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RESEARCH REPORT

The relationship between Cerebral-palsied children and their siblings: A maternal perception

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Supervisor: Clare Harvey

A research project submitted in partial fulfilment of the requirements for the degree of Masters of Education in Educational Psychology in the Faculty of Humanities, University of the Witwatersrand, Johannesburg, 19th April 2017

Declaration

I declare that this research project is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university

_____ _____

Signature Date

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Abstract

The current research focused on the relationship between Cerebral-palsied (CP) children and their siblings, from the mother's perspective. Further, the impact of CP on the sibling relationship, and the mother's perceived involvement in her children's sibling relationship, was explored. It is evident that there is a lack of research and literature on this specific topic internationally, as well as in South Africa. In addition, while there is an abundance of research concentrating on the relationship between disabled siblings, few studies focus on this relationship from the mother's perspective. However, by researching maternal perceptions, an alternative view is provided as to how these siblings interact and the relationship they form. A maternal perspective on sibling bonds will be of benefit to mental health practitioners who come into contact, and work with, families raising a child with CP and his or her sibling(s). Consequently, this study will add value to the field of Educational Psychology, as well as Psychology in general, as topics around disability, siblings, attachment and motherhood are often researched. The current qualitative study was conducted through individual interviews with eight mothers who have a child with CP, as well as another child who does not have CP (with the youngest child being at least two years of age). The information collected was analysed through thematic analysis in order to identify any pertinent themes amongst the mothers' reported experiences. The main findings emphasise that mothers perceive their children to have similar sibling relationships to that of non-disabled siblings. Although similar, there are also many aspects that the participants mentioned which were 'typical, but not' as typical to that of other, non-disabled sibling relationships. This highlights a uniqueness to their children's bond. Among numerous positive and negative differences between their children's relationships and those of other siblings, mothers identified feelings of guilt versus jealousy in their children. Additionally, mothers reported on the continuous battle for attention

from their children. Finally, each mother was able to reflect on the role that she plays in her children's sibling relationship. This involved either intervening in the sibling relationship to ensure her children develop a positive relationship or intervening less during conflict situations.

Keywords: Siblings, Sibling relationship, Cerebral Palsy, Disability, Maternal perceptions

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Chapter One: Introduction

Previous research (Brody, 1998; Howe, Petrakos & Rinaldi, 1998; Munn & Dunn, 1989; Stoneman & Brody, 1993) has been conducted exploring the relationship between siblings. Siblings can be defined as an individual's biological brother(s) or sister(s), but may also include half-siblings or step-siblings, who may become central figures throughout an individual's life (Whiteman, Senguttuvan & Gold, 2016). There is more recent literature focusing on the relationship between siblings when one child is growing up with a disability (Ali & Sarullah, 2010; Doody, Hastings, O'Neill & Grey, 2010; Dyson, 1999; Giallo & Gavidia-Payne, 2006; Heller & Kramer, 2009; Knecht, Hellmers & Metzing Jun, 2015; Meltzer & Kramer, 2016; O'Neill & Murray, 2016; Pit-Ten Cate & Loots, 2000; Shojaee, 2015; Wolfe, Song, Greenberg & Mailick, 2014). This research is mainly from the child's perspective who is growing up with a sibling with a disability. Although most research studies focus on disabilities in general, there is limited research focusing on the sibling relationship when one child specifically has CP (Dallas, Stevenson & McGurk, 1993; Stoneman, 2001). CP is defined as a common disorder that occurs in infancy and childhood as a result of pre-term delivery, pregnancy and birth complications, as well as multiple births (Shroff, 2016). Furthermore, children with CP may struggle with problems of sensation, cognition, communication, perception, as well as secondary musculoskeletal difficulties. There is a limited number of studies that have explored the mother's perspective of this relationship between her children. Moreover, only one research study (Nielson, Mandleco, Roper, Cox, Dyches & Marshall, 2012) could be found that has been conducted which briefly mentions the mother's perception of the siblings' relationship, when one child has CP. Maternal perceptions in the current research study can be described as the mother's understanding of, or how, she conceptualises her children's sibling relationship (Howe, Karos & Aquan-Assess, 2011). Additionally, no research could be

found on this topic of maternal perception when her one child has CP and the other does not, which has been conducted locally in South Africa. South African research on such a topic may be able to additionally address how differences in culture or socio-economic status could effect a mother's perception of her children's sibling relationship.

Due to the lack of research related to this area of study, it seemed fitting to begin to address this gap of knowledge on the maternal perceptions of the relationship between their CP child and his or her sibling(s). Not only does this study have theoretical implications, providing more knowledge about this topic, but it will also have practical implications. The current study will provide a different perspective on sibling relationships when one of the siblings has CP, and thus can be beneficial to those who come into contact with such families. This may include psychologists, teachers, physiotherapists and other medical health professionals. The current study could additionally have a wider impact in that the results could benefit other families who are raising a child with CP in South Africa, and internationally. Furthermore, such information may also have the potential to benefit families raising children with various other disabilities. This research study will ultimately provide an in-depth view into the sibling relationship, and this perception will be from one of the most important individuals in the siblings' lives, the mother. Finally, this study has relevance to Psychology in general, and specifically Educational Psychology, as it raises awareness around issues of children, disability, motherhood, siblings, as well as attachment theory. Such topics are often discussed and researched in the Educational Psychology field and therefore, this study will provide an additional source of knowledge to the field of disability, siblings and attachment theory.

The primary aim of this research study is to explore the maternal perception of the relationship between a mother's CP child and his or her sibling(s) through individual interviews. Two sub-aims include: to highlight, from a mother's perspective, how growing up with a sibling with CP has impacted the siblings' relationship; and to identify what a mother's perceived role is in the relationship between such siblings.

Chapter Two: Literature Review

The relationship between siblings is said to be one of the most enduring and lifelong relationships that children will develop throughout their lives (Doody et al., 2010; Guse & Harvey, 2009; Knecht et al., 2015; Nielson et al., 2012; Stoneman, 2001). This strong bond between siblings has been found to be important in contributing substantially to the development and adaptation of a child. According to a number of sources (Knecht et al., 2015; Nielson et al., 2012) this relationship contributes to physical, as well as emotional, contact through important life stages for children. This relationship results in aiding the child's personality and identity development, as well as the attainment of pertinent social skills. Furthermore, as Whiteman, McHale and Soli (2011) explain, siblings will also remain as each other's confidant, role models and sometimes source of support. These support bases will continue from childhood, through adolescence and finally into adulthood. Not only are these sibling relationships often the first that one forms in life, but they are ones that have an impact on family dynamics as well. Sibling relationships are therefore different from peer relationships that one may encounter or form in life. This is due to the fact that siblings are bonded together by familial bonds and, unlike relationships with their peers, they are sometimes harder to terminate (Stoneman & Brody, 1993).

Taking this strong bond into account, siblings who grow up with a brother or sister with a disability such as CP, may encounter a number of different experiences. With CP affecting between 1.5 and 4 babies per 1000 births (Shroff, 2016), studies indicate that children who have a disabled sibling are expected to have more negative experiences than those with non-disabled siblings and may need to cope with additional stresses (Magill-Evans, Darrah, Pain, Adkins & Kratochvil, 2001). The current research study therefore aims to explore the sibling relationship when one child has CP.

While it is evident that a considerable amount of research on sibling relationships has been conducted previously, few studies have focused on this relationship from different family members' perspectives. One such perspective that is pertinent to understanding a sibling relationship is a mother's perspective. Previous literature has identified mothers as the primary caregiver of children which suggests mothers may have additional insight into their children's sibling relationship (Mulroy, Robertson, Aiberti, Leonard & Bower, 2008). Not only is such information useful to parents and siblings, but also medical health professionals who assist children with CP. Thus, the literature review below aims to explore sibling relationships according to attachment theory. Further, the literature review discusses aspects related to disability both internationally and in South Africa. Growing up with a sibling with a disability, namely CP and what impact CP may have on siblings and other family members will also be explored. Literature focusing on motherhood and parental perceptions of the children's sibling relationship will also be discussed, with the main aim of highlighting the importance of exploring the maternal perception of the sibling relationship when one child has CP.

Theoretical framework for sibling relationships: Attachment Theory

It is helpful to explore relationships from a specific theoretical perspective in order to assist in understanding the development and functioning of personality in individuals, which can either be favourable or less favourable to one's health. Attachment theory, according to John Bowlby, endeavours to explain certain patterns of behaviour whereby infants maintain safety and survival through access to nurturance and protection provided by an attachment figure (Bowlby, 1969; Whiteman et al., 2011). Attachments are often formed by the time an infant is seven months old and are usually formed with only one person or a few individuals (Main, 2000). According to Bowlby's theory on attachment, relationships that infants form are bonds with primary caregivers.

Further, the quality of the attachment will vary in terms of the level of security, responsiveness and sensitivity that the infants perceive from their attachment figures. Thus, secure attachment in one's childhood years is essential for healthy development (Bowlby, 1973). The level of security will depend on the caregiver's level of sensitivity to the infant's attachment needs.

According to Bowlby (1973) a child develops a secure attachment to their primary caregiver when the caregiver is responsive and sensitive to the child's communications and needs. This will help the child to feel safe enough to explore his or her surroundings. However, if the primary caregiver is not responsive to the child, and if the child cannot rely on the caregiver as a source of security, then a secure attachment will not be formed. Consequently, an insecure attachment may develop between the parent and infant (Bowlby, 1973; 1988). In essence, siblings will often form an attachment with one another as well.

Whiteman et al. (2011) explain further, attachment relationships between an infant and a primary caregiver (who is usually the mother) will provide a 'blueprint', or essentially an idea, of the infant's relationships to be formed in the future. Interestingly though, theorists such as Mary Ainsworth (1967) discuss the possibility of infants changing attachment styles as they grow older, thus those with insecure attachments may potentially shift to secure ones. The implication of this is that these important attachment relationships between the mother and infant may affect the interactions that the child has later on in life with his or her parents and moreover, the relationships that the child will form with other individuals, including their siblings.

Bowlby (1988) maintains that there are three main patterns of attachment, namely secure; insecure-resistant/ambivalent; and insecure-avoidant. Bowlby (1988) describes these patterns as being largely persistent once developed, and self-perpetuating. Furthermore, secure attachment

develops when a parent (especially the mother) is readily available and sensitive to the infant's communications and needs. The infant is therefore likely to feel safe enough to explore his or her environment and is confident his or her mother will be responsive when needed. In contrast, a child with an insecure-resistant/ambivalent attachment is uncertain as to whether his or her mother will be available when called upon (Bowlby, 1988). This is as a result of a mother who is unpredictable and insensitive to a child's requests and communications and one who discourages independence. Lastly, a child with an insecure-avoidant attachment to his or her mother is not confident she will be available when the child seeks help. This results from a mother who constantly rejects her child when he or she approaches her for comfort or safety (Bowlby, 1988). Mary Main (2000) later developed a fourth category of infant behaviour, the disorganised/disoriented attachment style. This category is typically seen in children who have been physically abused or grossly neglected. Thus, it is evident that Main and Bowlby aim to explain how an infant may develop a resilient or healthy personality as opposed to a personality that can be prone to anxiety and depression.

One could also argue that if the primary caregiver's, in most cases the mother's, degree of responsiveness and sense of security does not meet the child's needs, a child may search for another attachment figure in his or her environment. This can be an older, and more involved sibling(s) (Whiteman et al., 2011). In fact, it is plausible that children form an attachment to their siblings even when they have an adequate attachment to their primary caregiver or mother. It is therefore possible for these infants to develop a secondary attachment to their siblings. Whiteman et al. (2011) also mention how studies have been conducted which highlight that siblings will often look to each other for emotional support when it is needed. This could occur during a distressing situation such as when siblings' parents are fighting. Importantly, Whiteman et al. (2011) maintain that these sibling attachment relationships can either reveal information about inadequate parental-

infant attachment bonds, or merely reflect and mirror these attachment bonds between parents and their children. Sibling relationships will also develop over many years and change in the process, and therefore most will last a long time. Given the importance and central role that siblings can play in one another's lives, it is an area that needs to be given further attention. Such attention may include exploring the impact sibling relationships can have on an individual's development and adjustment, as well as relationships they may form in the future. Furthermore, it will be interesting to explore the influence these relationships will have on siblings when one child has a disability, namely CP.

Introducing disability

Many individuals worldwide are affected either by a physical, developmental, mental or affective disability, or sometimes more than one disability. While there is no universally accepted definition of disability, disability may be understood as the difficulty or dependency on others an individual experiences when performing daily activities (Fried, Ferrucci, Darer, Williamson & Anderson, 2004). Additionally, the World Health Organization (WHO) states that disability is the inability for an individual to lead and maintain a lifestyle that is considered normal for his or her gender, age, social and cultural background (Goodley & Tregaskis, 2006; Sen & Yurtsever, 2007). Thus, a child with a disability would not necessarily be able to play, learn and take part in activities appropriate for his or her age.

On a daily basis, such individuals may experience the loss or limitation of functioning and/or opportunities to complete normal life activities and roles, thus restricting their independence (Goodley & Tregaskis, 2006; Guse & Harvey, 2009). As a result, these individuals will require the care of others to carry out simple activities, such as tasks essential for self-care which cannot be

done independently. Apart from self-care help, individuals may need assistance when travelling and may require aids and specialised equipment. Cardol, de Jong, van den Bos, de Groot and de Haan (2002) concur by suggesting that a disability is likely to have long-term effects on a person's life. Therefore, it is evident that the limited functioning caused by a disability is likely to influence the lives of those close to a disabled person, such as his or her siblings. Consequently, it will be worthwhile to document how this influences the relationship formed between siblings.

Sen and Yurtsever (2007) explain how 10% of the population in developed countries are disabled and 12% are disabled in developing countries. Importantly, children in developing countries are faced with additional challenges and risks such as poverty, poor health and malnutrition, as well as home environments that are not intellectually stimulating or supportive (WHO, 2011). This may exacerbate cognitive, physical and social-emotional difficulties in children who are already faced with a disability. Importantly though, while this might often be the case due to socio-economic pressures, it does not apply to every family living in poverty. Exploring more recent statistics on disabilities from the World Report on Disability indicates that over one billion people today (including children) experience a disability (WHO, 2011). This Report used the 2004 Global Burden of Disease Study to gather statistics of disabilities around the world. This study estimated that 15.3% of the population worldwide (978 million people) have moderate disabilities, with 2.9% of the world population (185 million people) experiencing severe disabilities (WHO, 2011). This Report further describes that 93 million children (aged 0-14 years) worldwide suffer from moderate disabilities, with 13 million children (aged 0-14 years) experiencing severe disabilities. Additionally, in 2005 UNICEF estimated that 150 million children (under the age of 18 years) are struggling with a disability (WHO, 2011). This evidently

shows how disabilities, such as CP, impact children across the world. South Africa is included as one of the countries where children suffer from disabilities on a daily basis.

