession let me down.” – Participant 3.*

Most of the mothers said they had no guilt feelings as they did not feel they did anything wrong. Many of them felt that the medical profession did not listen to them when they felt something was wrong with their child, they kept telling the mothers that their children were just slow developers because they were premature.

#### **4.4.1.4 Family actively involved in chores**

*“I get a lot of help. He baths him, washes his clothes. Now he helps with the dishes because he knows that I’m too busy. The only thing is he can’t cook.” – Participant 2.*

Some of the mothers appeared to deal with the tasks needing to be done by allocating chores to each member of the family. This would have actively involved each family member in household chores which appeared to help take some of the pressure off the mother.

#### **4.4.1.5 Disciplined all their children in the same way**

*“I think I’ve pretty much disciplined my two both the same, in the same way. Children need to be disciplined whether they’re disabled or not.” – Participant 4.*

Some of the mothers felt by disciplining all their children in the same way, they were able to be more in control of their situation. Although they said that this was the case, the mothers did not seem to treat their children in the same way, as the following quote suggests:

*“...my other two say..., you keep letting her watch her Barney... I say, hey you guys can do so much so just let her be. Because I normally don't let them watch, because they've got work to do, reading to do, but they say how come she watches. So now what do you do, you've got two normal...children and she's like that now you've got to try get a balance.” – Participant 1.*

#### **4.4.2 Factors contributing to poor coping:**

##### **4.4.2.1 Not enough time spent with their other children**

*“I really enjoyed when my daughter was away as I was able to spend time with my son because he tends to kind of step back...it was...nice to spend time with him on a very relaxed basis...” – Participant 4.*

A problem the mothers appeared to be experiencing was not spending enough time with their other children. They sometimes felt that their other children felt left out as a result. It would seem that whenever the mothers were given a chance to spend time alone with their able-bodied child, they would really enjoy this time alone with them. This issue is interesting since it suggests that stress is not necessarily caused directly by managing the disabled adolescent, but from feelings of guilt about not spending enough time with their other children.

##### **4.4.2.2 Afraid to look into the future**

*“I take it one day at a time ... I don't know what's going to happen, so I can't think that far ahead.” - Participant 3.*

It would appear that it frightened some of the mothers to think about their child's future, they mentioned they would rather take it one day at a time. This theme could be seen as a poor coping mechanism since they tended not to think about their child's future at all which could be seen as a form of denial. It seems that the mothers did not think about the future since they were not yet sure of what they would do with their children. It should be

noted that this mother's adolescent child was younger than the adolescents in the interviews which could also explain this.

(See Table 1: Demographics of participants, p. 34).

#### **4.4.2.3 Multiple roles**

*“I do everything. I have to be the mother, the friend, the pacifier, the nurse...because she never calls on her Dad...I don't think it ever stops, having a handicapped child. You never stop working” – Participant 3.*

Although some of the mothers felt their husbands helped them with some of the chores, as was indicated in theme 4.4.1.4, all of the mothers felt their husbands did not help enough. All the mothers felt their role included multiple roles such as mother, pacifier, nurse and friend. The mothers appeared to battle juggling their different roles as they mentioned they felt there was not enough time in the day and that they did not feel they had enough time for themselves. This could eventually cause the mothers to experience 'burn out'. The mothers also appeared to be frustrated as their husbands did not always help and it would seem that when they did help, they only helped with a few tasks therefore further reinforcing the mother's multiple roles.

#### **4.4.2.4 Difficulty in reprimanding their adolescent**

*“With my daughter, there's only so much you can take away from her, and then what does she get left with? So what do you do?” – Participant 3.*

It would appear that some of the mothers found it difficult to reprimand their adolescent child since they felt there was so little that they could take away from them as a form of punishment and when they did take things from them, this seemed to make the mother's feel guilty. This could be seen as an obstacle to good coping since it made it more difficult for the mothers to discipline their adolescent with cerebral palsy. It also made it difficult for them to discipline their other children who did not have a disability since

they would not be treating their children fairly if they only disciplined one of their children and not the others. This appears linked to a feeling of being at a loss since the mothers did not know of any other ways they could discipline their adolescent. The mothers' main form of discipline was using 'time out' and taking enjoyable things away from their adolescents. It appears that the difficulty in disciplining their adolescent could also be due to them feeling guilty since they may reason that their adolescent was already 'punished' by having a disability as the above quote suggests.

#### **4.5 Conclusion**

The above themes that were extrapolated from the focus group were developed into questions used in the semi-structured interviews. (Semi-structured interview questions are provided in Appendix 1). The following section explores the interview data.

## **CHAPTER FIVE: EMERGING THEMES FROM THE INTERVIEWS**

### **5.1 Introduction**

The data collected from the focus group was used to develop the questions that were investigated with the mothers who had adolescent children with Cerebral Palsy at the Special Needs School. This chapter provides a summary of the findings collected from the interviews as analysed using thematic content analysis (Krippendorff, 2004).

### **5.2 Phase 2: Interviews with the mothers of adolescents with Cerebral Palsy**

#### **5.3 Themes from the interviews**

Themes that illustrate factors related to coping mechanisms and defense mechanisms employed by mothers with adolescents who have Cerebral Palsy will be presented below.

##### **5.3.1 Theme 1: Problems with support and a sense of ‘aleness’/isolation**

*“Of course they all say they’re going to help, but...It’s mostly the mom, and it’s a very lonely path – emotionally, physically, mentally, and even spiritually, you’re just kind of waiting for something, and it doesn’t always come.” - Participant 5.*

A main theme that the mothers appeared to grapple with was related to them not having the support they needed. Some of the participants found that they had a good social support network, while others did not appear to have much support from anyone. Many mothers appeared to have friends who said they would help but did not live up to their word. Many of the participants felt their family was supportive however many of the fathers and siblings were not supportive in the early stages of their child’s development which appeared to leave the mothers to do everything on their own. This appeared to lead to a sense of being alone and being the only person responsible for their child’s needs.

The following quote suggests how participant 2 felt powerless since she did not have the support she felt she needed from her friends and family.

*“They won’t phone now and say are you ok? ... I can’t ask anyone... and that’s... terrible. I haven’t got a big support group. I need that...it seems like the parents in this situation, don’t get together...I think it would be lovely if there’s some support...then you can feel you’re not alone, I’m not the only one having this situation...we all want to feel normal...I’m very hesitant when I say I have support from him (husband), he will talk the talk, but won’t walk the walk. So, I cry a lot. I do.”*

Participant 5 felt resentment when her family did not provide her with support. The mother further emphasized the lonely path she had to walk, however she also showed insight into the reason for her family not supporting her since she felt that they could not cope with the situation.

*“Of course they all say they’re going to help, but...It’s mostly the mom, and it’s a very lonely path – emotionally, physically, mentally, and even spiritually, you’re just kind of waiting for something, and it doesn’t always come. It’s a long period of waiting to see results. Very lonely path. I found my own family...stayed away from us ...In fact my in-laws... never came...while I was in hospital... and only as I got older did I realize, they actually didn’t know how to deal with it ... I resented the lack of support ...I think had my husband been more involved, we might have got through it quicker...”*

Participant 4 appears to have a social support group however when her son was a baby, she was left alone to care for her child which made her feel resentful. She seemed to feel this way until she was able to speak out about it and tell her family that she wanted to be a part of the family activities. This mother was able to eventually ask for help by talking to her family about her feelings.

*“I’ve got a group of friends there, so yes I do have my time. When (my son) was a tiny baby I was his everything...there were times when I was resentful because the family would go off and leave me with this baby...until one day I voiced that and I*

*said 'I want to be joined in with the family' and then they realized...Yes I have learned, please help, I can't handle it. It's a coping skill. If you've got the opportunity available to you, you must use it...you cannot cope with everything on your own you have to negotiate..."*

Participant 1 appeared to first go through a phase where she did everything for her child until she reevaluated her situation and realized she needed to speak out and actively seek support. There is also a sense of her having to cope with a sense of loss whenever she was unable to attend certain family activities since she was looking after her child who has Cerebral Palsy.

*"I have a lot of support from...some friends...there are other friends whose lives have carried on...You find socially you get invited out less because of your child and socially you get left behind. I used to try and be supermum and do it all and there came a time when I actually had to sort of reassess the situation and say wow, I cannot do it all, so I've just made a thing over the weekend so everybody has to chip in. (My family) do a lot with boy things and... I don't mind, because I love just being at home but there are times... where I think... I would've loved to have gone to that."*

Participant 3 appeared to go through a phase of where she had to become angry before anyone would provide her with support.

*"I do have support if I need a lift or I need someone to look after him, that's not a problem. I must admit he (her husband) has been good. Not when he was born, he shied off. I seem to do everything. I tell him he's a father and I'm acting like mother and father, and this has been going on for too long...I've never said to him he should do things, but when I get angry and I've had enough, I tell him to take over, I've had enough and he does do. I have good support from my husband."*

### 5.3.2 Theme 2: Multiple Roles

*“...you’re everything, you’re teacher, mother, nurse, physio (therapist), engineer, everything.” – Participant 5.*

A main theme that stood out was the mother’s role in caring for their child. All the participants felt that their role incorporated everything. Although this appeared to be evident throughout their child’s life, during their child’s adolescent years, it would appear their role became more difficult when they handled their child physically as they used to when their child was younger. It would appear that the mothers realized that they were unable to do everything for their children and so in their child’s adolescent years asked more people for help. This appeared to allow the participants to focus on their main role which appears to be mother. This also suggests that once their children had become adolescents, the mothers were ‘forced’ to change or question their role since they were unable to look after their adolescents’ by themselves. This appeared to help ‘force’ the mothers to cope better since they had to ask for help.

Participant 1 emphasized how her needs tended to fall away because her child’s needs would get attended to first. This appeared to put much pressure on her which made her feel as though she was unable to continue in this way. However, she still goes on to say that mothers tend to suffer more since they always put their child first.

*“Everything. It’s a lot of pressure because it never goes away. It is constant. But you are everything to that child and I’ll be the first one to admit there are times where I just want to scream and just, I can’t do this anymore or just give me, just give me a bit of time you know. I think in the long run, however much everybody tried to help, it’s the mother who and I shouldn’t say suffers, I don’t know what the correct word is to use, um, disadvantaged or something at the end because um, the mother will always put her children first...There are times when you just think aah, if only I could have just a few hours.”*

Participant 5 seemed to compromise her various roles and prioritize her mothering role. This appears to demonstrate good insight and an ability to balance and distribute previous demands made on her so as to better cope.

*“In the beginning you’re everything, you’re teacher, mother, nurse, physio (therapist), engineer, everything. When he turned three, I became very angry and decided I couldn’t be all those things, and I took a little bit back for the others. I say a little bit because you only do it for a while then you take it back. I seem to do that. Give my problem away then take it back again and do things better. You have to, but you can’t always do it better because you’re so stretched. Now I don’t teach him – I’m not his teacher anymore. I pay a helper to help him. I’ve decided I’m not his teacher, I’m going to be his mother first, and whatever comes with the mothering, some teaching, but a balance. ...everybody has to chip in...so all the years, even today, there are still jobs that everybody has to do, otherwise we can’t get through the mornings, get him to school on time. So we divided up the work.”*

Participant 4 appeared to own her ‘mothering role’ since she was able to focus on this role as the most important role for her child. She seemed to learn that the only way she could continue to be her son’s mother was by giving up all her other roles.