Exploring disabilities in South Africa specifically, it is estimated that 436 123 children (or 2.5% of the total child population) experience a serious disability (UNICEF, DSD & DWCPD, 2012). The Census completed in 2001 estimated 436 123 South African children have at least one disability, with 44 790 children experiencing multiple disabilities (UNICEF et al., 2012). Furthermore, in terms of specific disabilities in South Africa, 100 345 children have severe visual impairments, 92 549 children are profoundly hard of hearing, 68 550 children have serious difficulties with learning, 64 911 children have a physical disability and 22 148 children experience a speech impairment. Children with CP are included in these statistics as CP is an umbrella term used to describe a neurodevelopmental disorder that persists throughout an individual's lifespan (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2009). Thus, children with CP may battle cognitively, with motor function, movement and/or posture. While the discourse around, and responses to, disability have changed over time, some children and adults may still feel separated or isolated in society today (WHO, 2011). Additionally, there have been increased efforts to shift communities and schools towards the inclusion of individuals with disabilities. Nevertheless, many still do not realise and acknowledge the affects that a disability can have on the development and functioning of a child on a daily basis, thus proving that the current research topic may provide some valuable insights.

Growing up with a sibling with a disability

Taking the above information into consideration, it is important to explore the relationship between siblings when one of the children has a disability, and whether this has implications for the sibling

relationship. There is abundant research (Ali & Sarullah, 2010; Doody et al., 2010; Dyson, 1999; Giallo & Gavidia-Payne, 2006; Guse & Harvey, 2009; Heller & Kramer, 2009; Knecht et al., 2015; Meltzer & Kramer, 2016; O'Neill & Murray, 2016; Pit-Ten Cate & Loots, 2000; Shojaee, 2015; Wolfe et al., 2014) exploring this topic and what it may mean to grow up with a sibling with a disability. These above mentioned sources relate to a number of developmental, physical and intellectual disabilities, providing evidence for the variety of different disabilities that affect children. It is likely that these siblings will develop a different relationship, than that of two non-disabled siblings. As a result, these siblings are likely to have a number of experiences, ranging from positive to negative. Such experiences will have an impact on the personal development of both children, as well as on the relationship they form (Pit-Ten Cate & Loots, 2000). Numerous studies (Ali & Sarullah, 2010; Knecht et al., 2015; Nielson et al., 2012) explain how the sibling without the disability often may experience some negative aspects to this relationship as they perceive their parents as more focused on their sibling with the disability and his or her needs. This perception may result from sometimes feeling forgotten or isolated in the family, as well as sometimes having feelings, thoughts and opinions ignored. This will lead to feeling that they are the family member who is neglected (Nielson et al., 2012; Stoneman, 2001). However, such feelings may possibly diminish once siblings are aware of, and understand, what their sibling's disability entails. Further, these feelings may decrease once they develop a sense of openness and acceptance that their sibling is growing up with a disability (Ali & Sarullah, 2010). This is likely to result in a clearer understanding of what the relationship means to both siblings. In addition, Pit-Ten Cate and Loots (2000) mention how children growing up with a sibling with a disability could possibly struggle with issues of anxiety and depression because their needs may be ignored

or forgotten by parents who are tending to their sibling with a disability. Thus, these children may become more withdrawn than children who are not growing up with a disabled sibling.

However, there are many positive experiences reported by children growing up with a disabled sibling (Wolfe et al., 2014). Nielson et al. (2012) concur with this statement, explaining that when there is a child with a disability it can result in a positive adjustment between siblings. Ali and Sarullah (2010) also agree, arguing that a child growing up with a disabled sibling may develop additional forms of acceptance by learning how to care for, and assist, a sibling with a disability. This would not necessarily occur in children who have a non-disabled sibling. In addition, information about the disability can help the sibling to understand what this means and that it may result in lifelong care. Pit-Ten Cate and Loots (2000) also coincide with these findings of positive experiences, by revealing that children with disabled siblings are often more social in nature and tolerant towards other children. This could potentially result in more mature, responsible and patient children. Therefore, one can conclude that there will be both positive and negative aspects to growing up with a sibling with a disability (Guse & Harvey, 2009). Evidently there is research that already exists on disabilities such as Down Syndrome (Wolfe et al., 2014) and Dwarfism (Guse & Harvey, 2009), with some research focusing on a number of developmental disabilities altogether (Ali & Sarullah, 2010; Doody et al., 2010; Knecht et al., 2015; Lobato, Miller, Barbour, Hall & Pezzullo, 1991). However, only a few studies explored CP (Pit-Ten Cate & Loots, 1999; Vikman, Stahle-Oberg & Fjellman-Wiklund, 2015). Focusing specifically on one developmental disability, namely CP, may give the reader an indication of the relationship between siblings when one child has a disability. Growing up with a sibling with CP is likely to include a number of positive and negative experiences as well as additional stressors, which are felt by the

non-disabled sibling. It is these experiences which may influence the relationship that is formed between such siblings.

Growing up with a sibling with Cerebral Palsy

CP is a common neurodevelopmental disorder that occurs in infancy and childhood. The result of CP can range from mild to severely disabling. As Pakula, Van Naarden Braun and Yeargin-Allsopp (2009) state, it is the most common form of childhood motor dysfunction. According to Eunson (2012), CP is defined as:

> "A group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of Cerebral Palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems" (p. 361).

With this definition in mind, it would be important to mention that the severity of CP ranges and therefore, the degree of the disability varies between children. When considering the severity of CP, it may be beneficial to highlight the four types of CP that exist. The first and most common is called spastic CP, and the clinical features of this form of CP impacts a child's limbs (Jones, Morgan & Shelton, 2007; Krigger, 2006). Furthermore, this type of CP can be broken down into four subtypes, namely Diplegia, Hemiplegia, Quadriplegia and Monoplegia/Triplegia) (Jones et al., 2007). Thus a child is likely to suffer from muscle spasms and tremors, which results in muscle weakness or stiffness in one body part (Jones et al., 2007; Krigger, 2006). The second type of CP one can develop is that of athetoid CP, or simply, non-spastic CP. With this type of CP, children are more likely to suffer from speech impediments as well as slow, withering movements in their

limbs or involuntary/jerky movements in the face, torso and limbs (Jones et al., 2007; Krigger, 2006). The third, and most rare, type of CP is called ataxic CP (Jones et al., 2007; Krigger, 2006). The clinical features of ataxic CP include impairment in one's balance, co-ordination and depth perception; and children will typically struggle with voluntary movements. Lastly, it is possible to have a combination of the above mentioned types of CP as more than one area of the brain may be affected, resulting in mixed CP (Krigger, 2006). Considering the above, it is clear that some children may suffer a mild form of CP where only one limb is affected. Whereas other children will be severely affected and will need to use a wheelchair due to having limited movement of more than one limb (Eunson, 2012).

The causes of CP can sometimes be the most important question for family members raising a child with CP. Thus it is important to mention what these causes can be as a result of. Asphyxia during birth is one of the more common causes of CP. Asphyxia, or the loss of oxygen, can result when a mother's labour is obstructed or when an umbilical cord prolapse occurs (Nelson & Grether, 1999; Reddihough & Collins, 2003). The consequence of a loss of oxygen for the baby, is a resultant motor dysfunction. Eunson (2012) and Pakula et al. (2009) also highlight that multiple births and babies born with a low birth weight, or premature babies, can also be at risk for developing CP.

Considering the above, it is evident that children with certain forms of CP will require lifelong care depending on the severity of their CP. Thus, children with milder forms of CP may have fully independent functioning later in life and will not require this lifelong care. This will result in families and children with CP seeking services from physiotherapists, occupational therapists, psychologists, increased care and attention from teachers and their family members, as well as other health specialists (Kent, 2013). These services will start early in infancy and continue

throughout the childhood years, depending on the child's severity of CP. Importantly, this increased care and stress will be felt by, and have an (indirect or direct) impact on, siblings as well as other family members raising a child with CP. More specifically, mothers are one such family member, and in fact are the primary member, who may experience the increased stress when caring for a child with CP.

The impact of Cerebral Palsy on the siblings and other family members

According to Knecht et al. (2015) when considering disabilities, one could refer to them as a 'family affair' due to a disability affecting and impacting all family members. Vikman et al. (2015) agree with such a statement, arguing that when there is a child growing up with CP the entire family will feel the effects of the disability. In the past children with disabilities often remained hospitalised for long periods of time; however this is no longer the case. Due to the improvement of medical technology and knowledge around the different developmental disabilities, and disabilities in general, children are now able to avoid these long-term hospital stays and instead be cared for in their home environment (Davis, Shelly, Waters, Boyd, Cook & Davern, 2009; Knecht et al., 2015; Nielson et al., 2012; Parkes & McCusker, 2008). Children with CP are therefore more likely to survive to adulthood. Although this is a positive aspect for children with disabilities, it may place increased stress and many additional challenges on parents caring for their CP child. Daily routines have to be changed and adapted specifically to suit the disabled child and his or her needs. This will ultimately result in long-term care by mothers specifically, and the rest of the family in general, who have a family member with CP (Knecht et al., 2015). However, this long-term care does relate to the severity of the child's CP, as children with milder forms may not require such intensive care and instead will function more independently later in life.

Vikman et al. (2015) also highlight that siblings of children with CP can be negatively affected if their sibling with CP is in pain. Consequently such children will be concerned for their sibling with CP, but may not voice their struggles so as not to place additional stress on parents and other family members. Further, these authors mention that while parents may worry about their child without CP in terms of emotional and psychological issues, they also highlight that these children are more often emotionally mature. Thus having a sibling with CP can result in positive and negative aspects for siblings, as well as for parents. It seems appropriate to explore the relationship between such siblings and expand on these positive and negative experiences.

Motherhood

While growing up with a sibling with CP may lead to positive and negative experiences for the non-disabled sibling, mothers can also have a variety of experiences in relation to raising their child with CP, as well as raising their other, non-disabled children. It seems evident many women prepare for motherhood even during pregnancy as a transition occurs during this time. As Smith (1999) describes, pregnancy can help mothers psychologically prepare for motherhood and the experiences that are to follow. With that being said, many women are faced with both pressures and rewards when entering motherhood, thus experiencing elevated levels of happiness, as well as feelings of anxiety. A mother's psychological distress during the transition and entry into motherhood can be buffered by the amount of support she has and whether or not she is a single parent (Baranowska-Rataj, Matysiak & Mynarska, 2014). While motherhood is often seen as an inevitable life event for many women, this stage in a woman's life demands time and involvement from her to satisfy her child's needs (Sevon, 2005). Thus, motherhood also demands women to delay fulfilling their own needs.

Mothers raising a child with CP, or any other disability, are likely to experience additional pressures and stressors during their time of motherhood compared to mothers of children without CP. This is due to the increased number and variety of medical appointments these mothers face when raising a child with CP. Specific challenges may include finding appropriate schools, weekly neurological and physiotherapy appointments, as well as sourcing specialised equipment that may be needed, such as wheelchairs or walkers. Thus, it will be interesting to study whether these stresses and pressures have influenced a mother's view of her children's relationship and more so, I argue mothers may have additional insights into the relationship that has formed between their CP child and his or her non-disabled sibling(s).

Raising any child requires a number of changes and challenges that are felt by the parents. However, raising a child with a disability, such as CP, is ultimately a different experience for mothers specifically, and the family in general. Mothers need to adjust how they support and care for their child with CP as new challenges and pressures arise on a daily basis (Milbrath, Cecagno, Soares, Amestoy & de Siqueira, 2008; Roper, Allred, Mandleco, Freeborn & Dyches, 2014; Ryan & Runswick-Cole, 2008). Evidently, this adjustment will result in the modification of old, and the development of new, skills for the mother in order to help raise her child with CP. In addition to this, mothers are often considered to be the primary caregiver of their children and specifically of their child with CP (Bourke-Taylor, Pallant, Law & Howie, 2012; Bower & Hayes, 2006), therefore making mothers one of the most important people in the CP child's life. While mothers play a vital role, fathers also experience the relationship between their children. Therefore, fathers may also experience the challenges, limited free time, lack of support, and financial impact of raising a child with CP (Davis et al., 2009). Moreover, literature (Mulroy et al., 2008) suggests that mothers and fathers have different perceptions regarding their children's sibling relationship.

Considering the above, and that mothers are often the primary caregiver of their children, one can assume that a mother may provide a particular insight regarding the relationship between her children. Hence, the chosen sample of mothers for the current study, as it seems appropriate to explore the mother's perspective of the sibling's relationship.

Maternal perceptions of their children's sibling relationship

Studies focus on the relationship between a CP child and his or her sibling. For example, Dallas et al. (1993) observe that children with CP seemed to act more passively and are unassertive in relation to their non-CP sibling, whereas non-CP children were more direct in their interactions with their sibling with CP. However, little research (Nielson et al., 2012) considers the mother's perception of her children's relationship when one child has CP. More specifically, no South African research could be found that has been conducted exploring this topic of maternal perceptions of the sibling relationship. In addition, no research was evident that considers the South African context, or issues related to poverty and culture, and how these may impact or alter the perceptions such mothers hold regarding their children's sibling relationship. By researching such a topic a mother's perspective of her children's relationship and whether maternal perceptions influence the development of the sibling relationship will be illuminated.

Further, I believe such a study on maternal perceptions of the sibling relationship will highlight our understanding of the way families view their social worlds. While there is research (Choi & Van Riper, 2014; Mulroy et al., 2008; Nielson et al., 2012) focusing on mothers', and even both parents', perceptions of their children's relationship when one child has a disability, only one study (Nielson et al., 2012) briefly explored this topic when the child has CP. The current study therefore begins to address this gap in knowledge around siblings when one child is growing up with CP. Bearing this in mind, Nielson et al. (2012) state that parents will often differ in their

perceptions of the relationship between their children. Roper et al. (2014) argue that mothers raising a child with a disability evaluated their children's sibling relationships as being more positive than mothers who are raising non-disabled children. Thus, it will be interesting and beneficial to explore whether the current study finds similar, or different, results relating to mothers' perceptions of the relationship between their CP child and his or her sibling(s).

Chapter Three: Method

3.1. Research Aims

The current research study aimed to explore the maternal perception of the relationship between a mother's Cerebral-palsied child and his or her sibling(s) through individual interviews. Two sub-aims included: to highlight, from a mother's perspective, how growing up with a sibling with CP has impacted the siblings' relationship; and to identify what a mother's perceived role is in the relationship between such siblings.

3.2 Research Questions

1. How does a mother perceive the relationship between her Cerebral-palsied child and his or her sibling(s)?
2. How, if at all, has having a child with CP impacted on the relationship between a mother's children?
3. What is the mother's perceived role in her children's sibling relationship?

3.3. Research Design

An exploratory qualitative methods approach was used in the current study. This type of research aims at gathering an in-depth understanding of the topic proposed in a study. Mistry (2012) states that qualitative research looks at gathering a thorough understanding relating to individuals' experiences, beliefs, and their perspectives. In addition, Snape and Spencer (2003) highlight that qualitative research is not related to quantifying and calculating certain phenomena. Therefore, this qualitative research looked at understanding the meanings that individuals associate with their experiences and perspectives. This study aimed to accomplish this by asking (and having individuals answer) questions regarding their lives and the experiences they have had. According

to Mistry (2012), such a research method will help provide answers to the 'why' and 'how' questions of a research study. The type of qualitative research instrument that was used was an in-depth individual interview. Lewis (2003) explains that individual interviews are often the most common method in qualitative research and they remain popular because they provide a focused view of an individual's experiences.

More specifically, the theoretical framework adopted in the current study is interpretivist phenomenological analysis (IPA). IPA aims to firstly understand or 'give voice' to participants' experiences and accounts and secondly, to contextualise and 'make sense' of these reported accounts and claims from a psychological perspective (Larkin, Watts & Clifton, 2006). Usually this leads to a researcher exploring the participants' experiences of a specific relationship or event. The current research study is phenomenological because I did not want to test hypotheses but instead I wished to explore, understand and communicate the participants' accounts of the relationship between their CP child and his or her sibling(s). This theoretical framework therefore, was also complemented by the methodology of the current study in the use of semi-structured interviews. Larkin et al. (2006) expand on this, in that IPA research studies involve verbatim accounts from a small number of participants, which are analysed intensively. Smith (1998) confirms the above theoretical framework for such a study as themes will emerge from the participants' accounts and therefore from the analysis. Additionally, I used existing literature to discuss and explain further the identified themes.

This research design allowed for the exploration and understanding of the perceptions that mothers have regarding the relationship between their CP child and his or her sibling(s). In addition, it focused on what ways she thinks her child's CP has influenced the sibling relationship or changed it when a child with CP had later been introduced into an existing sibling relationship.

Finally, her perceived role in her children's sibling relationship was also highlighted. This was achieved through a discussion with each mother separately. My role in the interview was merely to facilitate the conversation and help encourage the mother to discuss her experiences and perception of the relationship between her children. Furthermore, thematic analysis (TA) was used to analyse the data in order to highlight common themes between each mother's reported experiences.

3.4. Sample and Sampling

The participants for the current study consisted of eight mothers, as this provided enough information to analyse any themes that were common between the mothers' interviews. More specifically, these mothers needed to currently be raising a child with CP, as well as a child who does not have CP. The youngest of these siblings needed to be at least two years of age or older. This inclusion criterion of a minimum of two years of age is needed as the siblings would have then had the chance to form a relationship or a sibling bond. Thus, the relationship between the siblings could be explored from the mother's perspective. The two children were required to be living with the mother.

I conducted a study in 2014 which required a similar sample of mothers raising a child with CP, and therefore these mothers were contacted again and asked if they were willing to participate in another study. In order to find additional mothers for my sample for the current study I contacted a physiotherapist, who specialises in working with children with CP (who was also contacted in 2014). I asked her if she knew of any additional mothers who would be willing to participate in the study. The physiotherapist contacted potential participants first and asked if they were open to

being contacted by me. If they were willing to partake in the study only then was I provided with the contact details of these interested mothers.

Due to this study requiring a particular type of participant (i.e. mothers who are currently raising a child with CP and one without CP, with the youngest child being two years of age or older), purposive, non-probability and non-random sampling was used. That is, the participants were not selected at random from the broader population. Non-probability sampling involves selecting a sample which reflects particular features, characteristics or groups within the sampled population (Richie, Lewis & Elam, 2003). Furthermore, purposive sampling is an example of non-probability sampling, and is used when participants meet specific criteria or include particular characteristics that the researcher is interested in studying, and therefore are chosen with a purpose (Cozby, 2009; Mistry, 2012; Richie et al., 2003). This type of sampling allowed for a more detailed exploration of those certain characteristics of interest and provided a better understanding of them. Snowball sampling was also used at a later time to contact mothers to take part in this study. Snowball sampling (or chain sampling) occurs when participants who have already participated in an interview are asked if they know of other individuals who fit the selection criteria, namely mothers who have a child with CP (Richie et al., 2003).

3.5. Instruments

The method of data collection used in this study was individual, one-on-one, face-to-face in-depth interviews (Richie et al., 2003) with each mother. The interviews were conducted using a semi-structured interview format, in that the questions were asked to all the mothers in order to start the conversation and allow for it to flow. However, the conversation varied between mothers as the interview schedule was neither too structured so that it formed a questionnaire, nor was it

completely unstructured. The semi-structured nature of the interview schedule allowed for more flexibility by adding follow-up questions as an individual was interviewed, a feature which is lacking in structured interviews (Fylan, 2005). In addition, specific aspects of the topic that were important to the individual being interviewed were raised by them and they could discuss these further, which varied between participants. As Fylan (2005) explains, semi-structured interviews can be used for answering more complicated research questions such as maternal perceptions of the relationship between CP children and their sibling(s). This therefore highlights how important the interaction between the participant and myself was for obtaining detailed responses from each mother.

The interview schedule (Appendix 3), included open-ended questions which aimed to elicit information needed to answer the research questions of the current study. This helped to facilitate the conversation between the participants and myself. Due to this study having particular research questions, specific interview questions were created in order to explore this topic rather than using an established interview schedule. These questions were formed after reviewing the pertinent literature and existing research similar to the topic. The interview schedule was designed based on the broader topic of parental perceptions of sibling relationships when one child has a disability. The questions were piloted by two academics to determine their suitability for this study. Below are a number of example questions that are included in the interview schedule:

1. How would you describe the relationship between your CP child and his/her sibling(s)?

2. How do you think their relationship will change as they get older? Please elaborate.

3. How does your one child's CP affect the sibling relationship, if at all? (Or severity of CP?)

4. What role do you play in their relationship? (Follow up prompts with how she understands this role in relation to one of her children having CP).

3.6. Procedure

Once approval from the University of the Witwatersrand Psychology Department's internal ethics committee had been acquired, the questions in the interview schedule were piloted by two academics to ensure they were suitable for the current study. Once this had been conducted, mothers were contacted to take part in the study. I conducted a research study in 2014 that required a similar sample (mothers raising a child with CP) and as a result mothers who participated in the 2014 research study were first contacted and asked if they would like to participate in the current study. Specifically, five out of the eight participants in this study were mothers who participated in the 2014 study. In addition, a physiotherapist who specialises in working with children with CP was also contacted (who was contacted in 2014 as well) and was asked if she knows of any mothers who would be willing to take part in the current research study. The physiotherapist contacted potential participants first if they were willing and open to being contacted by me to take part, the physiotherapist only then provided me with their contact details. Once mothers had agreed to take part in the study, interviews were set up with each participant. Interviews were held during a time when each participant was available and at a place that was suitable for each as well. More specifically, the physiotherapist provided me with seven out of the eight participants (both new mothers and mothers from the 2014 study). The eighth participant, who also took part in the study in 2014, was contacted through another health professional, namely a social worker. Two of the interviews were held at the participants' homes, four of the interviews were held at the participants' place of work and two of the interviews were conducted at the physiotherapy rooms while their children were attending physiotherapy.

Before obtaining signed consent from each mother at the beginning of each interview, the Participant Information Sheet (Appendix 1) was given to each mother to read. This explained the motivation behind the research study and the process of the interview. During this time, I raised any ethical considerations that needed to be discussed, for example mentioning and explaining aspects of confidentiality and anonymity. Once the participant had signed the consent forms and been informed about the process of the study, an open-ended question was used to start the conversation. Follow-up questions were used to help continue the conversation between me and the participant. Importantly, this allowed the participants to discuss topics that were important to them and that they felt were worth mentioning. Each interview lasted between 45 minutes to one hour, and were audio recorded to allow for transcription purposes. I transcribed these audio recordings verbatim for analysis. Once the interviews had been transcribed, I followed the six steps of TA (Braun & Clarke, 2006) by reading through the transcripts, developing codes and searching for themes in each of the eight transcripts. I then found themes that were similar and dissimilar in the mothers' reported experiences and related these to pertinent literature about this topic.

3.7. Data Analysis

As mentioned in the research design section, TA was used as the method of analysing the data for this study. TA was beneficial in highlighting any prominent themes that stood out from the mothers' reported experiences, as well as any differences in the experiences between mothers. Braun and Clarke (2006) provide clear guidelines for analysing data using TA and highlight the advantage of flexibility that TA achieves when analysing data. The six steps proposed by Braun and Clark (2006) that were followed are:

Step 1: familiarising yourself with your data

Step 2: generating initial codes

Step 3: searching for themes

Step 4: reviewing themes

Step 5: defining and naming themes

Step 6: producing the report

Step one involves engaging with the data collected in order to familiarise oneself with it and understand it, which can be done by reading the transcripts a number of times. Step two involves determining the initial codes that I could use to make sense of the data collected. The third step in TA includes reading the transcripts and finding specific themes from the participants' spoken words, or even sorting the codes into the possible themes. Step four simply relates to refining the themes that were found in step three. Step five consists of giving these themes a name and refining them further. The final step in TA is the end result in the form of an analysis of the data and a written research report (Braun, Clarke & Terry, 2014).

The current study and its research questions were likely to involve each individual retelling their stories or experiences, which were verbally narrated during their interviews (Richie, 2003). Consequently the best method of analysing all of the transcripts was by searching for themes in the mothers' experiences that were similar or dissimilar, through TA. This inductive method of data analysis helped answer the research questions of the current study in the best way possible. TA was used in an inductive manner as coding and the development of themes from the eight participants' interview transcripts were directed by the content of the data as opposed to being directed by existing concepts (Richie et al., 2003). Although flexibility remains an advantage for

TA, there is a limitation which needs mentioning. Specifically, this limitation relates to the researcher interpreting the data and organising it in a way that may be incorrect to the participant's experiences, and thus divergent to a certain extent (Braun & Clarke, 2006; Marks & Yardley, 2004). This will result in the researcher interpreting the data and organising the material under themes that make sense to him or her, instead of the meaning the participant intended for that information. However, it is possible to reduce such a limitation by providing direct quotes of the participants' reported experiences in the final research report. This is something I have done in the current research study, as well as try to develop themes from the content of the transcripts instead of having pre-determined ideas or themes.

To ensure that the findings of the current study reflect the research's aims, rigor was assured. Rigor, which is often essential in qualitative research, traditionally has been characterised by how valid and reliable the research findings of a study are (Sin, 2010). The following criteria was therefore followed in order to assure rigor of the research findings: credibility, dependability, authenticity, transferability and confirmability (De Vos, Strydom, Fouche, & Delport, 2011; Sin, 2010). Firstly, credibility aims to address the element of truth in the research findings and was achieved by selecting participants through a purposive sampling technique. In addition, by ensuring reflexivity in the study also aided in upholding this criterion (Krefting, 1990). I aimed to maintain reflexivity by reflecting on my own experiences and thoughts throughout the research process. Reflexivity will be discussed in more detail below. Dependability was achieved by cross-examining the findings of the research study. Cross-examining the interview transcripts helped me to look at the data in different ways and ensure I did not reach any premature conclusions about the information and possible themes before writing up the final report. Thirdly, authenticity was maintained by applying Braun and Clarke's (2006) six steps of TA to highlight themes in the

participants' reported experiences. Transferability relates to the applicability of the current study's findings in other contexts, which was fulfilled by providing detailed descriptions of the procedure of the current study. Finally, confirmability is concerned with the findings being biased to the researcher's motives for the research study (Sin, 2010). To ensure that confirmability of the results was achieved, direct quotations of the participants' accounts were used in the final report.

While the above criteria provides insight into ensuring the trustworthiness of the research findings and therefore, maintaining rigor, Sin (2010) offers an interesting way of ensuring validity, reliability and generalisability of the findings in a qualitative study. While these three criteria are usually employed by quantitative research studies, Sin (2010) argues differently. Validity in a qualitative research study can specifically be ensured by clarifying and confirming the conceptual meanings provided by the participants' reported experiences. In addition, reliability (which relates to how replicable the findings of the study are) can also be achieved through qualitative methods. Sin (2010) contends that if a researcher practices interpretive awareness then not only will the reader be able to judge the research process as a whole but he or she will also be able to assess how reliable the findings of the study are. Interpretive awareness can be achieved by being aware of any changes in thoughts or experiences. This also includes meticulously documenting the research process and in particular, the process of analysis (Mays & Pope, 1995). Finally, generalisability (or possibly better suited for qualitative studies, transferability) refers to the degree to which the findings of the study can be applied to other contexts. Sin (2010) claims that this type of generalisability is often referred to as external validity, and can be ensured by providing readers with sufficient information about maternal perceptions of the relationship between CP children and their siblings in order to make their own conclusions and inferences.

3.8. Ethical Considerations

Once approval from the University of the Witwatersrand Psychology Department's internal ethics committee had been acquired, I contacted mothers who took part in the study conducted in 2014. In addition I contacted the physiotherapist to ask if she could gain permission from any new mothers for me to contact. Once the mothers had agreed to participate in the study, a time and day for the interview was arranged. At the start of the interview participants were given the Participant Information Sheet to read (Appendix 1) and then were asked to sign the two consent forms attached (Appendix 2). While full anonymity could not be assured in this study, as I met the mothers personally, no personal information was used in the final research report. Thus, final anonymity in the written report was assured. In addition, mothers were given pseudonyms (such as Participant 1) so that readers were unable to link specific quotes with each mother. In terms of confidentiality, I again knew who the participants were, and in some cases had gone to their homes or places of work in order for the interview to take place, however none of this specific information was shared in the final report.

Due to the fact that I asked mothers to give their personal experiences, the content may have potentially raised some sensitive topics for the participants. This did not appear to happen for any of the mothers interviewed as all were comfortable with ending the interview. Nevertheless, the mothers were made aware of the free counselling services offered on the Participant Information Sheet (Appendix 1) if they felt the interview had elicited emotional effects for them. In addition, if it was needed I would have provided a debriefing session for the participants at the end of each interview. However, this was not necessary. Debriefing is worthwhile in order to determine if the interview has elicited any sensitive thoughts or feelings for the participant. Such thoughts and emotions could have been discussed with me after the interview. In addition, a

debriefing session allows for the closure of the participant's experience (Qu & Dumay, 2011). Below are a number of debriefing questions that could have been asked to the participants when finishing the interview:

1. How did you experience the interview?
2. Did the interview raise any emotional feelings for you that you would like to discuss further?
3. Is there anything else you would like to discuss about the interview?
4. Are you feeling alright to finish with the interview now? (If no, how else can I help you?)

In addition, it was also explained in the Participant Information Sheet (Appendix 1) that the mothers had the right to withdraw from the study at any time, and could choose if they did not want to answer any question(s), with no consequences. While no identifying information was used in the final report (and only pseudonyms were used), the participants were made aware that direct quotes from their interviews would be used for analysis purposes and in the final report. The audio recordings from the interviews are kept on a password-protected computer, with only myself and my supervisor having access to them and these will be deleted after five years. Finally, the dissemination of the final report was explained to each participant and that they can request the results if they so wish when the study has been completed. For those participants who were interested, I took down seven participants' contact details (email addresses) at the end of the interview and a copy of the final report was emailed to the participant once the study had been completed. In addition, participants had my details, as well as my supervisor's details (provided

on the Participant Information Sheet), so that they could contact either of us at a later stage if they wanted to read the results of the study.