*“I’ve always said that I’m the mother, not the teacher and I’m not the caregiver. My role in life is his mother. I have handed (over) all those other roles, because I don’t want to be his nurse or his teacher.”*

### **5.3.2.1 ‘Protecting’ their husband from their children**

*“I protect my husband from my boys and my boys from my husband” – Participant 4.*

Some of the participants felt that they act as a buffer between their children and their husbands/partners. Often this appeared to occur when their husbands would complain about all the attention the mothers were giving their child. This identified another important role the mothers appeared to have to play.

Participant 4 felt that she had to protect her children from her husband.

*“...but I find that I protect my husband from my boys and my boys from my husband. As a mother, you do that. You keep the peace in the home.”*

Participant 5 appeared to often talk to her child about his father’s actions. She seemed to try to explain to him why his father was acting in a certain way towards him. This again illustrates a ‘protective’ or buffering role the mothers tended to have.

*“Emotionally you don’t get the support and then the problem is it comes into your marriage because the wife is now protecting this little thing from the hurt they’re hearing their father say. You try to get them away from it. Daddy doesn’t mean that. Daddy doesn’t mean not to play with you.”*

Participant 2 found it stressful being with her daughter and her husband at the same time since she would constantly have to watch how much time she was spending with her daughter and her husband individually. It seems that she would have to be aware of this since her husband would criticize her if she was spending too much time with her daughter.

*“It’s very stressful because I have to watch him and watch her, so I’m not overdoing it with her when he’s around because then he’ll say, ooh you know you baby her and stuff like that, so I must be very careful when I do it...but it is difficult.”*

### 5.3.3 Theme 3: No time for themselves

*“Nothing!...absolutely nothing. Come home, cook, clean, um give attention here and there. I’m here twenty-four hours...it’s just too much.” – Participant 2.*

An important theme would appear to be that the participants were unable to engage in any recreational activities since they felt they did not have the time for it. The participants also appeared to feel that they were not invited out as often as they were used to. This appeared to lead the participants to feel a sense of being alone and feeling isolated.

Participant 1 emphasized how difficult it was to leave her daughter with anyone, this would appear to put pressure on her since she would not be able to leave her daughter’s side other than when she was at school.

*“Because you always have to find someone who is um willing to look after her, now, like my Mum is a doting grandmother, she will do anything for her, but she can’t cope physically, um so I can’t leave (my child) with her for a day. An hour, an hour and a half is fine, she can cope with that but not longer than that because physically she can’t cope.”*

Participant 2 emphasized her feeling of exhaustion with all the chores she had. In this particular family, it appeared that the mother took on all the various roles and household chores by herself. Other family members did not seem to help.

*“Nothing!...absolutely nothing. Come home, cook clean, um give attention here and there. Um, when I can’t handle with life, I just go to sleep. I’m here twenty-four hours, it’s supper time, it’s husband, it’s his problems, it’s his kids coming and going the whole day, I sit with that, I’ve got financial problems, it’s just too much.”*

Participant 5 expressed her inability to have her own time to herself. This particular quote emphasizes this mother's feeling of finally having 'quality' time with her husband, however this was short-lived and was linked to feelings of guilt since her son had a seizure while she was not with him. This put more pressure on this mother since she appeared to not only feel guilty about this but a health professional directly blamed her for leaving her child. This further emphasized her feeling as though she was at fault and was a bad mother.

*“We had an incident a few years ago...My husband became...depressed (so) I decided to take him out (alone)...(Our son had) a Grande mal seizure which he hadn't had before...the boys (his brothers) were concerned as it hadn't stopped. While we were waiting (in hospital), a nursing professional came in and told me it was my fault for leaving him on his own. 'What is the matter with you parents?' That was burnt into my brain, so for a long time I would never leave him... it was very wrong of her to say that, as a Grande mal seizure cannot be stopped ... The guilt does catch you when something happens, it sucks you in, then you've got to swim your way out again, so that's quite hard. It took a few years before we would ever do anything on our own ...”*

Participant 4 felt she did have her time to herself, however she illustrates the need to have to assert herself in order to guard her time.

*“Me time is when I disappear into my book. I'll say, 'Just leave me alone, I'm reading'. I do go with friends and have tea. I'm a member of the book club, we meet once a month.”*

#### 5.3.4 Theme 4: Problems of adolescence, growing up and ongoing dependence

*“I think it was easier before...now it’s more difficult” – Participant 2.*

Participants seemed to find it more difficult the older the children became since they became heavier and more difficult to carry. This seemed to put much pressure on the mothers which for some mothers was expressed as panic when they were left alone with their child.

Participant 2 emphasized the feeling that her stress was ongoing and that it could not be resolved since there was a sense of exhaustion due to her ongoing monitoring of her daughter.

*“I think it was easier before. I carried her everywhere I went... now there are other demands ...Now...I deal with the fact that she’s going to be with me for the rest of my life. Where is she going to work...I must think about...It’s an ongoing stress... I’m thinking about it all the time. We are so close...I find it very difficult to let go...I actually get tired sometimes... you have to stimulate them the whole time. You have to get them new computer games that are stimulating, and give them books the whole time, it’s like a little child, to actually stimulate with new information, new stuff, they want that all the time, twenty-four hours.”*

Participant 4 showed how she was ‘forced’ to call upon support in order for her to cope differently since her adolescent had become more difficult to carry.

*“I need to have someone to help physically. I cannot lift my son, he’s way too heavy. I know that if I didn’t have my cousin, I would be lost. Absolutely lost. We would then actually have to employ somebody to live here or whatever, and it would be a whole new issue...I dress him in the morning, I can cope with that because he’s lying on his bed and I’ve got a certain way...there’s a whole technique to it... then my husband comes in the morning, picks him up and puts*

*him in the wheelchair and then we wheel him out. So I cannot be left alone with him, that's the big thing in my life that I cannot be left alone with (him)."*

Participant 5 explained the strain she felt and her particular difficulties she experienced with her son becoming an adolescent.

*"It changes considerably, because they're so tall and heavy. When he was smaller, we could hold him and support him and he'd be able to... support himself a little bit...Now he's about five foot eight, he's not very heavy, but he's almost like a stick puppet, where your arms and legs aren't able to move like ours do...emotionally things are different, physically there's a huge difference. Their bodies are changing, there's all the hairy stuff...and it's shaving... "You don't cope because your body is sore. My shoulders are 'shot'. I need to have treatment for that because I struggle to pick him up. I can't do it anymore. I'm getting old"*

Participant 1 emphasized her panic whenever she was left alone with her adolescent daughter since she was unable to lift her if she needed the toilet.

*"She's getting heavier and there are times when I'm at home, completely alone with her and she needs to be taken to the toilet, to be bathed, to be moved from one place to the other and there are times when I panic because I don't know how I'm going to carry on moving her around or lifting her"*

Participant 3 appeared to realize her son's ongoing dependence on her which appeared to lead her to push him to become more independent.

*"...it's very tiring looking after a handicapped child. He can't carry a cup of juice, because with the way he walks, he spills it. He can't do his shoelaces he battles with buttons, he can't wipe himself. It was one thing after another and everything was mom, mom. I was going off my head, still he relies on us too much. We're trying to get him out of that because we know that he can do it. Even if he*

*can't do it, we want him to try. I'm really pushing him to become more independent."*

#### **5.3.4.1 Social lives**

*"I have to think that he does want to go places...I do worry about what people will say..." – Participant 5.*

During adolescence their children became more aware of themselves and had tried to be more sociable. This seemed to pose a dilemma for mothers wishing to protect them and also wishing for their children to lead normal social lives.

*"I have to think that he does want to go places...does he want to go to a birthday party, will he be accepted there?...I do worry about what people will say, because it hurts, but he is the sort of guy who will go up to you and say, 'you know, he just called me a retard. Maybe he's just ignorant.' ...but a lot of the time, kids are just being cruel, as kids can be. I've always taught him that when somebody says that, go up to them and say to them, "excuse me, can you give me a minute of your time, and let me explain something to you and that way you'll understand." – Participant 5.*

Participant 2 felt worried about her adolescent child not finding friends. These feelings made her feel responsible for finding friends for her daughter. This added to the pressure placed on the mother since she mentioned that she constantly looked for friends for her daughter.

*"She cries for a friend, that makes me worried about it, I'm sad about it because I can see she doesn't just need me anymore, she needs more. She has one friend ...which helps I must say...she gets very irritated with other kids because her friend all she talks about is the stress about studying. She doesn't even want ...to come and visit...because she must study. It's like an ongoing search. I try*

*organize, can they (other children) come over, can they meet? It's worse than a single woman looking for a male. It's really terrible. I'm looking all the time, because you want her to have friends."*

Participant 1 noticed that her adolescent child went through a stage where she did not want to be seen in public since she became more aware of her disability.

*"...she went through a stage where she didn't want to go out in public. If I was going to a function at the boys' school, she would say to me she'd rather stay at home. She suddenly became very conscious that she was in a wheelchair and wherever we went there was no one else in a wheelchair and she would hide, just keep her face down...we've got over that now I think...(now) the first thing she will say, especially to people she knows, the family...she'll say please comment on how I look."*

#### **5.3.4.2 Mood swings**

*"I try and be as calm as I can and talk her through it..." – Participant 1.*

The mothers also found that their children went through more mood swings as they developed into adolescents.

Participant 1 noticed her adolescent child going through a hormonal change since she had been experiencing more mood swings.

*"I try and be as calm as I can and talk her through it. If she's beyond talking to which we do get to, I just take her into her room, put her radio on, she loves music and I just tell her I'll be back later to fetch her. I leave her there and she'll cry and then she calms down and she'll always come out and apologise. She always says 'I'm sorry I made such a noise'."*

Participant 5 found it useful to enforce rules and then explain why she had enforced those rules such as refusing to allow her adolescent child to do or have something.

*“If he gets cross he’ll still get a hiding...but I don’t have that very often. If he gets cross, it’ll be ‘I want this’ and I’ll say ‘no’ and he’ll turn his wheelchair around and drive out, then I’ll know he’s feeling frustrated...then I’ll say to him ‘let me tell you why I said no’.”*

Participant 2 noticed her daughter become clingy and moody.

*“...if I do something today and I’m with her the whole day, I’m going to battle tonight, she’s not going to leave me alone. I will say, ‘Can I help you just now, just give me some time with (my partner)’ ...I sometimes don’t know how to deal with it...now she gets moody, I never had that before...She gave me lip a couple of months ago...she had a sulky face...and she was moaning and grumpy about something...I asked what the problem was and she said ‘aargh’ like a real teenager, a real tantrum...I had my takkie and chased her to her room and I gave her a smack...she cried from embarrassment...but she knew...”*

#### **5.3.4.3 Adolescence and emerging sexuality**

*“We’ve talked about sexual issues and I’ve said it’s not that you are not going to be functional, it’s just the woman, she’s going to have to be an amazing woman to have a relationship with you because it’s going to be difficult, and...you would need a helper.” – Participant 5.*

Many participants appeared to have noticed their children becoming more aware of themselves and of how they look. Their adolescents were also becoming more interested in the opposite sex which seemed to cause some anxiety in the mothers. However, many of the mothers felt that the best way to cope with this was to be honest with their children. Many of the participants felt that their adolescent would be able to cope with

any issues they encountered as they become adults, especially with regards to meeting the opposite sex. An interesting point is that many of the quotes suggest that the mothers tended to cope with their adolescent's sexuality by talking about it as a 'friendship'.

The participants who had female adolescents appeared to not deal with their child's sexuality as well as the participants who had male adolescents. This could be due to the mothers of the female adolescents feeling a sense of needing to protect their daughters more. This would explain why these mothers were not as open with their adolescent's sexuality when compared with the other participants who had male adolescents. This would also cause these mothers to not cope as well as the other mothers since they seemed to avoid the issue of their daughter's sexuality. This further prevented them from thinking about their child's future which kept them in denial of these events actually occurring.

Participant 5 appeared to have coped with her son's sexuality by raising it with him and being open about it. This is interesting since many of the mothers appeared to be 'stuck in the present' since they had difficulty thinking about their child's future. More precisely, when these mothers were 'stuck in the present' it would seem to make it more difficult to think of their child's sexuality in the future.

Participant 4 appeared to have doubts about her son's future since she did not know what could happen, but at the same time would like to believe that something could happen with the opposite sex even though there could be limits.

*"I think he will think about it and he will come to terms with (whatever happens regarding his future with females) and he will work through it at the time, but at the moment he still thinks about girls, and I leave him because it's normal and it's natural. How do I know he won't be able to, how do I know that there's not going to be somebody that's going to be able to keep him, care about him and want to spend their life with him. How do I know?"*

Participant 2 appeared to feel stressed and found it difficult to cope with when she noticed her daughter not fitting in with the crowd.

*“I worry about her sexuality sometimes. She is looking for boys, but in school there (aren’t many of her same culture). She’s very friendly with them but there’s no way she’ll go out with them because of the culture and they’re the only ones that’s actually writing her little letters...It’s difficult. But she wants a boyfriend, for sure. There’s always a new thing that you have to evaluate and you have to think now how am I going to...handle this? That’s the difficult part...you see other teenagers similar to her age and they’re not mingling with her because they see the disability and they think she can’t think or talk. And then I can see that face, that hunger, ‘talk to me as well’. And ooh I battle with that. I do.”*

Participant 1 showed how she has had to learn to cope with her daughter’s emerging sexuality while at the same time appears to have difficulty thinking about it and possibly has tried to avoid this issue with her daughter. This can be seen when she speaks about her daughter’s relationship with a boy as ‘a friendship’.

*“There’s a little boy and he and (my daughter) have fallen in love...We played along with it and...everything she did at home was because he said she must do it and it almost got out of hand... he tried to kiss her... it was a bit of a wake up call... she’d come home and tell us they were getting married and I had to explain that they couldn’t get married. First of all they were too young and also that um they both need care because they’re both in wheel chairs and she told me...they’re going to live at a home...so we just... stopped asking about what was happening and that and it has sort of died down, now it seems to be they are friends...So I’m pleased she’s experiencing it but we also have to keep an eye on what’s happening...So that has been quite a learning curve.”*

There were some exceptions to the general difficulty or avoidance of thinking about sexuality in the future. This occurred when mothers were able to be honest and open with

their child regarding sexuality. For instance, the participant below does not seem to experience difficulty thinking about her child's future.

*“He...gets more emotional about issues, such as, the opposite sex, the girls are no longer finding them cute...they're now young men ... and in (my son's) case, he's always kept a happy smile...whoever comes into contact with him, will say 'the lights come on when he smiles' ... We've talked about (his sexuality) all our lives, we've never made it a secret that there's a very good chance that if he found a partner, it is generally after the woman's child bearing years, because she is more accepting that having children is more difficult...so there (are) a lot of changes that he's going to accept...I think we've always been honest and open ...I've said it's not that you are not going to be functional, it's just the woman, she's going to have to be an amazing woman to have a relationship with you because it's going to be difficult, and...you would need a helper. He's well aware that chances of him finding a marriage partner is going to be extremely slim. We have not tried to promote issues, we've tried to put that in his mind now that it's almost a love him and leave him situation, and that sounds pretty sad but that's probably what it's going to amount to for a long time. There's nothing wrong with him having feelings.” – Participant 5.*

#### **5.3.4.4 Dependence and the future**

Now that their children were older, the mothers appeared to realize the fact that their children were going to be dependent on them forever. It would seem that the older the child became, the more this fact became a reality. It would appear that this led the mothers to feel as though it was more difficult to deal with their child's adolescent developmental changes.

Participant 4 felt anxious whenever she thought about her son's aspirations such as wanting tertiary education and wanting to drive. She also felt that soon it would be necessary to build a cottage in her garden so that he could live close to them while still having some independence.

*“...when he finished school, the worry is University. You know, how do you get him to study. He wants to be a journalist, he wants to do journalism. You can't send him to another town because they don't do Journalism in Natal, he can't go to Rhodes and stuff like that. You need somebody to help him. We thought of a cottage in the garden, a 2 bedroom cottage where somebody could live there with him. A batman so to speak, to dress him, feed him, drive him to work, drive him to Varsity, whatever, you know, otherwise he's going to have to do it correspondence which we're not very happy with that then he's cut away from the world. He's come to terms with the fact that he won't drive, he's not happy with the fact that he won't drive. He would like to be able to drive, he says now that he's come to terms with it...I've also never said to him 'you won't be able to do that' I kind of tend to keep quiet. I can also have my own thoughts but I don't say it and disappoint him, because he's got to come to the realization himself, and I think it's less hurtful if he comes to the decision rather than somebody saying to him.”*

Participant 5 found it difficult to think about her son wanting independence.

*“It's truly difficult for me to think...one day my kid's going to drive, independence time, he can fetch bread and milk, well that's not going to happen, he's always going to have to have somebody to take him where he wants to be. I have to think that he does want to go places. He wants to go to the cinema, and make sure that somebody can take him.”*

Participant 2 realized that she could not hide from her daughter's questions any longer.

*“...you have to explain every day something to her, why she can't start learning to drive a car, why can't she this, what can't she that...lately I say when you're ready, we'll try. If it's not working, just realize...I just figured out it won't help if I'm just hiding away from these questions any more.”*

### **5.3.5 Theme 5: Ways of coping**

#### **5.3.5.1 It is easier to accept and cope with the disability from birth**

*“I think the fact that he was born with it made it easier for me.” – Participant 5.*

The findings indicate that many of the participants felt that it would be more difficult to accept their child’s disability if the child had not been born with the disability. Two of the mothers felt it was easier for them to accept the fact that their child had Cerebral Palsy because their child was born with it and they did not know anything different. One mother in particular thought it would be far more difficult for her to deal with, if her able bodied son suddenly became a quadriplegic.

Participant 5 felt that she would not have been able to deal with her son becoming disabled later in his life.

*“I think the fact that he was born with it made it easier for me. I do not think, in my own human-ness that if my twenty-four year old came home and said I’m now quadriplegic, I can’t feed myself this that and the other, I’m not sure I would cope. I think it must be extremely difficult to do that.”*

Participant 4 emphasized that she had been able to deal with it more since her son had never known how to walk, so it was not something that was ‘taken away from him’.

*“He was born like that, he’s never known walking. It’s not as if something has been taken away from him. I’d say to them, ‘who else must I blame? It was my body that had the asthma attack, but I looked at it like that. It was my body, it wasn’t a thing that I did on purpose.”*

Participant 2 felt the more she was able to realize and get involved in her daughter's physiotherapy the more it helped her accept her daughter's disability.

*"I'll never forget really, I had to go for outpatients that was once a week, then she started doing some physio and showed me what to do at home, and I could see the slow development and actually I met the other children and I met the other Moms and then I realized what's actually going on and I got involved with all this but getting more involved helped me go through the whole motion of accepting it and going through it."*

Despite it being felt it was easier to accept the disability due to their child being disabled from birth, there was also a sense that one never truly accepts the disability. Participant 1 emphasized how she felt as though she had never really accepted her daughter's disability. Participant 1's view contradicts the other mother's views of accepting their child's disability. The researcher understood this as illustrating human nature since people are different and view and experience events in their lives in different ways. The participants seemed to be trying to make meaning out of where they are in their lives by saying that it would have been worse if it was different. This is seen to be a way of coping with their current issues.

*"I don't think you ever accept it fully. You don't accept and say ok, I'm alright with it...you know inside you you're screaming out and saying I'm not actually coping."*

### **5.3.5.2 Emphasis is on discipline**

*"An undisciplined, unruly disabled child is worse" – Participant 5.*

The findings indicated that many of the participants appeared to have disciplined all their children in the same way. Some of the participants felt that an undisciplined disabled

child would be worse than an undisciplined child who did not have a disability. This emphasized the mothers need to control by using discipline.

The following quote illustrates how participant 1 felt it was important to discipline all her children the same and right from the beginning.

*“Right from the beginning, she has been disciplined like the other two children have been disciplined.”*

Participant 4 also emphasized how she disciplined all her children in the same way.

*“I discipline him in the same way as I would have disciplined any other child. The fact that his body didn’t work, didn’t make him any different, his mouth worked well.”*

It appeared that the emphasis on discipline emerged from a concern that a disabled, undisciplined child was worse than an undisciplined child who does not have a disability.

*“An undisciplined, unruly child is ugly. Let me tell you, an undisciplined, unruly disabled child is worse...because they’re not pleasant when they’re spitting and coughing, coughing their food all over the place, it’s not pretty, and if you’ve still got a disobedient, rude child, that doesn’t sit well and so we decided to discipline him as far as we could the same as the (other) boys...because you’re trying your best, and your best has to be good enough, because that’s all I have to give.” – Participant 5.*

Participant 3 suggested that a physical means of disciplining was used. This could possibly be due to her feelings of desperation.

*“...if he misbehaves, I’ll take TV or play station away. With (my son) it’s difficult because one time it’ll work and next time it won’t work...We smack our kids...I try to explain to him that we’re trying to make him a better person.”*

### **5.3.5.3 Openness is important for good coping**

*“...we’ve always been honest and open.” – Participant 5.*

Many of the participants felt that they needed to be open and honest with their adolescents in order to be supportive and deal with any issues they might have. The mothers seemed to feel that if they were open, their adolescent will be more willing to talk to them about their issues.

Participant 5 seemed to feel that her son could ask her anything since she had always been honest and open with him.

*“He knows that he can ask me questions, it doesn’t matter what they are. He’ll come and usually say, ‘I have a question’, then I know that I must sit down, know that this is going to take time – it doesn’t matter where I’m running to, it’s time to sit and listen, because it’s important to listen, he needs to know that I’m actually hearing what he’s saying, and I don’t always get it right...if I’m really running and I have to say I’ll be right back, but you need to stop and make time to listen...we’ve always been honest and open.”*

Participant 3 did not appear to hide anything from the family members.

*“Very open, we don’t hide anything. We’ve been like that with all our kids. We’re not the kind of parents who go into the room to have these private conversations or wait until they’re out of the room.”*

### 5.3.6 Theme 6: Negative experiences

*“I was absolutely devastated...I was given no information” – Participant 1.*

#### 5.3.6.1 Negative experience with medical professionals

One of the main themes that seemed to stand out was related to dealing with the shock of learning about their child’s diagnosis. This was exacerbated by a lack of information provided by the medical profession. The findings indicate that participants’ initial reaction of finding out their child had cerebral palsy was that of shock and devastation. Many of the participants felt that the medical profession should have been more empathic when diagnosing their children. They also felt they should have been given more information regarding the disability. Many participants were also not aware of what the terminology meant. The medical profession did not appear to cater for the mother’s needs which appeared to lead to the mothers feeling powerless and feeling as though their intuition was not validated. This exacerbated feelings of ‘being alone’ and not being heard.