Reflexivity:

Due to creating the interview schedule myself, I took into consideration the role that I played in every part of this study (i.e. data collection, interpretation of the data, as well as in the writing of the report). Reflexivity relates to self-awareness and self-reflection, and this evaluation of oneself is undertaken regarding the researcher's own experiences (Morrow, 2005; Shaw, 2010). These understandings in turn could influence the outcome of the research process. Reflexivity often needs to be acknowledged at every stage throughout a study. A reflexivity journal helped to track any changes in thoughts, feelings or behaviours that I experienced throughout the data collection process and therefore, that may have affected my interpretation of the data. As Hand (2003) contends, it is sometimes challenging to separate the researcher from the study and being reflexive acknowledges this relationship between the participant and researcher. However, while some may question the subjectivity of the researcher in qualitative research, one could also argue that the researcher may contribute different insights about the topic (Hand, 2003). I was able to manage this process effectively through supervision with my research supervisor as well as in my own psychotherapy.

Specifically, I found it difficult that some mothers were apprehensive and not as willing to share information regarding their families and children. This resulted in these mothers providing brief answers and not responding when follow-up questions were asked. Again, I found it helpful to raise this in my own research supervision and psychotherapy. After reflecting on this, I have wondered if it may be possible that some mothers have not come to terms with their child's CP

diagnosis and are still struggling to accept this. Furthermore, I noticed that during the interviews many of the mothers would stray from answering the question asked. Instead of discussing the sibling relationship, it was evident that many started to tell me about their CP child or their child who does not have CP. I tried asking the question again in such instances, but at times it was still difficult to retrieve specific information regarding the sibling dynamics. Thus, I have tried to remain cognisant of this when analysing the transcripts. In addition, it was evident that some mothers tried explaining how their children's sibling relationship is similar to that of non-disabled children. However, their responses then changed as they explained that the sibling relationship is actually different to other siblings, in that they are closer and more caring for one another. This is a direct contradiction to what many participants mentioned earlier in their interviews. Through research supervision consultations, my supervisor and I discussed and contended that such mothers may be psychologically defensive due to the guilt they feel for their one child having CP and that their children cannot share a similar relationship to other, non-disabled siblings. Nevertheless there were themes found in the transcripts which I almost anticipated, such as the constant battle for attention from parents; the impact of the CP on the sibling relationship; and how it affects each child in the sibling dynamic. However, there were some themes which I was surprised to discover, such as the experienced feelings of guilt versus jealousy; and how mothers explained their children were similar to other, non-disabled siblings but then changed this point of view, stating that they are in fact different to other siblings.

In addition, it is important to reflect on and remain cognisant of a number of issues. First, I am not a mother, I am not disabled, and nor do I have a sibling with a disability. These factors may have influenced the collection of data as well as how I interpreted the responses from each participant. Specifically, it is possible that I struggled to fully understand what each participant

was attempting to describe during their interviews regarding their children's sibling relationship. However, by including direct quotations in the results and discussion chapter this limitation was attempted to be controlled for. Further, while I am not a mother nor do I have a disabled sibling, I have grown up with a sibling and I have been mothered. These experiences may have contributed to my understanding of the results and provided some knowledge into what the participants were exploring during our conversations. Importantly though, I reflected on these issues throughout the research process and referred back to the pertinent literature related to this topic in order to fully understand the findings of the current study.

Second, it is important to reflect on how and why the topic of the current research study was chosen. I am interested in this field and this specific topic as a childhood friend of mine has a sibling with CP. Therefore, I have had the first-hand experience of knowing and observing the sibling relationship between them. Further, due to my passion in the Educational Psychology field, I believed it would be worthwhile to explore this sibling relationship from the mother's perspective, as this would highlight a crucial perspective. As mentioned in the above discussion, this topic has not been conducted in South Africa yet, providing me with additional motivation for the current study. Overall, I think this passion and desire to explore the relationship between mothers and their children, and specifically the relationship between siblings, has developed and contributed to my interest for the current study. While this may have led me to anticipate certain themes I thought I would find within the data, I believe I have explored my subjectivity thoroughly during each phase of this research process. This exploration has taken place both within my own on-going psychotherapy, as well as with my research supervisor. Thus, I believe the current research study will add value to the field of Educational Psychology, as well as Psychology in general.

To conclude this chapter, the principles of beneficence and non-maleficence should be raised. Due to the sensitivity of the work conducted in the Psychology field, it is important to ensure that during research studies researchers act in the participants' best interests (beneficence), and ensure that no harm comes to them (non-maleficence) at all times (Andersson et al., 2010). The current research study aimed to maintain as far as possible the participants' best interests and above all do no harm to those who took part in the current study. Further, the study aimed to achieve this by ensuring each participant understood and acknowledged that they could withdraw from the study at any point as well as refuse to answer any question(s) they did not want to. Additionally, I tried to ensure the interview schedule contained suitable questions so that no harm would come to the participants.

Chapter Four: Results and Discussion

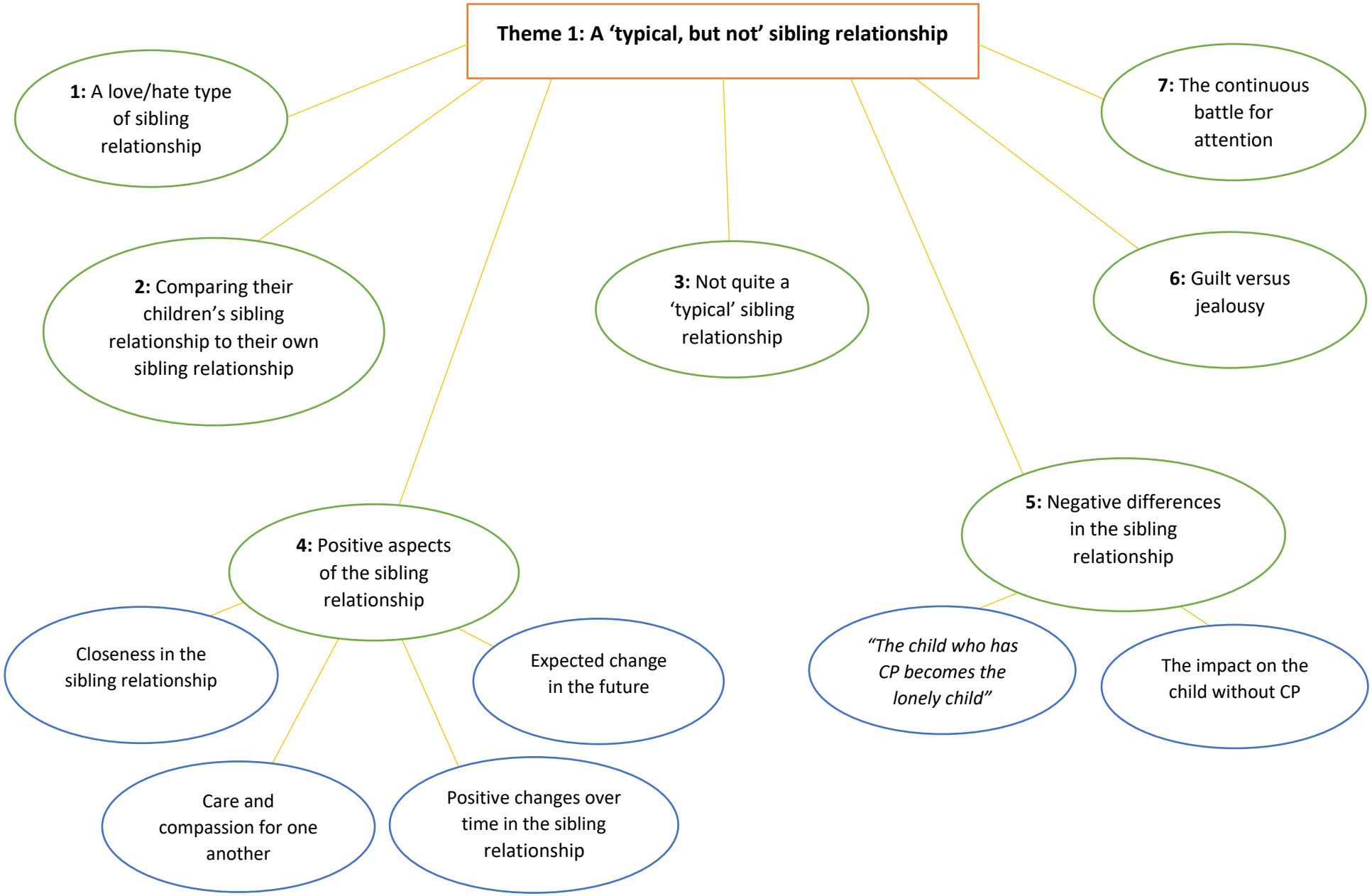
After transcribing and interpreting the eight interview transcripts, it is clear that a number of prominent themes are present from the participants' responses. These will be discussed accordingly.

Before starting this discussion of the themes, it is important to introduce the participants and their demographic information. Participant one (Sharon) is a 44 year old, White female who has three daughters. Her child with CP is a twin and both girls are 12 years old, while her other daughter is 13 years old. Her daughter's CP is mild and she is only affected physically. Participant two (Sue) is a 30 year old, White female and also has three daughters. Her child with CP is also a twin and both girls are 4 years old, while her other daughter is 5 years old. Her daughter is also only mildly affected and physically impaired by CP. Participant three (Michelle) is a 39 year old, White female who has two children. Michelle's daughter is 10 years old and her son with CP (8 years old) is severely affected, both mentally and physically. Participant four (Karen) is a 41 year old, Indian female with two children. Her son is 10 years old and her daughter with CP (18 years old) has severe physical impairments. Participant five (Wendy) is a 49 year old, White female with three children. Her son is 20 years old, her one daughter is 15 years old and her other daughter who has CP, is 13 years old. Her daughter is only physically impaired and this is mild. Participant six (Sam) is a 38 year old, Indian female who has two children. Her daughter is 10 years old and her son with CP is 7 years old. He is only physically affected and she describes his CP as mild to moderate. Participant seven (Sharika) is a 39 year old, Indian female with twin daughters, who are 9 years old. She describes her daughter's CP as only mild which affects her physically. Lastly, participant eight (Rebecca) is a 45 year old, Black female with two children. Her son is 17 years

old and her daughter with CP is 7 years old. Her daughter's CP is severe, affecting her both physically and mentally.

Now I will discuss the prominent themes evident in their stories. I begin by illustrating the numerous themes in a diagram below so as to give the reader a sense of how the various themes and sub-themes relate to one another.

Diagram introducing the themes and sub-themes



Theme 2: The mother's involvement in her children's sibling relationship

Theme 1: A 'typical, but not' sibling relationship

The first and most prominent theme that all eight mothers describe is the fact that even though one of their children has CP, they see their children as having a 'typical sibling relationship'. Regardless of the disability one of their children is currently living with, in one way or another, they still view the relationship between their children as similar to other sibling relationships where there is no disability present. However, in the many sub-themes that are to follow it becomes clear that their children's sibling relationship is 'typical, but not' quite as typical to that of other, non-disabled siblings. Although, this will be expanded on later in the discussion, it is evident that certain elements of this sibling relationship are more unique and pronounced than in other, non-disabled sibling relationships. As mentioned above in the reflexivity section, it is possible that some of the mothers are defending against their children's sibling relationship being different from other, non-disabled children. Thus, they have tried to portray their children as having similar relationships to those of other, non-disabled siblings. More importantly, the severity of the child's CP plays a crucial role in the sibling relationship that is formed between these children.

Focusing on the 'typical' sibling relationship identified, Sam highlights that she does not *"see any difference, just because he's CP their* (her children) *relationship isn't any different."* Rebecca mentions that she thinks *"the bond that they* (her children) *share as siblings and what they give each other is actually common in what you see with other sibling relationships."* These mothers describe their children's sibling relationships as normal when referring to the way they interact with one another. For instance, Sam mentions that her children have *"a normal sibling relationship so there's arguments and so on but there's a closeness that they have…like typical siblings."* Sharon's statement agrees with Sam's, as she mentions *"they play beautifully together, they fight like typical siblings…and in that way they are, I feel typical siblings."* It is therefore

evident at this point that mothers perceive that their child's CP does not significantly influence the development of a sibling relationship. Moreover, while their children may possibly have a 'typical' sibling relationship, the discussion below will highlight that these mothers may also be defending against the fact that their children do not have a typical sibling relationship.

1.1 A love/hate type of sibling relationship

While mentioning that their children have a normal, 'typical' sibling relationship regardless of the fact that one of their children is growing up with a disability, all eight mothers describe that their children have a love/hate kind of relationship. This relationship is described as one in which their children are able to fight and argue, as well as love and care for one another. According to the participants this love/hate aspect is indicative of a 'typical' sibling relationship. Sharika explains, *"they* (her children) *fight and they want to kill each other, but they love each other and can't live without each other…so very normal."* Furthermore, Wendy mentions that her children *"have this love/hate relationship where some days they absolutely hate each other and then there days where um, they just love each other…the typical thing…I think it happens to all families."* I think it is important to question whether this 'hate' their children have for each other is related to the CP or not. I contend that this hate is to a certain extent more pronounced because of the challenges faced in relation to one of the children having CP. Lobato et al. (1991) highlight how siblings of children with disabilities may experience more aggression and anxiety towards one another compared to children whose siblings are not disabled. Thus, although these siblings may fight like typical siblings, the mothers of the current study may have been apprehensive to share detailed negative experiences, and instead highlight how they have a 'typical' sibling relationship. Evidence further suggests that these siblings experience more rivalry than non-disabled siblings, which ultimately can lead to increased conflict or 'hate' between them (Knecht et al., 2015). Michelle describes the

interactions between her two children as *"similar* (to other, non-disabled sibling relationships) *in that they keep each other company and also in that they get a bit of sibling rivalry, like normal children as well."* Interestingly though, Knecht et al. (2015) argue that siblings experience conflict due to the non-disabled child having to help his or her disabled sibling, while trying to take care of his or her own needs. Karen explains the relationship between her children, *"they can fight like it's nobody's business…that is absolutely normal and I've accepted that a long time ago."*

1.2 Comparing their children's sibling relationship to their own sibling relationship

Moreover, when mothers were asked about the relationship between their children most of them refer to the relationship they have with their own siblings to describe this. When explaining her own children's relationship, Sharon mentions *"…and in that way they are, I feel typical siblings…as they fight for attention, which I think is typical…my brother and I did the same thing."* Karen also explains how her daughter with CP was telling her that she does not want her younger brother to get involved, *"when I find a boyfriend I don't want him to come between and don't tell me what to do…you see, I was the eldest and I had my brothers so much smaller than me – always wanting to be there, wanting to interfere."* This may be indicative of Karen's attempts to understand her daughter's concerns about her brother's involvement by relating it to what she experienced with her younger brothers. While there is a lack of literature focusing on how mothers compare their children's relationship to that of their own relationship with their siblings, Dunn (1985) makes an important point arguing against such a comparison. Dunn (1985) contends that regardless of a disability, the relationship between a particular pair of siblings is so different to that of any other siblings and therefore it is difficult to compare such relationships and state that they are similar. In addition, when speaking about how her children fight Karen mentions:

> *"…that is absolutely normal and I've accepted that a long time ago because I've got a sister and two brothers so I've seen it…you can be so close and then in the next moment you'll fight over certain things, whether it's clothes or toys, it's a movie – what you want to watch on TV, absolutely."*

When explaining the love/hate interactions between her children, Sharika states "*…you know very normal…having siblings as well, I mean I come from a big family."* Lastly, Sam suggests that *"they play a lot together and they'll find games that they both can do…and ya, I just think when I look at, I've got two older brothers and the relationship is very, very close so I compare it to them…but ya, I don't see any difference."* It is evident that Sam does not perceive any difference between her children's sibling relationship and the relationship she has with her siblings. Further, explaining how her children's sibling relationship is 'typical' to that of other, non-disabled siblings. Thus, while the above discussion provides important insights into how mothers perceive the relationship between their children by comparing it to that of their own siblings, it is difficult to compare such relationships and argue that they are the same.

1.3 Not quite a 'typical' sibling relationship

When asked further, all eight mothers are able to offer examples and provide explanations of how the sibling relationship between their children is actually different to that of other siblings. This highlights the perception that their children's sibling relationship is not as 'typical' as that of other children and therefore, a contradiction to this first overall theme. While mothers may want to emphasise that their children's sibling relationship is similar to that of other, non-disabled siblings, many mothers realise and cannot deny that their children have a different relationship to other, non-disabled children. Thus, highlighting the defensiveness mentioned above regarding their

children's sibling relationship, and the fact that mothers may not want to share negative experiences between their children. In addition, mothers may feel guilty that their children have a different sibling relationship and therefore, are trying to argue that their relationship is actually similar. Nevertheless, it is this uniqueness to their children's sibling relationship that may be a possible reason for the contradiction in the themes of the current study. Whether this is a positive or negative difference, each mother is able to identify some variation in the relationship their children share compared to other children. This difference relates back to the fact that one of their children has CP which results in a *"relationship that is so unique"* according to Sue. Further, Rebecca states *"but it's a different kind of relationship."*

One of the main positive differences between their children's sibling relationship compared to other siblings is that *"everyone's always there helping* (the child who has CP)", states Wendy. Ali and Sarullah (2010) confirm that children who have siblings with a disability do indeed have a different kind of experience with regards to the sibling relationship they share, due to the disability. This ultimately suggests that sibling relationships in which one of the children has CP, does not always involve independent individuals, and instead, it is one that involves constantly thinking of the other person in the sibling relationship. Thus, growing up with a sibling with CP may create a dependency between siblings as the child with CP will sometimes need extra help and care from his or her family, which is not always found in non-disabled sibling relationships. Magill-Evans et al. (2001) claim that the physical and intellectual impairments as a result of a disability limit the independence in sibling relationships due to this additional and continuous care that is required.

1.4 Positive aspects of the sibling relationship:

1.4.1 Closeness in the sibling relationship

Evidently, most of the participants' positive perceptions of their children's relationships compared to other sibling relationships related to the fact that their children constantly care for and help their sibling with CP. Sam suggests *"being a girl, she's* (her daughter without CP) *a lot more caring and considerate…she's completely aware of his physical disabilities, she doesn't always understand it but they're very close, they've got this very nice, sweet relationship."* Furthermore, she describes her daughter as *"constantly encouraging him to walk and if, when he does take a few independent steps she videos him or you know, it's like a big thing."* This quote is indicative of the type of relationship between siblings when one child has CP and how the positive experiences between them differ to those children who do not have a sibling with a disability such as CP. As noted at the beginning of this report, Roper et al. (2014) argue that mothers raising a child with a disability evaluated their children's sibling relationships as being more positive than mothers who are raising typically developing children. This positive relationship is clearly evident in the current research study as well due to the closeness such siblings share. Importantly, mothers again may not want to highlight any overly negative experiences and rather describe their children's sibling relationship more positively compared to other sibling relationships, suggesting a certain level of psychic defensiveness. Furthermore, Wendy relates *"they're* (her two children who do not have CP) *always looking out for her* (their sibling with CP) *and thinking a little bit more outside of the box, where with other families they don't have to think about any obstacles, you know?"*

Alternatively, when comparing her daughters' sibling relationship to other siblings, Sue states *"I definitely think they've got a stronger bond, definitely…and I think they do help each*

other a lot more…they stand up for each other." Sue contemplates that it is difficult to describe how they have a similar relationship to other siblings, *"I actually can't, it's such a unique thing…so I actually can't, I think they're so different".* She continues, it is this uniqueness to their relationship *"that makes a difference – when you've got a sibling so close."* Importantly, it is interesting that some mothers are able to highlight similarities, whereas others believe their children's sibling relationship is completely different to that of non-disabled siblings. It is possible that some mothers are psychologically defending against the fact that their children are different to other siblings and possibly feel guilty that their children are not similar to other siblings or have that 'typical' relationship. Reichman, Corman and Noonan (2008) confirm this statement as often mothers of disabled children will experience feelings of guilt and self-blame. Mothers who have a child with CP have been described as guilt-ridden (Magill-Evans et al., 2001). Mothers may therefore defend against any negative experiences between their children to compensate for this guilt they may feel. Sharika substantiates this claim in her interview as she reflects *"I used to feel guilty all my life because I used to think it was my fault you know…until I realised, no it wasn't, it was meant to be."*

Michelle's response is in agreement with the above statements because even though her children fight, she reflects *"their sibling rivalry is probably less than what I see in, with normal kids."* In addition, Sharon mentions *"I don't think there is the same resentment that typical siblings would have"* but rather, *"it is a closeness that you don't find with typical siblings…it's something just the two of them have and that they share."* Some participants emphasise this difference between their children's relationships compared to those children who do not have a sibling with CP as a positive experience. It is this element of 'closeness' that is perceived as different to those relationships where both children are able-bodied.

1.4.2 Care and compassion for one another

It is evident that the type of sibling relationship described thus far is dynamic and at times, complex. However, a positive bond has still formed between such siblings and this relationship is different to other sibling relationships. Interestingly, evidence suggests that the relationship between a disabled child and his or her sibling(s) is actually more positive compared to non-disabled siblings (Stoneman, 2001). Another main positive aspect highlighted by all eight mothers is a caring nature of the relationship between their children. Although it is mainly the children who do not have CP that are helping and caring for their CP sibling, this is reciprocated as well. For instance, Rebecca mentions *"my daughter doesn't understand a lot, but you see affection towards her brother and you see affection from her brother towards her."* In addition, Sam states *"if he's in a play area and if he needs to go, she can take him to the toilet on her own…so I think she's very capable of being there and knowing exactly what to do."* This ability to help their sibling who has CP is indicative of another difference between these children's sibling relationships and siblings who do not have CP. These children who have a sibling with CP are not only caring for their sibling but they also take responsibility for them. Stoneman (2001) claims that interactions between disabled children and their siblings are more nurturing and prosocial compared to non-disabled siblings. It is this positive, caregiving role that I contend benefits and contributes to the sibling relationship, and the attachment formed between them. It is argued that children of disabled siblings who take on additional caring roles and responsibilities are noticeably more empathic and understanding of differences than in instances of non-disabled siblings (Nielson et al., 2012). Considering this, Sharon reflects on the positive aspects between her children, mentioning *"they can be very warm to each other and they can be very nice to each other, which is beautiful."* Even though Sharon's daughter with CP experiences feelings of jealousy towards her non-CP sister's

abilities, she also highlights how her daughter with CP is proud of her sister's achievements. For example, she reveals that her daughter with CP says her sister "*is so clever*", but according to Sharon *"there's a lot of pride attached to the fact that her sister is so smart."* Sharon perceives this feeling as not only involving jealousy, but also as genuine feelings of satisfaction and happiness for what her sibling has achieved, which may positively influence the sibling relationship.

In agreement with the above discussion, Sharika states that her daughter often *"wants to be maternal"* to her sibling with CP. Whereas Wendy argues that her two children who do not have CP are *"always looking out for her* (their sibling with CP)*…they try and treat her as normal as possible…it's part of us to always look out for her, for us it's just a natural thing."* Interestingly though, Stoneman (2001) contends that if these caregiving roles are too demanding, this may result in more conflict between such siblings, which may relate to the 'hate' mothers notice between their children. Karen also speaks about the caring nature of her children's relationship as she claims *"they stick together…they have their ups and downs but I notice the difference."* Karen highlights how her children's sibling relationship is different to that of other siblings in that they are more caring and protective towards one another than in the case of non-disabled siblings. Ali and Sarullah (2010) confirm that care-giving activities are more evident between siblings when one child has a disability. While I postulate all siblings care for each other, this positive aspect may be more pronounced in these sibling relationships as the caring element has a lot more attached to it. This caring element involves helping their CP sibling with basic activities, such as bathing, feeding and dressing. In essence, the care these siblings offer may be more pronounced to non-disabled siblings as they are providing the assistance which their CP siblings cannot fulfil themselves. This

may not be evident in non-disabled siblings as these children will be able to take care of their daily needs independently.

Michelle explains that it is difficult for her children to communicate and interact because her son's CP is quite severe, but she expresses that her son is *"quite devoted to her* (his sister without CP)*, he always asks for her and he likes to sit next to her…to try and participate in whatever she's doing."* Michelle relates *"even though he's disabled, they still keep each other company…even though they can't do all that much together, they like to be together."* Finally, Sue reflects on this caring aspect of her children's relationship when mentioning *"they are very, very close and the twins look up to their older sister."* Thus, up until this point it seems quite evident how dynamic and complex the relationship between CP children and their sibling(s) is, according to their mothers. Importantly, Ali and Sarullah (2010) argue that it is these care-giving roles and shared activities that contribute to the development of the sibling relationship. Although there are aspects that, at times may negatively influence their relationship I contend that it is evident there is a caring and compassionate nature between such siblings.

1.4.3 Positive changes over time in the sibling relationship

Importantly, another sub-theme that appears in the mothers' responses is the change in their children's sibling relationship. More specifically, most participants mention how their children's relationship has changed over the years and how they think it will continue to change as they grow older. Wendy highlights that her children's sibling relationship is changing for the better over the years, in that *"it's definitely improved."* Sharika mentions *"they've become very close and I think they've learnt to accommodate each other, when they need that space."* Thus, to a certain extent Sharika describes how her children continue to mature and develop their sibling relationship as

they get older. Mulroy et al. (2008) substantiate that children with disabled siblings are described as more mature than their peers who do not have a sibling with a disability. Karen speaks about her son who does not have CP and explains that *"he's become so helpful to her* (his sister with CP)" when reflecting on how her children's relationship is changing as they grow older. Sue also comments on the noticeable positive change in her children's sibling relationship stating that,

> *"as the twins got older it was easier for her* (their older, non-CP sister) *to play with them or relate to them…I think when they hit three and she was four their relationship changed 'cause now they could start playing together…so I would say yes, it's definitely changed over time."*

Further, Sharon relates that as her children have gotten older "*they've become closer…because of the play therapy she's* (her daughter with CP) *become more and more yielding, and the more yielding she's become the better the relationship's become with* (her sisters)". This suggests that play therapy has helped Sharon's daughter to develop her understanding of what CP is, what it means to grow up with such a disability, and how this in turn has helped with forming a positive relationship with her twin sister and older sister who do not have CP.

Interestingly, three of the participants raise the idea that their children who do not have CP have started to understand certain aspects of their sibling's disability as they have grown older. Their children are then able to acknowledge why their sibling is unable to do certain things that they can do, and therefore are more accepting of the diagnosis of CP, and ultimately of their sibling. Nielson et al. (2012) confirm that the more accepting a child is of their sibling's disability, the more positive their relationship is likely to be. Sam mentions that her daughter who does not have CP has *"become a little bit more aware of it"* when speaking about her son's diagnosis. Michelle

on the other hand states her children's sibling relationship has *"improved as they've gotten older…she's more patient as she's gotten older and more understanding"* of her brother's disability. Rebecca also raises a similar point, that as her son who does not have CP is getting older,

> *"he's more understanding…as he's growing up and as they're both growing up he's becoming more receptive of her* (his sister with CP) *and more accommodating and more understanding and even the emotional bond has really improved quite a lot."*

It is possible that by recognising and acknowledging this change in their relationship as they grow older, this could provide a better understanding of the relationship between CP children and their siblings. The above responses seem to indicate the complexity of the relationship between these siblings and how these siblings have to accept and cope with many additional factors due to the disability. Ali and Sarullah (2010) also argue that acceptance of a sibling's disability results in a stronger relationship between children and further, such acceptance is attributed to the increase in feelings of empathy and care between siblings. This provides siblings with the ability and patience to deal with additional factors present when growing up with a sibling with CP that may sometimes prove stressful. For these reasons, the additional challenges experienced may positively reinforce the sibling bond (Mulroy et al., 2008).

1.4.4 Expected change in the future

Interestingly, the eight mothers also mention how they think their children's relationship might change in the future as they get older and *"will get stronger definitely"* as Sue mentions. Sharika concludes *"it's just going to get stronger – they going to kill each other as sisters normally do but it's going to get stronger."* This expected positive change appears in literature as Stoneman (2001)

highlights how the quality of relationships between disabled children and their siblings improves over time. More specifically, this relationship is described as growing more positively as children develop. However, I argue this is a normal desire for most mothers and many women wish for their children's relationship to strengthen in the future. Similarly, Stoneman (2001) contends that most parents hope that their children will enjoy each other's company and form a strong relationship that will continue into adulthood.

However, some of the participants showed concern as to what would happen when their children grow older. Sharika mentions later in her interview that *"they going to be very good for each other and I just really hope and pray for the positive…I think they need each other and I think that's what they going to rely on a lot."* This quotation identifies a potential positive shift and continued growth in the sibling relationship as they grow older. Wendy also mentions that she thinks her children's relationship will continue to change in the future however,

> *"you don't know 'cause they going to grow up and they'll become adults leaving the house, having their own lives and hopefully they'll still be there for their sister. Hopefully they'll still look out for her…stay the close family we are but you never know."*

I believe this aspect of staying close in the future is unknown for all sibling relationships as children grow older but may possibly be more pronounced for these siblings due to the disability and additional care needed. Moreover, Sharon discusses *"I hope it stays like that"* when explaining how her children have become closer over the years. Sharon relates how *"their relationship is so dynamic so I see it changing as things happen"*, indicating that the relationship changes regularly between her daughters. Karen also expresses her concern about her children staying close when they are older,

> *"I hope they become closer, I mean with them upset with each other and fighting with each other it's not serious, it's things that we grew up seeing and experiencing – typical…the main thing is I hope they stay close."*

At this point in the discussion, maternal wishes and desires about their children's sibling relationship is evident. Further, I argue that these wishes and desires play out in how mothers encourage and try to shape their children's sibling relationship when they are growing up. I speculate that mothers of such children may be trying to initiate and enhance the bond between their children so that this relationship will continue into the future. I relate this specifically to the caring responsibility of the non-CP children for their sibling with CP later in life when parents are no longer alive or able to care for the CP child. I assume mothers may be under the impression that non-CP children are more likely to take care of their CP sibling if they share a strong, positive relationship. Although related to a different disability, Mulroy et al. (2008) mention that the continued care from abled-bodied children for their sibling(s) in the future was the exact concern of parents who have a child with Down Syndrome. I will argue and expand on this further in the sub-theme to follow.