As well as not receiving information as a means of support after hearing about the diagnosis this also sometimes led to ‘false hope’ as Participant 1 illustrates below.

*“Um, I was absolutely devastated, I didn’t know what CP was and the only explanation I got was ‘it’s brain damage’. And that was the information I got. And he also said to me go to physio...and I actually thought that I could go to a physiotherapist and everything would come right. The thing was, it took me eight months to get a diagnosis because as a mother I knew there was something wrong from very early on and I went from doctor to doctor...to say there’s something wrong with this child... and it took them eight months by which time I was at my wits end and I knew there was something wrong with her. No one was prepared to help me.”*

Further to that, Participant 2 felt as though she was not given the correct information.

*“He never gave me the correct information. The Doctor said, “You must talk to your baby, you are not going to see her again.” Every single day he said the same thing, and I was so fed up with him actually. He said there is damage because they took too long with the oxygen because there was nothing ready, and there could be damage and that’s it.”*

Participant 4 found that the information that she was given was experienced as very negative.

*“That was devastating...He told us he might never walk or talk. He gave us all the negative stuff... he bursts my bubble and shattered my world. So that was the devastation. I can only explain it that they took my child away that I had all these dreams for, and they gave me another one...Then he rushed out and told his nurse to make us an appointment with a Doctor for a second opinion...I never ever saw him after that day, I never went back to him again. So he diagnosed my child, rushed us out for the next people to look at him and I never ever saw him again. It should have been diagnosed at birth, and then we would have been a year down the line with physio.”*

Although Participant 5 appeared to feel alone, it seemed too difficult to talk about it and label it. In addition to her experience of shock upon finding out about the diagnosis of her child, this was exacerbated by the medical profession acting in an unsupportive manner.

*“I went a bit crazy. No one has any idea as long as you’ve walked it, how you feel at that moment. You try so desperately you have no idea, you just get lost in an instant. But slowly and surely you find people who will help you, but it’s a very lonely path. I wasn’t ready to give it a title. I was ready to hear that things are not right, things are slow, maybe, maybe, but when you give it a title, it’s so definite, and it’s almost like somebody writes you off...I started to cry, as mothers will do, and he (the doctor) just walked out after giving me a tissue and left me there.”*

### 5.3.6.2 Overcoming negative experiences

It would appear that the mothers overcame their negative experience by talking to other mothers who were in a similar position or they obtained more information from other, more helpful professionals.

Participant 1 found that talking to another mother who had gone through the same experience helped her cope with the shock of finding out her child was disabled.

*“...fortunately somebody who has a cerebral palsy child heard that (my child) had been diagnosed... and I was able to chat to her, she gave me more insight and she also gave me the name(s) of (helpful professionals she had dealt with). (What also helped me deal with it was)... just talking, talking, mainly to (that) lady who helped me”.*

Participant 2 felt that she coped better with her shock by getting more involved in helping her child. One female medical professional also seemed to help her deal with this new information about her daughter.

*“I must say the Physiotherapist ... was the best thing that ever happened ... (also) getting more involved helped me (go) through the whole motion of accepting it”*

Participant 4 seemed to cope with the shock of finding out her child was disabled by getting support from her husband and from a female doctor she had met at an assessment centre.

*“...it was the first time my husband had ever gone to the doctor with me. It was always my job ... so my husband took over and he asked all those questions which were going through my head ... I walked around with tears pouring down my face for days. One day my mother said to me, “You feel sorry for yourself. Stop crying”. And my maid said to me, “you’re going to make yourself sick, stop*

*crying.” ... (what helped me come to terms with it was) ... time (and) ... The doctor at the Assessment centre ... she sat me down and she explained a little bit more to me. She was the one that said to me, “You know, you’re crying today, but there’s going to be a day when you’re going to laugh again”.*

Participant 5 seemed to cope once she had calmed down and thought about who she could contact to help her.

*“...I got into my car... and starting to yell and scream and go a bit crazy...somebody knocked on the window and then I was fine. I thought, okay, what do we do with this information. But it was tough and... slowly and surely you find people who will help you...”*

### **5.3.6.3 Coping with anger, negative affect and self blame**

*“There are times when I really am so so angry...there are times when I blame myself...I just feel if I hadn’t been so stupid, they could have stopped the labour early and she wouldn’t have been born early...I do blame the medical profession” – Participant 1.*

Another theme that seemed to stand out related to the mothers’ feelings of anger towards the medical profession for their negligence as they felt the disability could have been avoided. Some of the participants felt anger and blamed themselves for having a child with Cerebral Palsy as they believed that they could have prevented the disability from occurring by being more assertive with the medical profession. This appeared to lead to a sense of powerlessness and an inability to voice their concern since they were not being heard. These feelings of guilt could have impacted on the mothers taking more responsibility for their children since they felt they were the reason the child was born with a disability. One mother felt this had resulted in her having depression ever since her child was born.

According to Participant 1, she blamed herself for not seeing the signs. She also blamed the medical profession for their medical negligence.

*“There are times when I really am so so angry...there are times when I blame myself because I went into early labour...um I had never experienced labour before...and I went to just the GP instead of my Gynae..., I just feel if I hadn't been so stupid, if I'd just gone straight there, they could have stopped the labour early and she wouldn't have been born early, so I get cross with that. I feel I could have prevented it her being born early. I do blame the medical profession...as far as I'm concerned it was the medical negligence.”*

Participant 4 felt as though she knew that there was something wrong however she did not feel heard by the medical profession.

*“...I had felt for a while that there was something wrong. I knew there was something wrong. But I was angry...I had been saying for months, there's something wrong...and he kept on fobbing me off like I was a stupid mother that knew nothing.”*

It appeared that Participant 5 overcame her feelings of self blame by realizing that there actually was not anything she could have done to avoid it.

*“So then you sit there and you think maybe if I'd made more of a fuss when I was bleeding...(I feel) angry that it could have been avoided ...I had missed signs, I had seen them ... and I had been for checkups, and you think if I'd been more forceful, maybe if there'd been more money, maybe if ... then I thought, maybe nothing, I can't change it, this was not my fault, we're the victims here and that's it, we're going to get on with this and then I could move on from what I thought I'd get, to what I had, and I very quickly moved on to 'what am I going to do about it', because that's the kind of person I am...But, when you take stock at night, on your own, and your husband says something like, this should never have*

*happened, and that's all he has to say. You don't think he's having a guilt feeling, your brain says that he's blaming you and boy it says it so loud. And you sit there and try to analyze it and think what you could have done differently...so then I decided, I'm not guilty. I did everything I was told to do, I rested when they told me to rest...I went through more guilt at having to deprive my other boys of time and I didn't know how to not do that. That was the hardest. I had to get it into my head that I don't just have one child, I have three. It was a hard, long walk, but spiritually it made us stronger, it does tear you apart as a family, because you spend so much with one and you can't get to everyone else, how do you tell your four year old, 'wait now, I can't be with you now, this kid needs to be stretched, he needs physio', it was very hard, it was tough on the family."*

Participant 2 appeared to cope with her feelings of self blame by overcompensating for her daughter's disability which caused her to try and do everything for her daughter.

*"I'm better now than before I must say, but it made a huge impact. I took it totally on myself because I'd been in quite a lot of stress that year. Now I deal with it, it's just when she can't do things I think, she could have been normal if it wasn't for me. She could have been doing this or that. I think, it's not her mistake, I must make up for it, I want to do everything for her because I'm making up. It's there all the time."*

Participant 3 did not feel responsible for the disability or experience self-blame since she blamed the hospital for her child's disability.

*"No because I know I didn't do anything wrong. It was the hospital – but we found out too late to press charges."*

Participant 2 felt she had been suffering from depression since her child was born. This quote provides a sense of her stress being ongoing and cyclical. It appears that she has not coped well with her stress since she did not get support from any members of her

family. This quote further provides a sense of her feeling as though she could not live like that anymore. She also indicated that her daughter had saved her life many times because when she was at her lowest she realized that her daughter needed her, and that there was no one else who could take care of her daughter.

*“... I’ve got this thing where I say I’m tired lately. So I stay away from everybody, and say I’m tired, but it’s depression. Since she’s born I’m very depressed. I’m on medication which helps, I wouldn’t say it makes me feel one hundred percent, but I have my moments. I’ve been on medication for so many years. You get very strong for a period, then you break, you get very low for a period and you have to get up again. You just have to get on and go. If it wasn’t for her, she’s saved my life many times. When I think I just can’t take it anymore, then I think of her, who is going to look after her? No, I can’t leave her. I’m trying, but I’m tired, I’m tired. I am getting tired, if I get any frustration at work, it’s too much, it’s just that one drop too much, and it happened. I have to be strong all the time...lately everything that’s happened, it’s something that I can’t handle, because everything at the moment for me is too much. Even if it’s just a stupid little simple thing, then afterwards I laugh about it and I think what? But at that moment, it’s too much.”*

#### **5.3.6.4 Dealing with the loss of a child they never had**

*“I find when it comes to her birthday, I myself grieve...because it’s not a happy it’s not a happy memory for me...”- Participant 1.*

A theme that appeared to stay with the mothers was the feeling of loss of a child they never had. Because grieving did not involve the actual loss of a child, but was about loss due to disability, some mothers indicated that this complicated their ability to cope. It would seem that being able to grieve the loss of a child who has died could provide closure. For the mothers of this sample, this complicated matters since the mothers were not able to totally grieve as their children were still alive. The feelings of loss further

caused the mothers to feel guilty of any negative thoughts or feelings they had about their disabled child. Grieving for their loss could also be seen as an opportunity for good coping since it helped the mothers deal with the fact that their child was disabled.

Participant 1 appears to use significant events to mourn her child as a way of coping with her child's disability.

*"I find when it comes to her birthday, I myself grieve...because it's not a happy it's not a happy memory for me. Everybody else is quite happy and makes a big thing about it but I myself grieve inside because I just think what if."*

According to Participant 5, the mourning process was aided when she actively put her anger behind her.

*"We had to go through the mourning process of losing what we'd expected. We had to go through being a little cross, and we were. My husband stayed angry for many years, but I'm glad I didn't. I got cross, got over it, and moved on."*

### **5.3.7 Theme 7: Fear of the future**

*"It frightens me it absolutely frightens me because we're not getting any younger and um I don't know. I don't know. I'm actually too frightened to look into the future" – Participant 1.*

While some of the participants felt their child's future looked positive and that they only wanted the best for their child, a number of the participants appeared to have put off thinking about their child's future. However it seems as they and their child grew older, they had realized the need to seriously think about what would happen in their child's future. For some of the participants this prospect appeared to be frightening.

Participant 5 appears to have coped by having a sense of giving back to the community and fighting for the disability cause by hoping to turn her house into a care centre. This may be seen as a good way of coping since thinking about her son's future means she had to think about future separation issues between her and her son.

*“We’ve often spoken to other parents and they’ve all said, God will provide when we die... of course he does but you also need to... put structures in place so you don’t make it someone else’s problem... We have sat down with the trustees...and set up a plan if we die simultaneously, those plans are in place. He will always have a nursing assistant and his medical etc., has been taken care of into his old age. We’ve done the best we can with the money that is available. He will live here with (someone who cares for him) if that is where he chooses to live. The whole plan is later – hopefully, this home will be turned into a Care Centre for Working adults who have Cerebral Palsy.”*

Participant 1 appears to have felt frightened when she thought about the future since she could not begin to think about putting her daughter into a care centre. She even mentioned it would have been better to have put her child into a home from the beginning. This appears to illustrate her underlying separation issues that emerged when she thought about the future.