Alternatively, Sam raises the idea that she does not *"think anything will change"* as her children grow older. She thinks that her children are already so close and that her daughter is aware of her brother's disability. Sam's son who has CP has started experiencing seizures and her daughter has witnessed him having a seizure which she believes *"is something that has changed the relationship a little bit in terms of them caring a bit more for each other…but no, I don't think anything will change"*, when referring to their sibling relationship. Interestingly, Michelle narrates how her daughter is more patient and aware of her brother's disability but she seems unsure as to how this might change in the future. She claims *"I think as she gets older they probably will be…I*

imagine she will…I don't know if it'll change that much but she'll probably become more involved with other friends." In terms of Rebecca's children, she states that their relationship has become stronger as her daughter with CP has started to gain mobility and the ability to walk. In addition, she reflects that if her daughter *"starts with some verbal communication where she can say what she wants, then they can probably communicate as to who wants what and what they can do together…I think it will get stronger."* Nevertheless, I think the above responses all provide evidence in attempting to answer the first research question of this current study: How does a mother perceive the relationship between her Cerebral-palsied child and his or her sibling(s)? Mothers not only provide their perception of their children's sibling relationship as it is now, but they offer details of how this will change in the future.

However, there are also some negative aspects to this difference in sibling relationship that are highlighted in the mothers' responses. It is possible that these good and bad moments, and interactions the participants speak about are more pronounced in siblings where one child has CP. Thus, all siblings are likely to experience a love/hate relationship, but these interactions may be more exaggerated in relationships between a CP child and his or her sibling(s). Interestingly though, Stoneman (2001) reports on the mixed findings of sibling conflict when one child has a disability and suggests that some studies found increased conflict between siblings, while other studies reported less conflict compared to non-disabled siblings. Furthermore, Howe et al. (2011) claim that mothers may view arguments between children as more conflicted than the children do; thus influencing the perception of sibling conflict described in the current study. The continued discussion below aims to clarify further how the interactions between such siblings are more pronounced than those experienced between non-disabled siblings, according to maternal perceptions.

1.5 Negative differences in the sibling relationship:

1.5.1 *"The child who has Cerebral Palsy becomes the lonely child"*

It is the negative aspects or experiences that mothers indicate which may affect or influence the sibling relationship, thus making it different to those children who do not grow up with a sibling with CP. The discussion below therefore seems to show less defensives from the mothers in the current study as they were able to speak more openly about the negative experiences. One of the most prominent negative aspects when examining their children's sibling relationship is the fact that their child with CP is often unable to communicate and/or play with his or her siblings. When referring to communication or play, this differs between mothers where some refer to play and communicate like 'typical' siblings. However, other mothers relate this to their child's inability to communicate and play at all with his or her sibling. Therefore, this ability to communicate and/or play relates to the severity of the child's CP. Nevertheless, research indicates that children with CP do in fact play less with their siblings than other, non-disabled children do (Stoneman, 2001), which I anticipate has a negative effect on the amount of time siblings spend together. Michelle explains *"well, they can't play actively together and they can't really have a conversation like other siblings would have...I think it just restricts it a bit in that they can't play together as normal siblings."* Sam further highlights *"I think their games are obviously a bit different because of his disabilities…like you won't find them outside kicking a ball...but you'd find them playing some imaginary game."* Interestingly though, Sam communicates that *"they* (both her children) *don't realise it but obviously as parents we see it, you know there's certain things that they don't do because of him."* I assume that Sam is referring to the certain physical activities that her children cannot do together. Rebecca also reflects that,

> "*Cerebral Palsy makes it worse, the child who has Cerebral Palsy becomes the lonely child. There's a serious impact I think on social perception and on a social level because you already become prejudiced or neglected because you're* (the child with CP) *the one that doesn't understand what's going on."*

Rebecca's response is powerful and important to consider when exploring the relationship between such siblings. From her perspective, it is possible that a CP child and his or her sibling may struggle to form a relationship. This may be especially so when others assume the child with CP does not understand what is being discussed. It is possible some siblings may automatically not attempt to engage with their siblings if they are under the impression that he or she cannot follow and respond. Thus according to the mothers interviewed in the current study, their children's sibling relationship is affected by the CP child's ability or inability to play and interact with his or her sibling(s). Dallas et al. (1993) claim that CP children not only struggle to play and communicate with their siblings but they also struggle initiating any social interactions with them. Sue mentions that her daughter with CP sometimes has difficulty keeping up in the different games that her children play, *"in a negative, you know if they're playing tag… she's obviously slower and falls a lot."* Later she adds,

> *"…the difference is minimal, obviously like if there's certain things she can't do, she tries – that's why she injures herself so much, she is like in the wars you have no idea. She's fallen down stairs, she's fallen out of cars trying to climb in…she's trying to do what they're doing."*

This quotation is indicative of Sue's daughter wanting to keep up with her sisters so she can be included and interact with them but at times her mild CP prevents this from happening. Karen mentions that it is *"the physical part…they* (her children) *would be doing more physical things*

together, we would be doing more physical things together as a family if she was not in that condition." When the child with CP is unable to take part in activities that his or her sibling(s) are doing it is likely to influence the development of their relationship. These siblings' interactions are limited, which may impact the bond that develops between them. Karen later adds that her son who does not have CP would say to her *"tell her* (his sister with CP) *to come out and play with me or why can't we play ball outside? So that, that is the big difference to a normal family."* Therefore, not only do children with CP sometimes struggle to communicate with their siblings but they also have difficulty playing physical games which both affect the relationship that forms between these siblings.

Rebecca highlights how her daughter's inability to communicate and interact with her brother or other people for that matter, has a negative effect on her. Rebecca considers that the difference between her children's relationship and other siblings' relationships relates to,

> *"communication – that's what is affected, it's more communication. The affection is there but it's affecting them…engaging as siblings and talking to one another about expectations from one another or what the other one wants…so it's more communication issues.*

I contend that this above response by Rebecca highlights how the relationship between a CP child and his or her sibling is to a certain extent 'typical' due to the love/hate relationship experienced and that affection is evident. However, it is possible that this love/hate relationship manifests differently between these siblings due to the presence of CP. Further, it is likely that the CP child's inability or struggle to communicate and play with his or her siblings results in more conflict between the siblings, ultimately affecting the type of relationship that they form.

Rebecca also states,

> *"I think they* (children with CP) *also suffer from a little bit of depression these children because you know they just throw tantrums and you can see she's frustrated and sometimes you can see she wants to say something to people then it's like her words are trapped in her mind and no one is listening, no one can hear what she wants and that's when she gets frustrated."*

This quotation substantiates the previous response from Rebecca as children with CP are likely to become frustrated when siblings, parents and friends assume they do not understand and therefore do not listen to, or communicate with, them. This may negatively influence the sibling relationship if a child with CP feels as though their sibling is not trying to understand or listen to him or her. Later, Rebecca indicates that her son also struggles to understand what his sister is trying to say which strains their sibling relationship. Thus *"it becomes a bit challenging for these kids that are Cerebral Palsy, especially those with less comprehension because they don't get enough attention that they should from their siblings."* This response concurs with the above discussion, substantiating that if siblings feel that they are unable to communicate and understand their sibling with CP then they are less likely to interact with them. Therefore, children with CP receive less attention from their siblings. Importantly, research suggests that as the severity of a child's CP increases, sibling engagement and interaction decreases (Stoneman, 2001). This further emphasises that the severity of the CP plays a crucial role in the development of the sibling relationship and how often siblings interact with each other. Similarly, Karen states her son who does not have CP *"talks to her* (his sister with CP) *and he reacts to her very normal, unless he cannot understand her…then he tries to guess."* She adds *"but a lot of the times…we have to try and guess until we get what she's saying and that's how frustration gets in for her."* This suggests that if a child is unable to communicate and understand what their sibling with CP is trying to say,

they may have less interactions together. Trying to guess and understand what their sibling with CP is saying is frustrating for both children and may strain the relationship between them.

1.5.2 The impact on the child without CP

It is quite evident that the child with CP is sometimes limited in their ability to communicate or play with his or her sibling(s) due to their disability. This ultimately affects the relationship that is formed between these siblings from a young age. However, some responses from the participants indicate that their children who do not have CP are also affected negatively. Sources (Ali & Sarullah, 2010; Knecht et al., 2015; Williams, 1997; Wolfe et al., 2014) argue that a child who has a sibling with any kind of disability, including CP, is likely to be negatively affected. The sibling of a disabled child may develop a low self-esteem, experience feelings of loneliness, isolation, unimportance, rejection, anger and withdrawal. Often these children experience such feelings due to disabled siblings living in the home environment with them (Williams, 1997). However, I postulate that it is possible that such feelings may decrease once children are aware and understand their sibling's disabilities, as Ali and Sarullah (2010) also claim. Sharika tells about her daughter who does not have CP, stating *"we've sacrificed a lot and especially her sister…she's also growing and she's also a little girl."* Moreover, Sharika notices how her daughter who does not have CP,

> *"wants to be maternal to her at times, watch over her which I had to many times come and intervene because um, it's not been healthy for her…she doesn't need to take that responsibility and I've made her aware of it but it just comes naturally to her."*

Sharika's response identifies roles and responsibilities within this sibling relationship which are more pronounced than in relationships between non-disabled siblings. More specifically, there is

an evident element of protection which is present in many sibling relationships but seems more pronounced in this instance and evidently more one-sided. Thus, the sibling without CP is more often protective and helping of his or her sibling with CP. Dallas et al. (1993) agree as they found the child without CP is likely to take on the leadership and caregiving role compared to his or her sibling with CP. Sharon's responses mirror those of Sharika's, as she explains that her youngest daughter's reading abilities started to catch up with those of her daughter's. She further mentions that because her daughter without CP is *"exceptionally bright and has already caught up from a reading perspective…we just tried to hold her back and hold her back"* so that her older sister with CP could *"kind of get the upper hand."* Importantly, I believe this will affect the child without CP as she may feel she is unable to excel or is not supported by her family members, impacting her academic functioning and performance. Furthermore, this is then likely to have an impact on the sibling relationship if the child without CP is held back so that the sibling with CP does not feel incompetent. Although this may boost the CP child's confidence, this may have the opposite effect for the child without CP as he or she may start to doubt his or her abilities.

According to Sharon, this attempt by her daughter with CP to keep up with her siblings also influences the relationship between her children as her daughter with CP will often then try to be *"the mother figure, always tries to be the more authoritative figure."* Dallas et al. (1993) however, found a different dynamic as the sibling without CP often took a positive but more controlling stance in the sibling relationship. Nevertheless, Sharon mentions that she does not want her daughters who do not have CP to feel limited in anyway, explaining to her daughter with CP *"I'm not prepared to hold back your sister because she's able to do stuff that you aren't able to do."* Sharon also realises that she *"can't keep on saying to her sisters 'you have to look after her'…I want them in themselves to do it but ya, I can't force them…so that's been really, really*

tricky." This aspect of voluntarily caring for their CP sibling is an important aspect to consider about the sibling relationship and is again indicative that some mothers try help their children develop a relationship and increase their interactions. The reasons for mothers encouraging a relationship between their children will be expanded on later in this discussion.

Therefore, it seems evident that these mothers are to a certain extent trying to help ensure that their children form a relationship that will continue into the future. When speaking about her two children, Sam mentions that *"because of his physical disabilities he often relies too much on her* (his sister without CP)*…so as parents we've got to always make sure that he is pulling his weight."* Furthermore, she adds *"I think there is a bit of a burden on her…she's the only child that's able-bodied but we've got to constantly remember that he* (her son with CP) *can try."* Sue discusses with her daughters who do not have CP, saying *"listen, you understand what's going on with your sister…and I don't always want to do that because she* (her daughter without CP) *also has opportunity to say what she feels and must get out her frustrations rather than feel like I'm always protecting* (her daughter with CP)." Interestingly, the sibling relationship may also be affected if the child without CP feels as though he or she is not allowed to voice his or her feelings. Younger siblings may view their parents as 'protecting' or favouring their sibling with CP, straining the relationship between the children. Lastly, Rebecca speaks about her 17-year-old son who does not have CP, and the relationship he has with his sister stating that,

> *"there's the 17-year-old one who wants to do stuff and he can't do anything because we're probably always saying 'but she's the needy one, she's the Cerebral-palsied one, you are the ok one so you need to understand'."*

It appears that there are a number of factors that can influence the sibling relationship between a child with CP and his or her sibling(s). This may be due to the sibling with CP not receiving as much attention from his or her sibling(s) and/or due to the negative impact on the child without CP. These experiences will have an effect on, and may strain, the sibling relationship. It is also evident that these siblings do have a 'typical' sibling relationship to a certain extent, but many elements and interactions are more pronounced as a result of the presence of CP. I believe it is evident how the above sub-themes contribute to the first two research questions that this current study aims to answer. First, the sub-themes describe in detail how mothers perceive their children's sibling relationship. Second, a child's CP has a noticeable effect on the sibling relationship compared to non-disabled children's sibling relationship, and aspects of this relationship are more pronounced when the child's CP is more severe.

1.6 Guilt versus jealousy

Another prominent sub-theme within the theme of a 'typical, but not' sibling relationship raised by some of the participants is the feeling of guilt versus feelings of jealousy that they observe between their children. It is clear from the interview transcripts that the children with CP are often jealous of their sibling(s) who can do more than them physically and/or mentally. In contrast to this, the children without CP have voiced to their mothers that they feel guilty for being able-bodied compared to their CP sibling who may be more physically and/or cognitively limited. This in turn would likely transpire in the sibling relationship as the child with CP may envy his or her sibling who is more capable than him or her. Further, the sibling without CP may try to overcompensate due to feeling guilty that he or she is able to do more. Ultimately, this would influence how the siblings interact with one another and the type of relationship they form. For example, Karen highlights that her daughter with CP and her son are close,

> *"but recently she's been telling me she's jealous of him…because he can do uh, physically does more, and because her disability is such that she cannot speak clearly and cannot move, she can't do all of those things so when he does something she gets upset…she gets upset and you can see it in her, on her and she says 'I'm sorry I'm jealous' but she acknowledges it...now she verbalises it."*

There is jealousy in all sibling relationships but the above response indicates that the jealousy is unique in these sibling relationships as it is aimed at their physical and/or cognitive limitations due to the presence of CP. However, I argue that it is evident that the experienced feelings of guilt are especially unique to this sibling relationship and may be less pronounced in non-disabled sibling relationships. Sharika mentions how her daughter with CP *"can see that she's not doing stuff and she's very aware of it, saying 'but mommy I can't do that because everyone else can'"*, including her able-bodied twin sister. Sam also raises the same dynamic in her children's sibling relationship by explaining that her son with CP *"gets a little bit jealous…I think he maybe gets a bit frustrated because he can't do everything that she* (his non-CP sibling) *does."* Sharon states that her daughter with CP *"is jealous because of the fact that her sister can do so much and she's not able to do the same kind of things."* This is likely to influence the sibling relationship as the child with CP is unable to take part in the same activities as his or her sibling(s). This may negatively impact the relationship if they are unable to spend as much time together as that of other siblings. Furthermore, Sharon states *"they fight like typical siblings but then again there's the side of this guilt and jealousy and which, I think normal siblings have but I think theirs is more pronounced."* Interestingly, a study (Knecht et al., 2015) found that non-disabled siblings experience feelings of jealousy (as opposed to guilt) due to their disabled siblings receiving more attention from parents. I will expand on this type of jealousy in the sub-theme to follow.

Alternatively, according to the mothers interviewed in the current study the siblings who do not have CP experience feelings of guilt. Michelle states that her daughter who does not have CP sometimes feels frustrated and then guilty *"because we* (the family) *can't do everything she* (daughter who does not have CP) *wants to do because he can't or it's too difficult to get him there."* Although different to the results of the current study, research on children with Down Syndrome interestingly finds that non-disabled siblings did not experience these feelings of guilt (Mulroy et al., 2008). Instead, non-disabled siblings were aware of their abilities, felt more grateful for their health and did not take this for granted, highlighting how this guilt may be specific to and more pronounced for siblings in the current study. Sharon mentions that her CP daughter's able-bodied twin struggles with *"feeling guilty about the fact that she's able and she had loads of issues because she could do everything and to a large extent, wanting to do loads of stuff with her sister which her sister can't do."* However, she reasons her daughter who does not have CP *"is more empathetic and sympathetic and…she's a lot more understanding and I think it's because of* (her sister who has CP)…*it's made her a lot more accepting and empathetic towards differences."* Non-disabled siblings may not be as aware of differences and therefore, less empathic towards children who are growing up with a disability. Nielson et al. (2012) also convey this finding as parents perceive siblings to be more empathic than children who do not have a disabled sibling. Michelle suggests a similar aspect between her children, stating *"she's quite sympathetic and understanding towards him* (her CP brother)*, quite patient with him."* Finally, children are perceived as more empathic and caring once they have accepted and understood the meaning of their sibling's disability (Ali & Sarullah, 2010).

1.7 The continuous battle for attention

Another prominent sub-theme from the interview responses which contributes to the sibling relationship as 'typical, but not' quite typical argument is the constant battle for the parent's attention by each child. It is suggested that the non-disabled children want attention from their parents as they experience their parents as spending more time with their sibling who has CP. This assumption may arise from parents taking their child for medical appointments, occupational therapy and physiotherapy, for example. Sharon mentions that her children *"fight for attention."* This is substantiated by McHale, Updegraff, Tucker and Crouter (2000) who argue that siblings do indeed fight for parental attention, and this may be more pronounced in siblings where one child has CP. Sue also states that *"obviously we spend more time with* her (her daughter with CP)*...so I try then to sort of do something separate with the other two but you know, life gets in the way."* Importantly, I argue this will create a resentment and competitive nature between the siblings if the child with CP is perceived as receiving more attention. Although the study relates to a different disability, namely Down Syndrome evidence suggests that parents do in fact have less time for non-disabled children as the disabled sibling needs continuous support, time and attention from parents (Mulroy et al., 2008).

However, because Sue's daughter's CP is so mild she claims *"I can in my mind sort of imagine the kids who have got more serious CP that demand more of the parent's attention, there would be a lot more rivalry…I think that would definitely be a different kind of relationship."* This describes how the severity of the CP affects the relationship between siblings and further, is likely to transpire into different levels of rivalry or 'hate' between siblings. I contend that this is an important point raised by Sue as it provides evidence about how a relationship between a child with CP and his or her sibling is 'typical, but not'. This 'typical, but not' relationship is impacted

by the severity of the child's CP as more severely disabled children may require more attention from parents and understanding from their siblings. Children who are less accepting and/or aware of their sibling's disabilities may withdraw from the sibling relationship, resulting in less positive interactions. Interestingly, Stoneman (2001) claims that differential treatment and parental attention results in negative sibling interactions. Specifically, this leads to an increase in competition and additional conflict between siblings. Michelle reflects that her daughter who does not have CP feels jealous because *"I think that she sort of perceives him* (her son with CP) *as getting more attention, even if it's not necessarily positive attention and things like going to physio…they still see it as he's getting something that she's not getting."* To add to this, Sharon states her daughter who does not have CP perceives her sister with CP as being,

> *"loved more and the perception of love is a physical love because she gets picked up more, she gets carried more, she got a lot more attention when she was younger – we'd be driving her to physio so we spent more time with her…the perception from a child is then because you spend more time with her you love her more."*

Sharon's response signifies that when a child perceives their sibling with CP as receiving more attention, they assume he or she are loved more. This may result in feelings of resentment between the siblings and thus, negatively influence the relationship between them. I also postulate that to a certain extent this perception of a sibling being loved more may be evident in other non-disabled sibling relationships but it appears more prominent in this instance between a child with CP and his or her sibling(s). Wendy mentions that this perceived additional attention creates jealousy between her children because those who do not have CP perceive their sibling with CP as "*getting all the attention."* Lastly, Sharika states that *"maybe there's times they compete for love"* and her daughter who does not have CP will question *"why's she getting more love and I'm not."*

Interestingly, some participants went on to explain that their child with CP does get more attention compared to his or her sibling(s), confirming what the majority of the literature (Knecht et al., 2015; Nielson et al., 2012) describes. Sam states that her son with CP *"is getting the special treatment in the background…the special treatment in terms of his therapies and taking him places."* This ultimately shows how the child with CP does in fact receive more attention from parents which may be perceived differently and negatively by his or her sibling(s). If the sibling without CP perceives this attention as his or her sibling being loved more, this could create some instability between them. Knecht et al. (2015) reason that parents may be restricted in dealing with other siblings' wants and needs due to the disabled child requiring a considerable amount of attention. Karen highlights this, *"we didn't pay attention…us thinking ok, he walks and talks normally but there's a big difference in how we dealt with it, completely wrong on our side, we should have paid more attention to him* (her son without CP) *I think."* This has in turn had a negative effect on her son without CP as she revealed *"we just took for granted you can do these things so you're ok, but emotionally he's struggling."* This emphasises the impact on the child without CP and can be substantiated by literature as often able-bodied siblings are 'forgotten' and their needs are disregarded (Knecht et al., 2015). This experience of feeling forgotten influences the children without CP and many experience depression or anxiety as a result (Williams, 1997). In addition, Wendy suggests that her son without CP has also been negatively affected, *"I don't think he really shows um, what effect it's really had on him because he's always just there helping you know and everything's always had to be about* (his sister with CP)." Wendy later mentions that her other daughter without CP *"was actually placed a little bit in the background…without realising it and only realising it much, much later…nearly too late I would say."* Knecht et al.

(2015) claim that such experiences will inevitably have a negative influence on the sibling relationship.

Wendy went so far as to say this is the tip she would like to give future parents who have a child with CP, that *"they must never forget that the other child is there."* In addition, Sharon highlights how her daughter with CP *"draws so much attention, especially adult attention."* These quotes draw attention to, and provide evidence for, the substantial importance of this sub-theme and what can transpire in the sibling relationship as a result. The sibling(s) without CP may try to distance or withdraw themselves not only from their sibling relationship but also their relationships with parents, family members and friends. Such children may try to withdraw if they perceive they are 'loved less' due to receiving less attention than their sibling with CP. This may also occur more often in younger children or children who are less aware and/or accepting of their sibling's disability. Thus, this sub-theme has crucial implications for parents of children with CP and will be re-visited in more detail in the concluding chapter of this current research study.

Theme 2: The mother's involvement in her children's sibling relationship

A final theme that is evident between all the mothers' responses is one relating to their involvement in their children's sibling relationship. This theme pertains to the final research question of the current study which seeks to understand the role that mothers perceive they play in their children's sibling relationship. However, the responses between the participants differ. Some mothers mention that they try and not get involved in the sibling relationship when their children fight, whereas other mothers state that they are always present and involved in their children's lives. For example, Michelle voices that she is *"unsure how to answer that"* when asked what she thinks her involvement in her children's sibling relationship is. Instead she describes her involvement by

stating that as a family they *"try and do as much as we can together."* On the other hand, Rebecca appears to view her involvement as one that is needed to help form a relationship between her children and to ensure they continue forming a bond as siblings. She reflects,

> *"I'm really trying to make them have that bond because one day I won't be there and if they don't form it while I'm alive, they never going to form it. So for me, I think I play a very crucial role in the sense that I enforce it even though I know it's a bit difficult on both of them but somebody has to do it."*

The above response is powerful in that Rebecca feels she needs to 'enforce' a bond between her children. This implies that if she were not present to create a relationship between her children, they would not form one. Thus, Rebecca perceives that her CP child's inability to communicate and play with her brother has a negative impact on their sibling relationship. Furthermore, Rebecca may be under the impression that it is purely her daughter's CP that influences the formation of a sibling bond and if it were not for the presence of CP they would be able to develop a strong relationship on their own. Research (Dallas et al., 1993) indicates that mothers who have a child with CP intervene more often in sibling interactions than mothers who do not have a child with CP. This theme emphasises the maternal wishes and desires for their children to form a strong, positive bond early on in life so that this will continue into adulthood. McHale et al. (2000) suggest that it is a common concern for parents that their children (disabled or not) form a supportive and close relationship. Karen reflects on her involvement in her children's relationship as one where she really tries,

> *"to calm things down, sometimes it can get heated you know? If you just look at the whole picture it's not that bad, I keep putting in there – realise we've got no one else here and*

you just have each other 'cause all your cousins, everybody else is so far away…but I just try and be there for both."

While this response signifies the uniqueness of the relationship between Karen's CP child and her sibling, this is also a reality for other siblings. This again emphasises how this sibling relationship is 'typical, but not' compared to other, non-disabled sibling relationships. Nevertheless, this response suggests the role that Karen perceives she plays as one that helps her children to form a bond with each other. Sue also highlights that with *"everything they do I'm involved, every sort of conversation they have I'm pretty much there for."* Sam raises that she thinks she is *"kind of like a mediator."* Wendy's answer is similar stating, *"I'm always trying to make peace…I think I'm just the one that's always there for them."* This response reflects on a similar dynamic these siblings share with other non-disabled siblings as mothers are often 'trying to make peace' regardless of whether one child has CP. Although the study by Howe and Ross (1990) focuses on two non-disabled siblings, I argue that the results have some applicability for the current discussion. These authors argue that when mothers intervene, a less positive sibling relationship sometimes develops. Often mothers try intervene because they perceive their children's interactions as hostile or that they are not engaging enough together (Howe & Ross, 1990). Further, instead of encouraging friendlier interactions, no change in sibling behaviour was found when mothers intervened. Interestingly though, another study (McHale et al., 2000) finds that parents intervening in the sibling relationship resulted in more adaptive conflict resolution strategies for siblings. Although the above literature reveals mixed results regarding the outcome of parents intervening in the sibling relationship, a variety of strategies can be used with disabled children and their sibling(s). The same results appeared in the current study as well, highlighting further that these sibling relationships are 'typical, but not'. Sharika mentions that she,

> *"helps them* (her children) *in this journey…I think as life goes on they, well I hope and pray that* (her daughter who does not have CP) *sees the disadvantages on her sister's side and rises above those and that* (her daughter with CP) *doesn't stop for anything and every challenge that comes to her she'll tackle head on."*

In contrast, Sharon states that she tries to *"not be involved"* with regards to her role in her children's relationship. She relates this specifically to when her children are fighting and arguing saying, *"try and sort it out yourselves…I'm not going to get involved unless it's really mean or unless it's physical."* Sam's response mirrors that of Sharon's as she indicates as parents they *"don't interfere…we just treat them both the same."* Furthermore, Karen suggests later in her interview that she tries *"not to take sides at all…and they both get a scolding if they need to."* Interestingly though, Sharon highlights that she will *"talk to them privately…I do try separately to chat to them about stuff and about respect, about being nice and about being a bit more understanding and empathetic."* Thus, it seems evident from this quote that although Sharon does not like to get involved when her children are fighting, she is aware of the role she plays in her children's sibling relationship.

From the above discussion it is evident that the current study describes two themes; one with a number of sub-themes. The first theme relates to the 'typical, but not' relationship that CP children and their sibling(s) share compared to other, non-disabled siblings. This involves sharing a similar love/hate type of relationship with other siblings but more so, includes positive and negative aspects which results in their relationship being dissimilar to non-disabled siblings. This 'typical, but not' sibling relationship also includes sub-themes relating to feelings of guilt versus jealousy, and the continuous battle for attention from parents. Importantly though, some of the mothers seemed to defend against sharing any negative experiences between their children and

instead wanted to portray a more positive, ‘typical’ sibling relationship. Finally, the second theme describes the role that mothers perceive they play in their children’s sibling relationship. This role involves either intervening in the sibling relationship or not intervening at all. Due to the lack of literature around this topic, the recommendations and limitations of the current study are of importance for future research. Thus, the concluding chapter to follow will highlight the weaknesses in the current study and suggest future research that can be conducted on this topic.

Chapter Five: Conclusions and Recommendations

5.1 Conclusions

The current research study aimed to explore the relationship between Cerebral-palsied children and their sibling(s). Specifically, this relationship between siblings was investigated from their mother's perspective through detailed discussions and conversations in the format of interviews. The current study was able to answer the research questions set out at the beginning of this report. I was able to gather useful, in-depth information about the relationship between such siblings as well as how the presence of CP affects their sibling bond. I also discovered how mothers perceive their role in their children's relationship. Although previous literature on this topic about CP siblings is lacking, particularly in South Africa, the results of the current research show similarity with literature relating to other disabilities (Ali & Sarullah, 2010; Giallo & Gavidia-Payne, 2006; Heller & Kramer, 2009; Knecht et al., 2015; Meltzer & Kramer, 2016; O'Neill & Murray, 2016; Shojaee, 2015; Wolfe et al., 2014). Moreover, relating this to John Bowlby's theory of attachment (1973), the important attachment relationships between the mother and infant may affect the interactions that the child has later on in life and the relationships that the child will form with other individuals, including their siblings. It is also possible for individuals to develop a secondary attachment to their siblings, as seems to have been the case with most of the siblings in the current study. Even though the CP does affect the relationship formed between such siblings, they are still able to attach and form a bond with one another. Thus, this study seems to contribute to the understanding of attachment theory between CP children and their siblings.