*“It frightens me...because we’re not getting any younger and...I’m actually too frightened to look into the future. I sort of take a year at a time. I have already started looking around... all her life she’s going to need someone to take care of her... and... we’re not getting any younger...there are often times when I’ve hit rock bottom and I’ve thought I wish we had just put her into a home when she was a baby. That’s how desperate you get...(We need to find a place) where we can take the wheelchair. And there are times when I think, ahh I wish I could just leave her somewhere for a month...and then... you’re at home with her and she’s chatting to you and she tells you how she loves you... I think how can I put this*

*child in a home?...and the bond unfortunately, unfortunately the bond is so very very strong.”*

Participant 4 appears to deal with issues she had about caring for her son by concentrating on the ‘here and now’ which ultimately seems to prevent her from thinking about her son’s future.

*“I think (his future) is positive because he can achieve anything. His disability might make it hard for him, but if he wants to achieve it, he will. As he gets older, we’ve kind of been thinking ... we’ve got a few years to play with, so we’ll worry about it when we actually get there. We’re actually getting there now he’s got one year left at school ... You know, you cope with situations. As they happen you just kind of deal with them.”*

#### **5.4 Summary of the findings**

The major emerging themes show that many of the participants felt that they had a problem with support and that they felt a sense of being isolated and alone. Many of the mothers felt their role was a multiple one which included being the mother, nurse, teacher and carer. Most of the mothers felt there was not enough time for themselves. Many of them felt that most of their time was taken up caring for their child and family. Since all of the participants had children who were in the adolescence phase of their development, many of the mothers noticed a change and that it became more difficult now that their child was older and was an adolescent. Some of the factors that contributed to the mothers finding it more difficult was that their adolescent was much heavier which made it difficult for them to be picked up. The mothers also noticed their adolescent having more mood swings and that they were more aware of their disability and their own sexuality which seemed to cause more issues for the mothers. All of the mothers felt it was easier to accept their child’s disability since they were all born with a disability and the mothers had to try and cope with this from the beginning. The mothers appeared to favour discipline for their children if they misbehaved and it seemed that they did not have feelings of guilt when they disciplined their child who has cerebral palsy.

Most of the mothers felt that it was important for their child's development to be honest and open with their children. It seemed that this helped their children become more open with them too, and enabled them to ask any questions they have about their disability. The mothers also had to deal with negative experiences when they first learned that their child had a disability. Many of the mothers felt shocked and devastated. This was exacerbated by a lack of sensitivity and lack of information provided by the medical profession. Many of the mothers also went through a phase where they felt angry at themselves as well as the medical profession since many of them felt that something could have been done to prevent their child from having a disability. The mothers also seemed to grieve for the loss of the child they never had. An important theme that emerged was that many of the mothers did not want to think about their adolescent's future. Some of the mothers seemed to 'take it one day at a time' which helped them to not think about the future. It was interesting to find that since their children had become adolescents, it had slowly forced the mothers to start thinking about their adolescent's future since they realized that they needed to think about what would happen once their adolescent finishes school.

These themes indicate that the mothers used negative as well as positive ways of coping with the issues they experienced when caring for their adolescent. The findings show what coping mechanisms benefited these mothers as well as what compromised that ability to cope. For instance, whether they had support from family and whether they had the ability to speak out and voice their concerns seemed to impact significantly on coping. The findings also show how adolescence has had an impact on the mothers ways of coping, since many of the mothers felt they experienced more difficulty now that their children were adolescents.

## **CHAPTER SIX: DISCUSSION**

### **6.1 Introduction**

The following chapter is a discussion of the findings presented in the previous chapter. This chapter compares the findings of this study with the theories and previous studies acknowledged in the literature review.

The major findings of the study will be listed below:

1. The mothers had problems with support and felt isolated. This forced them to have multiple roles when looking after their child which resulted in them never having time for themselves. This seemed to affect their coping even when their children became adolescents.
2. They experienced an increase in problems when their child became an adolescent. These problems seemed to force the mothers to cope differently. Many of the mothers used discipline which helped them deal with behavioural and mood changes their adolescent's experienced. Some felt that open communication was another way to deal with difficulties, especially when their adolescents were becoming more aware of themselves and the opposite sex. Some mothers appeared to experience discomfort around confronting their adolescent's sexuality which was related to their need to protect their child from becoming a sexual being and the implications thereof.
3. Many of the mothers found different ways to cope with their adolescent's disability. A dominant perception was that the mothers felt they were more accepting of the disability since their child was born with it. They seemed to feel this way since they mentioned they felt it would be worse if their adolescent suddenly became disabled after birth.
4. The mothers had negative experiences with the medical profession where they blamed the professionals for negligence and incorrect information as well as blaming themselves. This had an effect on their coping style from the birth of their child up to adolescence. This emphasized that coping was predominantly affected by initial experiences.

5. The mothers also had to deal with the loss of a child they never had which complicated their ability to cope, since grieving did not involve the actual loss of their child.
6. Some of the mothers eventually started dividing tasks up for each member of the family which alleviated some stress. They also started talking to other mothers and to more helpful professionals.
7. Many of the mothers feared for their adolescents' future. There was a sense of ambivalence around the need to protect them versus the need to let go.

The present study found that the mothers used a number of defences to buffer their response to stress. These will be discussed in conjunction with problem-focused and emotion-focused coping.

As the literature suggests, it appears that the mothers in this sample used problem-focused and emotion-focused coping. Problem-focused coping incorporates active problem-solving, seeking social support and interpersonal efforts to alter the situation (Judge, 1998). Emotion-focused coping includes efforts to maintain emotional responses to stressors and includes detaching from the situation. This form of coping also includes more negative ways of coping such as blaming oneself for the actual event and wishing the problem would disappear (Judge, 1998).

## **6.2 Coping mechanisms employed by mothers**

### **6.2.1 Problem-focused coping, facilitative factors and defences**

There appeared to be a number of facilitative factors that helped mothers use problem-focused strategies which made them use more adaptive defences. These facilitative factors were used which led to more problem-focused coping.

Social support seemed to be a very useful facilitative factor. Three of the mothers actively sought out social support. Some of the mothers felt they could rely on their families which seemed to be linked to them having a more positive outlook. Although this was the case, it appeared that the support provided from their families only

developed later in their child's life. It appears that problem-focused coping was used when the mothers said they dealt with issues on a daily basis and tried to find ways to handle the situations they encountered. This way of coping appeared to be particularly useful when they encountered stressors brought about by their children becoming adolescents.

One mother felt religion helped her cope since she felt she did not have many people she could turn to. This particular participant appeared to be using altruism as a defence mechanism as she worked with the church. This mother could possibly also be using sublimation as a defence since she had organized for her home to be turned into a future Care Centre for working adults who have cerebral palsy.

Research suggests that having a good social support network was beneficial for mothers as this alleviated much of the stress associated with caring for a child with cerebral palsy (McGuire et al. 2004). This appeared to be consistent with the findings of this study as the participants who had more support appeared to cope more than the participants who did not have the support. The findings show that just as the fathers found it difficult to deal with the fact that their child was disabled, so did some of the extended family members. One participant mentioned how her father and her in-laws did not visit in the early stages of her child's life. It appeared that the extended family members were unsure as to how to approach disability and therefore were not able to deal with their relative having a disability. This unfortunately came across as not showing support towards the parents. The findings indicated however, that many of the participant's extended family members did help with looking after the child later in the child's life. There appeared to be a difference in the way each of the parents accepted their child's disability. This was understood since mothers tend to do most of the caring of their children, which possibly forced them to start, if not accepting the disability, at least trying to deal with it sooner. Since the fathers were not the primary caregivers, they kept their distance from parenting which ultimately prolonged their difficulty in accepting their child's disability. There was one participant who felt that she had never had support from anyone. She mentioned that she felt that she needed support so that she could feel as though she was not alone.

Many of the mothers felt they did not have adequate support from the medical profession which seemed to have a long term effect on their way of coping. This would suggest that medical support and clear information regarding the disability would be another facilitative factor that could help the mothers use more problem-focused strategies of coping.

A third facilitative factor was when the mothers found courage to speak out and relinquished their multiple roles. Research claims that poor coping mechanisms are used when the mother does everything without the help of a social network (McGuire et al. 2004; Ones et al. 2005; Taylor, 1992). Although many of the participants appeared to do most of the caring for their adolescent even when they had support, two of the participants who did not have any family members or extended family they could rely on, did everything for their adolescent. Although one of these participants felt she could rely on her husband when she asked him to help, the other participant felt she could not trust anyone with her adolescent. This appeared to further reduce her opportunities to socialize and have her own individual time which contributed to social isolation. Some of the mothers eventually found courage to speak out and managed to relinquish their multiple roles and emphasized their role as mother. This is linked to the mothers being 'forced' to ask for help as their children became adolescents and brought with them issues such as being too heavy to be lifted, mood swings and behavioural changes.

A fourth important facilitative factor was acceptance of the disability. The literature suggested that a disagreement in accepting the child's disability and negativity about the disability are poor-coping mechanisms. This occurred with all of the participants' husbands which was consistent with the literature in stating it caused more stress in the family. This then left the mothers to be the sole care providers.

Research by McCubbin and Huang (1989) found that stress in families increased due to the severity of the child's disability while the findings by Ones et al. (2005) showed that poor motor functionality for example did not have a detrimental effect on the mother's

quality of life. Interestingly, the current study supported the findings of Ones et al. (2005). Three of the mothers who had children in wheelchairs appeared to have better coping mechanisms than the other two mothers who had children who are able to walk and have the opportunity to be more independent. This could be explained since the three mothers who had children in wheelchairs had the most support from their husbands and their other children, as well as other support systems found in their extended family and friends. This is an important comparison since it illustrates that the severity of the disability is not necessarily what makes coping difficult, it is lack of support that appears to make it more difficult.

A fifth facilitative factor was dividing tasks up between family members. All the participants felt they did the most work when caring for their adolescent. They especially felt this during the early stage of caring for their child since they felt they had no help from anyone. Based on their need to cope with many things at once, it seemed that suppression was a common defence used by these mothers. However, many of the mothers realized that they could not care for their child alone and so appeared to have asked for help whenever they needed it. This was mainly done when the children became adolescents since the mothers had no choice but to ask for help since they could not lift their adolescents anymore. The findings indicated that even though their husbands appeared to be better at dealing with the concept of having a disabled child later on in their child's life, they still would not voluntarily help with child care. Three of the participants had managed to divide tasks up between each family member in order for the family to get through the day. This lends support to the literature that explains that sharing the child care tasks and obtaining help physically plays a buffering role to stress (McCubbin & Huang, 1989). It appears that problem-focused coping was used later on in their adolescent's life when the mothers actively sought social support.

Taylor (1992) suggested that problems with other siblings was a contributing factor to the family developing poor coping mechanisms. Although the participants in this study appeared to have experienced this when their adolescent was a child, it seems that the participants in this study had to focus more on acting as a buffer between their

adolescents and their husbands or partners. This appeared to have added more stress to the mothers. Here it would seem that the mothers used problem-focused coping since they used interpersonal efforts to 'keep the peace' between their adolescents and their husbands or partners.

The participants of this study felt that it was more difficult now that their adolescent was older and heavier. They mentioned how they could not be left alone with their adolescent as they were unable to lift them by themselves. The mothers appeared to use problem-focused coping since their solution to this was to not be left alone with their adolescent in case they had to be picked up. This is consistent with other studies (Eker & Tüzün, 2004). As Hintermair (2000) suggested, the current study found that the adolescents with cerebral palsy often became clingy toward their mothers, which added to the stress placed on the mother.

Another facilitative factor was being honest with their adolescents. Taylor (1992) suggested that the adolescent stage is likely to give rise to new forms of anxiety among caregivers relating to the actuality of the constraints put upon the adolescent's emergent opportunities and identities. The participants of this study dealt with this by being honest with their adolescents. Problem-focused coping was used since some of the mothers tried to solve the possible problem of their adolescent's sexuality issues by being honest with them. Many of the mothers felt their adolescents could talk to them, however, if they could not, they would be able to talk to their siblings. Many of the participants felt that their adolescent would be able to cope with any issues they encountered as they become adults. They especially felt this with regards to meeting the opposite sex since some mothers felt they had always been honest about any issues regarding sexuality.

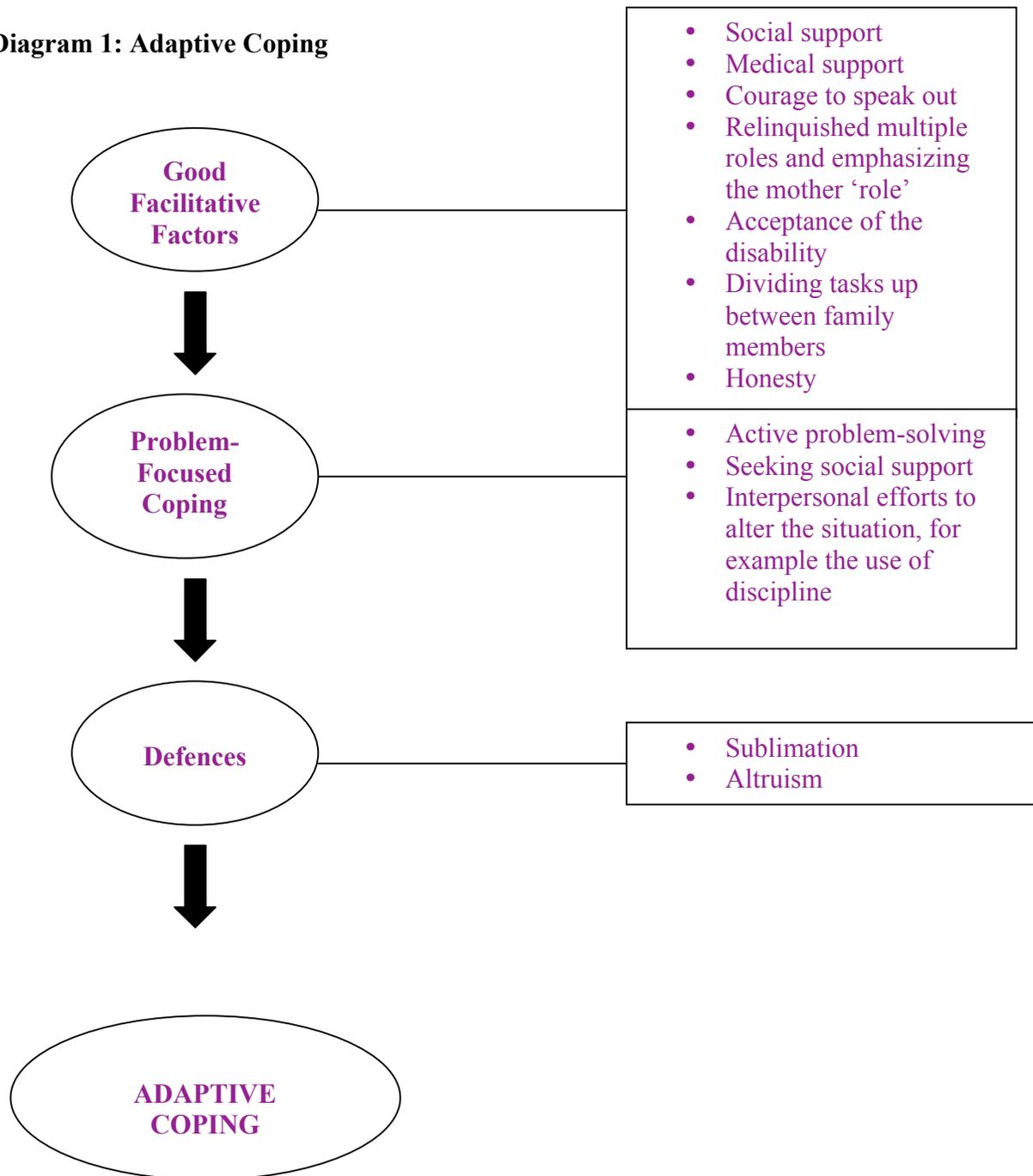
Research suggests that stress increases if children with cerebral palsy develop behaviour problems. None of the participants reportedly experienced added stress due to their children behaving inappropriately since each participant employed strict disciplining techniques to each of their children (Floyd & Gallagher, 1997). Each participant reported that they disciplined their disabled child in the same way as they disciplined their other

children. This appeared to be useful right from the beginning since the mothers were still able to discipline their children when they became ‘moody’ adolescents. Here, problem-focused coping appears to have been used since the mothers felt that disciplining their adolescent would benefit the adolescent as well as reduce the stress on the parents. The mothers actively tried to solve any issues that could possibly surface by disciplining their adolescent.

Mature coping mechanisms as suggested by the literature (Taanila et al. 2001) include open communication in the family and good family cohesion (Raina et al. 2005). Four of the participants felt that they had good communication with their family where each member could discuss their thoughts with each other. The mothers also mentioned that they were always honest with their children. Problem-focused coping appears to have been used since the mothers provided open communication with their adolescents which would possibly help reduce stress levels.

The diagram below illustrates how adaptive coping can be conceptualized as informed by the research findings. Firstly, useful facilitating factors seem to have a positive effect on the ways the mothers coped. This led the mothers to use problem-focused ways of coping which influenced them in using better defences. This led to more adaptive ways of coping.

**Diagram 1: Adaptive Coping**



As illustrated in the above diagram of the adaptive coping style, various facilitative factors helped the mothers come to terms with their child having a disability. This in turn influenced the certain coping styles that were used by the mothers. This is synonymous with certain defence mechanisms that were used. The researcher chose participant 5 to illustrate the use of problem-focused coping since adaptive ways of coping was more evident in the themes from her interview. Participant 5 realized that it was not her fault

that her child had a disability. Although initially she did not receive social support and explained the process as ‘a very lonely path’, she was eventually able to realize that she could not look after her disabled child alone and asked for help. Here she used problem-focused coping by actively seeking support. As she realized that she needed help and was able to ask for it, it appeared that she was able to manage her time more effectively since she divided tasks up for each member of her family. This allowed her to have more time to herself and it took much of the pressure off her.

Participant 5 decided that she was not going to be every role to her adolescent. She decided that her main role would be mother. This seems to have prevented her from having multiple roles which would cause stress and poor coping. Participant 5 also felt that her religion helped her get through this experience since she felt she had spiritual support when she did not have support from her family or friends around her. She could have used altruism as a defence since she was working with the church. Participant 5 appeared to overcome her negative experience with the medical profession by talking to other more helpful professionals. The participant also reported that she felt in some ways it would be easier to deal with her adolescent being disabled since he was born with it. She felt that she would not have been able to deal with it if her adult child suddenly became disabled.

Participant 5 also experienced difficulty when her child became an adolescent, but she was able to be honest with him and disciplined him in the same way as her other children which again helped her cope better. The participant found that it was better to be honest and have open communication with each member of her family. She organized her family to go out every month and discuss any issues they had with each other. Here, she actively used problem-solving techniques to help alleviate the stress that she experienced if she had to do it on her own. This participant was also able to think about her adolescent’s future. She seemed to be using sublimation as a defence since she had organized for her house to be turned into a future Care Centre for working adults who have cerebral palsy. This participant appeared to be more hopeful with regards to her and her adolescent’s future.

### **6.2.2 Emotion-focused coping, poor facilitating factors and defences**

It appears that from the present research there were a number of 'poor facilitating factors' that contributed to emotion-focused coping which led to the use of more negative defences which led to maladaptive coping.

An important poor facilitative factor was not having social support. Many of the mothers initially did not receive the support they needed. This led the mothers to use more emotion-focused ways of coping such as grieving for the child they did not have.

A second poor facilitative factor was not accepting the child's impairments. Many of the mothers experienced shock and were in denial when they first found out their child had cerebral palsy.

A third poor facilitative factor was not having time for themselves. Research (McGuire et al. 2004; Taanila et al. 2001) suggests that mothers who maintain their own identity and take time out for themselves are more likely to cope better as they keep their individuality. Only one participant appeared to have still kept her friends and made time for herself. Some of the remaining participants appeared to have tried but found it difficult to leave their adolescent with anyone for long periods of time, one of the reasons being that they could not be lifted by the caregiver and another reason being that their adolescents became clingy towards their mothers. The mothers appeared to use emotion-focused coping when they had difficulty solving the problem of finding individual time for themselves.

A fourth poor facilitative factor was not obtaining the correct information regarding their child's diagnosis. The mothers found it difficult to obtain the correct information regarding the diagnosis which made them feel uninformed and powerless.

A fifth poor facilitative factor was having a negative experience with the medical profession. The mothers felt anger directed at the medical professionals due to what the

mothers called negligence as they felt the disability could have been avoided. They also found the medical profession to be unsympathetic towards them. This is consistent with the literature (McKenzie & Müller, 2006) which explains the experience with medical professionals as a disempowering one for parents. Many of the mothers also blamed themselves for not intervening more. This appeared to play on their emotions since they felt that if they had intervened in time, maybe their child would not have been disabled. This seemed to allow the mothers to fantasize about 'what if' their child had not been disabled. Emotion-focused coping appears to have been used here since the mothers felt responsible and guilty and so blamed themselves for their child's disability which added more stress to the mothers and resulted in poor coping.

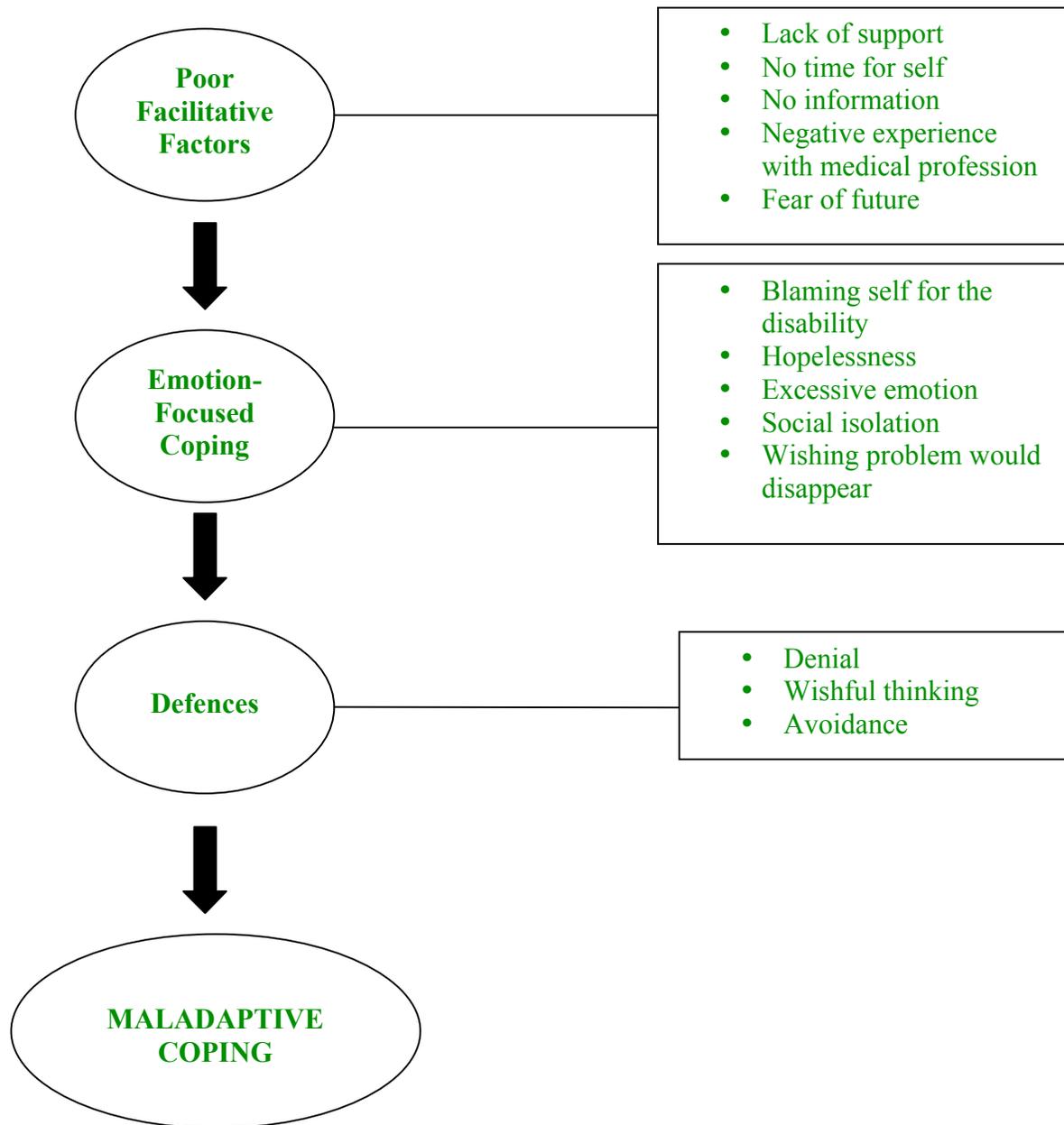
Interestingly, the sample in the Focus group did not appear to feel guilt regarding their child's disability since they did not feel as though they did anything wrong. This was different compared with the sample from the interviews since many of these mothers did feel guilty, especially when they first found out their child had a disability. This could be due to the mothers in the focus group answering the questions in front of other mothers and therefore they might not have been as open about their initial feelings about their child's disability. Further they were a group that were happy about their support at the school and therefore felt they could use problem-focused ways of coping.

One of the mothers felt that every time her child had a birthday, she did not experience this as a positive event, it appears that this was related to a prolonged grieving process for what her child 'could have been'. Many of the mothers seemed to feel a loss of the child they could have had. The feelings of loss appeared to be complicated since their child was still alive it just was not the child they thought they would have. These participants also experienced wishful thinking about what their child could have been. Emotion-focused coping seemed to have been used since these emotions the mothers appeared to go through further caused the mothers to feel guilty of any negative thoughts or feelings they had about their disabled child. This became complicated when their child became an adolescent since there were added stressors now that their adolescent was more moody and challenging.

Another poor facilitative factor was the mother's fear of their adolescent's future. Many of the participants mentioned how they felt frightened when they thought about their child's future. Many of the mothers admitted that they believed their adolescent would be able to cope, however they preferred to think about their adolescent's future one day at a time instead of focusing on what could happen in the future. It would appear that emotion-focused coping was used since the mothers still seem to avoid thinking about their adolescent's future. This appeared to indicate that the mothers tried to detach from the thought of their adolescent's future and avoidance was also used as a key defence when emotion-focused strategies were employed.

The diagram below illustrates how maladaptive coping can be conceptualized as informed by the research findings. Firstly, poor facilitating factors seem to have a negative effect on the ways the mothers cope. This led the mothers to use more emotion-focused ways of coping which influenced them in using more immature defences. This then led them to more maladaptive ways of coping.

**Diagram 2: Maladaptive Coping**



As illustrated in the above diagram of the Maladaptive coping style, various facilitative factors can be seen to feed into ways the mothers have used certain coping styles. As was evident in diagram 1, this is synonymous with certain defence mechanisms that were used. It appears that more emotion-focused coping was used when the participants had little support. It appears that a lack of support, a lack of information regarding their child's diagnosis and experiencing no time for themselves could have an overwhelming

impact on the mothers which could cause them to use particular defences that seemed to be associated with more emotion-focused coping. This appeared to lead to a more maladaptive coping style since some mothers blamed themselves for their child's disability and did not actively seek social support. This in turn would possibly keep them in a cycle of maladaptive coping since they still had no time for themselves which would keep them feeling overwhelmed. Some of the participants also experienced feelings of resentment with regards to not having enough time for themselves. One of the participants felt angry that she had to often stay at home to look after her child who had cerebral palsy while her husband took the able-bodied children out for the day. One of the participants wished she could have time alone and that her child with cerebral palsy could stay with someone for a month just so she could have time for herself. This was quickly followed by feelings of guilt at having wished for this.

The researcher chose participant 2 to illustrate the use of emotion-focused coping since maladaptive ways of coping was more evident in the themes from her interview. Participant 2 felt shocked and was in denial when she was told her child had cerebral palsy. She reported that she had been depressed ever since her child was born. Participant 2 felt as though she was not given the correct information from the medical profession initially and had to deal with the knowledge of her child having cerebral palsy alone. It appears that this participant received no support from the medical profession or from her family which caused her to feel powerless since she did not have the support she needed. She was forced to have multiple roles which caused her to feel overwhelmed and stressed which led to poorer ways of coping. This also prevented this participant from having time for herself which made her feel more isolated. Participant 2 also reported how she would often feel absolute exhaustion from all the chores she had. She mentioned she thought of taking her life because she felt hopeless, often wished the problem would disappear and felt she could not deal with it any longer. The only reason she did not take her life was due to her thinking of her adolescent and realizing that no one would take care of her. She appeared to constantly worry about her adolescent and would feel that her stress was ongoing and her ongoing monitoring of her daughter caused a sense of exhaustion. It is evident that this participant experienced feelings of hopelessness about her situation

which caused her to feel as though she could no longer deal with it. There were also feelings of guilt at having thought about taking her life and ultimately leaving her daughter which exacerbated her feelings of self blame.

Participant 2 appeared to cope with her feelings of self blame by overcompensating for her daughter's disability. This mother saw herself as the cause of her adolescent's disability which made her feel as though she should try and help her daughter all the time. This then caused her to do everything for her daughter. Participant 2 also avoided thinking about her adolescent's future. The defences she used and poor facilitative factors seemed to influence her feelings of hopelessness for her and her daughter's future.

### **6.2.3 Grief stages**

The findings of this study illustrated how many of the mothers' ways of coping can be understood on a continuum. Not all of the participants of this study fitted into the stages of grief as described by Kübler-Ross (1970). Although many of the participants went through some of the stages, they did not necessarily move through them in that order as described by Kübler-Ross (1970) and they did not necessarily move through each stage. The participants seemed to fall between the concepts provided by Kleinman (1988) and Kübler-Ross (1970). Kleinman (1988) identified the importance of acknowledging each person as an individual. Suffering was seen to be an individual process that each person would experience. Each person's illness narratives included their own cultural and personal experiences (Kleinman, 1988, p. 49). Two of the mothers were still having difficulty accepting their adolescent child's disability. This illustrated the importance of looking at each person as an individual.

Initially all the mothers went through shock when they found out that their child had cerebral palsy. Three of the mothers were aware that there was something wrong with their child, but they felt the doctors did not listen to them when they inquired about it. The majority of the participants also felt the doctors did not give them any sympathy and did not give them the correct information with regards to their child's condition.

Initially one participant was in denial that there was something wrong with her child. Denial occurred when the mother refused to acknowledge a painful aspect of reality or her subjective experience that would be noticeable to others (American Psychological Association, 2000). All of the participants felt anger and resentment toward themselves and toward the medical profession as they felt their child having cerebral palsy could have been avoided if they had acted more quickly and had stood up to the medical professionals. As the literature suggests, anger could help shield against feelings of guilt and helplessness (Taylor, 1992).

Many of the participants went through the feeling of loss of their expectations for their child. This is consistent with the literature, which examines the fact that the child cannot be mourned as the child's presence precludes a proper grief process. The continuity of the child's disability also leads to a sense of guilt when the mother attempts to grieve (Taylor, 1992). Many of the participants experienced intense feelings of guilt over their child's disability. As suggested by the literature, one mother felt she had to 'make up' for her child's disability as she felt it was not her child's mistake (Taylor, 1992). One of the participants mentioned how she mourns each year on her daughter's birthday. This is consistent with Kleinman (1988) since the literature suggests that the emotions one goes through during the mourning process are a part of each day and do not necessarily end once the stage has been experienced.

Although the literature (Carter, 2004, Kübler-Ross, 1970) suggests that once people have gone through all the stages of grief, many of them eventually find acceptance, this was not accurate for all of the participants of this study. One of the participants felt that she had never really accepted her adolescent child's disability since she often thought about what would have been if her adolescent was not disabled. This is in keeping with Kleinman's (1988) view that each person is different and experience events in their lives differently.

Not all of the participants' husbands accepted their child's disability immediately. In the majority of cases, participants reported that it took approximately 7 years before their

husbands were able to accept the reality of their child's disability. It would appear this would have put added pressure on the mother, as she would not have had support from her husband during the early stages of their child's life when they themselves were trying to come to terms with the disability.

Some of the participants showed signs that they were unable to pass through the grief process successfully and displayed signs of prolonged grief. This is in keeping with Kleinman's (1988) view that each person goes through the grieving process differently and one should not fit people into specific stages of grief.

Experiences that seemed to make it more difficult for mothers were not obtaining the correct information regarding their child's disability as well as not having social support. This was linked to more emotion-focused coping where one of the participants was overly emotional regarding the disability and also lived with depression. It seems as though acceptance was the core stumbling block to the grieving process.

One of the participants felt responsible for her adolescent's disability. This appeared to hamper her coping and prolong her mourning. She felt she has had depression since the birth of her child. This shows that her child's disability possibly had an influence in her developing psychological problems of her own such as depression. Depression has been known to occur when there is a realization that the child has a disability that is permanent and the mother feels responsible for the disability (Taylor, 1992).

Although many of the participants used coping mechanisms that fell in the mature coping group, it would appear that these mothers did not necessarily stay in this mature coping group. This emphasizes that there does not seem to be a consistent use of coping mechanisms since it depends on what different events arise and what stressor they are experiencing. Many of the participants appeared to have used many of the maladaptive, emotion-focused coping mechanisms initially since they were trying to come to terms with the disability, but with having more experience with their child, when they started

accepting their adolescent more and when they were able to voice their opinion and ask for help, they appeared to use more adaptive, problem-focused ways of coping.

Since the mothers had negative experiences with the medical professionals and received no support, they seemed to have difficulty dealing with their grief with as much resolution. Obstacles that appeared to block the mourning process included one mother going through depression and the other mother crying every year on her adolescent's birthday. A core obstacle appears to be adolescence in general and the problems that come with it. Issues in adolescence include more behavioural and mood changes, the difficulty of lifting the adolescent and coming to the realization that their adolescent would be dependent on them forever. With their children becoming adolescents, it forced the mothers to renegotiate the mourning of the disability because new stressors linked to normal adolescent issues surfaced. This also added to the process of mourning and how it never gets fully resolved and constantly has to be renegotiated.

#### **6.2.4 Implications for Management**

This study highlighted that emotion-focused coping is not particularly useful while it appears that problem-focused coping is much more helpful. If the mothers did not negotiate the different stages of mourning (although these are ongoing), this could also impair their functioning therefore it appears that management and counselling should be highlighted.

Based on the above findings it appears that increased attention to facilitating support from family would facilitate better coping. Further, increased attention and awareness to how mothers experience being told about the diagnosis of cerebral palsy from medical professionals would also offer better support and facilitate better coping in the initial phases. The findings suggest that future implications for management should include the medical professionals acting in a more sensitive and sympathetic way when they provide feedback to mothers that their child has a disability.

It would be useful for psychologists to address and work with these mothers in therapy on any issues of anger that was directed at the medical profession, family and husbands. It would also be useful to work on feelings of guilt and a loss of the child they had hoped for. Counsellors should be made aware that mothers with children and adolescents who are disabled, have to constantly renegotiate mourning, every time the parent experiences a new stressor. Counsellors should not push mothers into a model of dying that might not be relevant to that particular mother's life, it is important to see each mother as an individual. Counsellors should also be aware of the problems of adolescence which could exacerbate the mothers' stress levels.

Counsellors should encourage and teach more problem-focused strategies since emotion-focused strategies have found to not be very helpful. Counsellors should be aware of how to help the mothers move from emotion-focused ways of coping to more problem-focused ways of coping.

Counsellors should also not assume that from birth, mothers have had adequate information regarding their child's disability. A full history around this information should be assessed. Anger towards the medical profession which appears to block the mourning process should also be investigated. A full assessment on how angry the mothers are at the medical profession should be assessed.

Counsellors should also facilitate emotional support for the mothers. Possibly group therapy could help the mothers benefit from universality as this would help them realize that they are not alone. This would also allow them to obtain support from other mothers who have had a similar experience to them.

It is important for Counsellors to be made aware of what to look out for in the mourning process and to be made aware of the possibility of obstacles that the mothers could encounter such as how fathers might have more difficulty in accepting the disability, the lack of support from family and friends and the difficulty in finding time for themselves. It is also important to focus on conflicts/tensions and ambivalence which likely result in

psychological impairments of their own. A full assessment of the nature of the stressors should also take place in counselling. Counsellors should be aware of the difficulties that increase the stress the mothers go through when the child becomes an adolescent and how to overcome these stressors of adolescence. Counsellors should present coping in adolescence as a developmental sequence and should facilitate the mothers dealing with their adolescent's future in a more adaptive coping way.

### **6.2.5 Limitations of the Study and Areas for Further Research**

Limitations that could have been encountered in this study could be that the participants may not have answered the questions truthfully. Although this study included adolescent children, they were not the focus and so the study is limited to mothers. Another limit to this study is the inability to comment on how good coping mechanisms benefit the adolescent, although this is not the focus of the study. Some limitations in using an ideographic study are that generalizations cannot be made from a single case study and causal links are quite difficult to test (Terre Blanche & Durrheim, 2002). A further limit is that the adolescents in this sample did not fall into one category of Cerebral Palsy. Three adolescents were in wheelchairs and two were able to walk. An area for further research could be one where the adolescent's involved are in the same category of disability, however it must be noted that each child who has Cerebral Palsy is unique with regards to their severity. Future research could focus on different culture's reactions to disability, which could include a more culturally diverse sample and enhance the generalizability of the study. Another area that could be researched in the future could focus on father's coping mechanisms when they discover their child is disabled. Future research could possibly compare the differences between male and female medical professionals in informing parents that their child has a disability.

There appear to be a number of problems encountered in obtaining a more representative sample in terms of culture and race. As mentioned earlier, there may have been a number of reasons for this (for example, alienation due to an individualistic perspective and access problems, cultural belief systems, internalized discrimination, inequalities between Black and White people under the Apartheid regime and language barrier). It would be

important to address these issues when using a similar sample in future studies. For this to be addressed, it could be useful for the researcher to contact each individual to allow them to explain their feelings with regards to participating in the research and also for allowing them to feel heard and understood. Another way to address the language barrier is by using an interpreter during the interviews and also when contacting the mothers. The letter inviting mothers to participate could also be written in isiZulu.

#### **6.2.6 Reflection**

The researcher felt conducting this research would have had an impact on each participant since one cannot study something without it having an effect on the participants. The process could have allowed the participants a platform to voice their feelings that they did not often speak of as well as to show a sense of resiliency to the stressors they experienced in their lives. In a few cases, it was a forum where the mothers felt heard.

It could also have had a negative effect on them by bringing up issues they might not have dealt with completely with regards to the cause of their child's disability. One of the mothers became quite emotional while talking about her child's disability. Another mother expressed her wish for a support group as she felt so alone and depressed. This participant in particular was informed of the student psychologists at the Psychology Clinic with whom she could make an appointment if she felt the need.

Many of the mothers mentioned that they wanted to participate as they wanted their experience to be recorded so as to help other mothers in a similar position.

#### **6.2.7 Concluding remarks**

Hopefully, the findings will allow for the discussion of the benefits of this research for other parents who have children with disabilities, for schools, clinicians and the community.

This study found that many of the participants seemed to use maladaptive ways of coping initially when their child was first diagnosed. Although this was the case, many of the participants changed to more adaptive ways of coping when their child became an adolescent since they realized that they were not at fault and that they needed to verbally, and more assertively ask for help since they were aware that they could not care for their adolescent with cerebral palsy alone.

Coping mechanisms that were found to benefit mothers included obtaining support from the medical profession as well as obtaining support from family and friends. This study identified the importance of dividing tasks up for each member of the family in order to prevent the mother from having multiple roles. This would help alleviate stress placed purely on the mother which had been made more difficult in adolescence. The importance of disciplining their adolescents in order to manage new issues that emerged due to their child becoming an adolescent. The need for mothers to speak their mind about how they were coping and what they needed from others to help them cope. Coping mechanisms that benefited mothers was the importance of being honest with their adolescent regarding their sexuality and their future, and the ability to think about their adolescent's future.

Factors that appeared to compromise the mothers coping style were a lack of information and lack of sensitivity from the medical profession, a lack of support from their friends and families and the guilt feelings many of the mothers experienced. Mothers who had multiple roles which prevented them from having time for themselves also compromised their coping style. The mother's inability to think about their adolescents' future also compromised their ability to be honest with their adolescent regarding their future.

Although adaptive and maladaptive coping styles were identified in the way mother's coped with their adolescents, it appears that coping styles differed depending on the nature of the stressors the mothers were dealing with.

It was hoped that such information obtained from these mothers would add to the literature on therapeutic approaches used in supporting mothers with adolescent children with cerebral palsy. The information from these interviews will hopefully add to the clinician's evidence about mothers' experiences of having an adolescent with a disability. The identification and understanding of coping mechanisms used would enhance our understanding of the way mothers cope and could be beneficial to clinicians and people seeking help. Such knowledge will assist clinicians in being able to focus in the appropriate areas when working in this field.

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*Appendix I: Focus Group: Questions used to develop the semi-structured interview questions*

1. How did you respond when you found out your child has Cerebral Palsy?
2. Where do you feel you are in phases of coping?
3. Were you able to cope initially and if so did that continue?
4. What helped you come to terms with the disability?
5. Did you feel any guilt/disappointment about your child having Cerebral Palsy?
6. How did you cope with your child?
7. How do you cope now that your child is an adolescent?
8. How do you cope with the rest of your family?
9. Do you get help from your partner?
10. How did you cope with the reactions of your adolescent's siblings?
11. How do you cope with your role as mother?
12. Do you feel you have other roles?
13. How do you manage your adolescent's behaviour/other adolescent issues?
14. Do you attend a support group?

## ***Appendix II: Semi-structured interview questions***

### Mother's resources

1. Can you tell me about how you felt when you first found out that your child has Cerebral Palsy?
2. What helped you come to terms with your child's disability?
3. When your child was diagnosed, were you given the right information regarding the disability?
4. Can you tell me your experience of living with your adolescent? (Need & demand for attention – how do you cope with this?)
5. What support do you feel you need?
6. Do you use social support groups/networks? How do you feel this helps you?

### Common behaviours and Coping

7. Are things different now compared to when he/she was a child?
8. What areas do you feel you cope in?
9. What tends to make it more difficult?
10. How does the disability impact on a daily basis? (Time) – How do you cope with that?
11. What happens when your child misbehaves? How does that make you feel when you punish them?
12. How do you cope with adolescent issues on top of the disability issues?
13. How do you cope with your child's identity issues?
14. What do you expect from your child?
15. Do you have any guilt feelings about the disability?
16. How do you cope with your adolescent's sexuality issues? If you don't think about it, does this help you cope? By not thinking about it? (anxiety?)

### Menstrual cycle?

17. Do you feel you have spousal, financial, emotional support? (buffer to stress)
18. Do you ever feel burned out? Exhausted? Stressed? Depressed?

### Role and Attitude

19. What is your attitude regarding your child's future? Positive? Negative?
19. What role do you perceive yourself to have? Mother? Nurse?
20. How do you share the responsibilities of caring for your child and housework between you and your husband/family?
21. How do their siblings cope, (feel left out?) and how do you deal with this? Do you feel guilty about not spending as much time with siblings?
22. What do you do for recreation?

***Appendix III: Informed consent letter to mothers***

To whom it may concern

I am currently in my Masters year of Counselling Psychology at University of KwaZulu-Natal. My research dissertation is an investigation into the coping mechanisms of mothers of adolescent (12 to 19 years) children with Cerebral Palsy.

For the investigation into this research topic, I will be interested in talking to mothers who are happy to participate. All information acquired will remain confidential and mothers are able to withdraw from the research at any time. I will make arrangements to meet you at any time best suited to you. I will be asking a few question related to the coping mechanisms you use and what support networks are available to you.

I am passionate about working on this topic as I feel this research will benefit parents, the school and the community regarding the stressors put onto parents who have children with Cerebral Palsy and to provide ways to help parents cope with these stressors.

If you are interested in helping me, please inform Lynda Pretorius at The Open Air School.

Thank you so much for your time.

Yours sincerely,  
Sharon Draper

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031 5633125  
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***Appendix IV: Informed Consent Form***

Title of Research: Coping mechanisms used by mothers when caring for their adolescent child with Cerebral Palsy.

This study hopes to explore how mothers cope with their adolescent with Cerebral Palsy as well as focusing on behaviour problems that could emerge during the adolescent phase of the child with Cerebral Palsy and how this added stress impacts on the mother's life.

I, ..... hereby give consent to take part in this study. I understand that the interview I will be participating in will provide information for a study on the coping mechanisms of mothers with adolescents with Cerebral Palsy. I understand that I will remain anonymous in the case of the publication of this research, that the information obtained from the interviews will remain confidential and that I am able to withdraw from the interview at any time I wish and that there will be no negative consequences if I withdraw. I hereby declare that I was not forced to participate in this study and did so under my own free will.

.....	.....
Signature of Participant	Date
.....	.....
Signature of Researcher	Date
.....	.....
Signature of Supervisor	Date

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