It is evident from the current study that children with CP and their sibling(s) have a dynamic, yet complex, relationship which can be compared to that of other, non-disabled siblings.

Evident from the reported experiences above, mothers view their children as having a 'typical, but not' so typical relationship compared to non-disabled children. While siblings, when one has CP, have a similar love/hate type of relationship to other sibling relationships, mothers suggest that there are many elements to their children's relationship that are dissimilar and unique to that of other siblings relationships. Specifically, this uniqueness involves both positive and negative differences. Exploring the positive aspects to their children's sibling relationship, mothers viewed their children as closer, more caring and compassionate compared to other children growing up without a CP sibling. Further, many participants commented and reflected on how their children's relationship had strengthened and developed over the years and that this will possibly continue to grow in the future. With the negative aspects however, each mother was able to discuss that her child with CP often cannot play and communicate with his or her sibling(s), like non-disabled siblings would, thus impacting the sibling relationship. Moreover, the sibling(s) of CP children are described by literature (Nielson et al., 2012; Stoneman, 2001) as the 'forgotten' children due to their CP sibling requiring a lot of time and attention from their parents. This experience of feeling forgotten influences the development of a sibling bond and may strain the interactions between siblings if children view themselves as being loved less compared to their sibling with CP. Interestingly, each of the eight mothers in the current study were able to draw on examples of how their children with CP felt jealous of their siblings' abilities and how the child without CP felt guilty for what he or she could do compared to his or her CP sibling. This is likely to have an influence on the relationship between siblings and how they interact with one another. In addition, mothers described the continuous battle for attention between their children. Some mothers even went so far as to say that their children without CP do in fact receive less attention due to the additional care and time required to look after the sibling with CP. Finally, each mother described

their involvement in their children's sibling relationship. Whether this meant intervening less when they fight or constantly intervening to ensure their children develop a strong relationship that will continue into the future, each mother recognised that they do play some role.

This detailed information on the relationship between children with CP and their sibling(s) emphasises that while they experience similar interactions to other, non-disabled siblings, often their experiences are more pronounced. Whether it is positive or negative aspects to the sibling relationship, the feelings of jealousy or the continuous battle for attention from parents, all siblings experience this. However these experiences may be more exaggerated among children with CP and their sibling(s). Importantly, it was also noted that the severity of the child's CP has a crucial influence on the sibling relationship as this impacts a child's ability to play and communicate with his or her sibling(s), amongst other factors. The current study provides important information relating to the sibling dynamics between such children which could be useful to health professionals who work with these families, as well as for these individuals with CP, their siblings and their family members.

5.2 Limitations

A number of important limitations of the current study need to be discussed. First, this research study focused on mothers in South Africa only and therefore, the applicability and generalisability of the results to mothers in other countries is something to consider. Although generalisability is not necessarily sought after in qualitative research studies, the information gained is still considered of great use for various individuals, most notably the individual with CP, his or her sibling(s), his or her parents, as well as various health professionals.

Furthermore, as discussed within the reflexivity section of the methods chapter, I am not a mother and this may have impacted the research process and interpretation of the data collected. I may have been unable to identify with the eight mothers on some level and fully understand what they meant by their reported experiences. However, this limitation was attempted to be controlled for by including direct quotes in the discussion and results chapter in order to represent exactly what the mothers reported. In addition, while I am not a mother I have been mothered and have experienced growing up with a mother. This may have helped to make sense of some of the findings of the current study and the experiences the mothers were describing with regards to the sibling relationship. Finally, I also relied on pertinent literature related to this topic which is believed to have further contributed to understanding the findings.

The current research study only focused on the perception of one parent and therefore, the results may have differed if both parents were interviewed or if fathers were the chosen sample group. However, the previous study I conducted in 2014 found that even though fathers play a part in the care-giving role, mothers are the primary caregiver of their children with CP. Thus, it seemed relevant to interview mothers as it was thought they would have greater insight into the development of their children's sibling relationship.

While I do have a sibling and have experienced growing up and developing a sibling relationship with her, she is not disabled. This fact may have also influenced my understanding of the mothers' perceptions of their children's sibling relationship. Finally, it is also important to consider that I do not have a disability and this may have had some implications during the data collection and interpretation process. In addition to possibly having a preconceived idea about the sibling relationship that these mothers would describe, I may have been unable to fully understand the mothers' reported experiences about their children's sibling relationship. As a result, I could

have misconstrued their described experiences in the final research report. However, I do not believe this was the case as I constantly engaged with my subjectivity within my own psychotherapy, as well as within my research supervision sessions.

5.3 Recommendations

After completing this research study, a number of recommendations seem applicable for future research of a similar topic. In addition, the recommendations below include clinical, and theoretical implications of the current research study.

Research

First, I would recommend using the criterion of the youngest child being at least four years of age or even older in order to provide further time for a sibling relationship to have developed. I found that mothers who had older children were able to provide richer information regarding the topic at hand. However, due to struggling to find a large enough sample group I included children who were slightly younger and therefore, extended the criterion to include children as young as two years old. In addition, it may be beneficial for future research to include fathers' perceptions of the relationship between CP children and their siblings. Literature (Mulroy et al., 2008) has found mothers and fathers perceptions to be different and including fathers in the sample may provide an alternative, and even contrasting, perspective on the sibling relationship. As with most research, a larger sample will provide more detailed information about the sibling bond. Although a theme of the current study included the change in the sibling relationship over time, exploring this change as the main topic of a study may lead to interesting findings that would be useful to parents, siblings, and health professionals.

Theoretical

I believe the current study is of vital importance as there is a gap in knowledge relating to the relationship between children with CP and their siblings. Further, this type of study has never involved exploring the relationship from the mother's perspective. There is an abundant amount of previous literature (Ali & Sarullah, 2010; Doody et al., 2010; Dyson, 1999; Giallo & Gavidia-Payne, 2006; Heller & Kramer, 2009; Knecht et al., 2015; Meltzer & Kramer, 2016; O'Neill & Murray, 2016; Pit-Ten Cate & Loots, 2000; Shojaee, 2015; Wolfe et al., 2014) that specifically focuses on the relationship between siblings when one child has a disability and thus the current study involved the mother's perception instead. In addition, little research on children with CP and their siblings has been conducted locally in South Africa. Further, research that is conducted locally in South Africa would be able to consider the context specific to this country and therefore, could also highlight the potential intricacies in maternal perceptions as a result of differences in culture and/or socio-economic status.

Clinical

The findings of the current research could have important practical implications for health professionals, individuals with CP, his or her sibling(s), as well as parents of children with CP, in South Africa and internationally. Information that is particularly useful for health professionals, including psychologists, physiotherapists, teachers and medical doctors, could also be shared with parents. For example, reiterating to parents that their non-CP children require care and attention, as well as their child with CP. This was a recommendation from one of the mothers in the current study as she mentioned this important piece of advice would have been helpful to her when her children were growing up. This consideration of the needs of their non-disabled children could

ultimately influence the interventions health professionals provide for such families as they could include suggestions regarding activities that they whole family can participate in, as well as opportunities for the siblings' needs to be acknowledged. This information and advice may help non-disabled siblings to feel a part of the family and not forgotten. This in turn would have a positive impact on the sibling relationship when one of the children has CP. Consequently, the current research study provides additional in-depth information that will aid in closing the gap of knowledge around children with CP, their relationship with their siblings, and their families. Thus, not only were the theoretical implications of the current research study highlighted, but also practical implications as well.

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Appendices

Appendix 1: Participant Information Sheet

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

The relationship between Cerebral-palsied children and their siblings: A maternal perception.

Dear Madam,

Good Day! My name is Nicole Soames, and I am currently doing my Psychology Master's degree in Educational Psychology at the University of the Witwatersrand. I am conducting a qualitative research project in the form of an individual interview which will explore your perception of the relationship between your Cerebral-palsied child and his or her sibling(s).

I would like to formally invite you to take part in my research study. This will involve you taking part in an interview with me around the topic mentioned above. The interview should last about 45 minutes to one hour and participation is completely voluntary. Taking part in the interview will not advantage or disadvantage you or others in any way. Therefore there are no foreseen risks to you or others, as well as no benefits to you or anyone else for taking part in this study. For analysis reasons, the interview will be audio-recorded, however only my supervisor and I will have access to these tapes. Once the information of the interview has been transcribed verbatim, the tapes and transcripts will be locked away and finally destroyed after five years. Although I will have access to your name, you will remain anonymous and anonymity will be maintained by not disclosing any of your personal information in my results or the final research report. During the study, I will assign a pseudonym to all the participants, such as Participant 1, Participant 2 etc. Thus your confidentiality will be assured. Importantly, you have the right to withdraw from this study at any

time and therefore also have the right to not answer any questions that you do not wish to, without any consequences.

Once the study has been completed, you may request a summary of the study and the findings if you so wish and this can be emailed or sent to you by either myself or my supervisor. You can find our contact details at the end of this letter and the results will be available six months after the data collection.

If by the end of the interview you feel the discussion has elicited sensitive and emotional effects in you, then please make use of the free support and counselling that is available below:
Emthonjeni Community Psychology Clinic (Based at Wits University) – 011 717-6396
South African Depression and Anxiety Group- 011 262 6396 (Or SMS 31393)

Before the interview can begin, I will ask you to read through and sign the two consent forms and detach them from this letter. These forms will just confirm that you understand what is required of you and the confidentiality for the study. If you have any questions or concerns, please feel free to contact myself or my supervisor.

Kind Regards,

Nicole Soames

_____

0731768477
nicole.soames@gmail.com

Clare Harvey (Supervisor)

_____

011 717-4509
clare.harvey@wits.ac.za

Appendix 2: Consent Forms

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

The relationship between Cerebral-palsied children and their siblings: A maternal perception.

I,_____ consent to taking part in the individual interview conducted by Nicole Soames, for her study exploring the maternal perceptions of the relationship between a mother's Cerebral-palsied child and their siblings.

As a participant in her study, I understand that:

- My participation is voluntary.
- There are no foreseen risks to me or others, as well as no benefits to me for taking part in this study.
- I am able to withdraw from the study at any time.
- I do not have to answer any question(s) I do not wish to.
- All my personal details and information will remain private and confidential, although I may be quoted in the final report.
- If however I am quoted, it will be under a pseudonym given to me.
- None of my personal information will be stated in the final research report (I will remain anonymous).
- The results of the study will be used in the research report that is required for the completion of the Masters in Educational Psychology degree.

Signed: _____

Date: _____

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 4503 Fax: 011 717 4559

The relationship between Cerebral-palsied children and their siblings: A maternal perception.

I,_____ consent to the audio recording of the individual interview with Nicole Soames for her research study. I understand that:

- The tapes and transcripts from the interview will remain confidential to only Nicole and her supervisor and therefore will not be available to anyone else.
- The tapes and transcripts will remain on a password-protected computer until they are destroyed five years later.
- No personal or identifying information about any of the participants will be used in the transcripts for the final research report.
- Although I may be quoted in the research report, I will be referred to by the pseudonym given to me at the beginning of the interview, and thus my identity will be protected.

Signed: _____

Date: _____

Appendix 3: Interview Schedule

Demographic information:

1. How old are you?
2. How many children do you have?
3. How old is your child with CP?
4. What gender is your child with CP?
5. How old is/are your other children?
6. What gender is/are your other children?
7. When did you learn that your child has CP?
8. What level of disability does your child with CP have? (Or how severe is your child's CP?)

Questions:

1. How would you describe the relationship between your CP child and his/her sibling(s)?
2. What are some of the positive aspects of their relationship? (Follow up questions with asking for examples).
3. What are some of the negative aspects of their relationship? (Follow up questions with asking for examples).
4. In what way is their relationship similar to other sibling relationships? (I.e. other siblings in your family or other children you know of from other families?)
5. In what way do you imagine that their relationship is dissimilar to other sibling relationships?
6. Has their relationship changed over time? Please elaborate.
7. How do you think their relationship will change as they get older?

8. How does your one child's CP affect the sibling relationship, if at all? (Or severity of CP?)
9. How much time do your children spend or play together? (Follow up question relating to whether they spend more time playing separately? How do you make sense of this?)
10. How does your child without CP interact/engage/play with your child with CP? (I.e. what games or activities do they play, or how do they spend time together? Possibly vice versa as well.)
11. How would you describe their interactions? (For example warm, positive, close, cold, distant, disengaged, neutral etc.)
12. How do you think their difference in age affects their relationship?
13. How do you understand their shared/different gender plays out in their sibling relationship?
14. Have you noticed any sibling rivalry/conflict between your children? (Or when/if your children 'clash'?)
15. Please describe your involvement in their sibling relationship?
16. What role do you play in their relationship? (Follow up with how she understands this role in relation to one of her children having CP).

Debriefing Questions:

1. How did you experience the interview?
2. Did the interview raise any emotional feelings for you that you would like to discuss further?
3. Is there anything else you would like to discuss about the interview?
4. Are you feeling alright to finish with the interview now? (If no, how else can I help you?)

16. STATEMENT OF PRINCIPLES FOR POSTGRADUATE SUPERVISION

IN A CONTEXT OF ACADEMIC FREEDOM AND WITHIN A FRAMEWORK OF INDIVIDUAL AUTONOMY AND THE PURSUIT OF KNOWLEDGE THIS AGREEMENT IS WRITTEN IN THE BELIEF THAT THERE IS A RECIPROCAL RELATIONSHIP AND MUTUAL ACCOUNTABILITY BETWEEN SUPERVISOR AND STUDENT.

THE SUPERVISOR AND THE STUDENT:

1. Will establish agreed roles and clear processes to be maintained by both parties. In the case of joint supervision everyone's role needs to be clarified.
2. Will meet regularly and as frequently as is reasonable to ensure steady progress towards the completion of the proposal, research report, or dissertation or thesis. This time varies but the normal minimum requirement for face-to- face contact, spread across each year of registration is: 10 contact hours for an Honours project, 15 contact hours for a Masters by research report and 24 contact hours for a Masters by dissertation and a PhD.
3. Will keep appointments, be punctual and respond timeously to messages.
4. Will keep one another informed of any planned vacations or absences as well as changes in his or her personal circumstances that might impact on the work schedule. Unplanned absences or delays should be discussed as soon as possible and arrangements should be made to catch up lost time.
5. Will ensure that research on animal or human subjects is conducted according to the procedures and the requirements of the relevant University Ethics committee.
6. Will together complete progress reports on the research project, as requested by each Faculty Graduate Studies Committee.

THE SUPERVISOR:

1. Undertakes to provide guidance for the student's research project in relation to the design and scope of the project, the relevant literature and information sources, research methods and techniques and methods of data analysis.
2. Has a responsibility to be accessible to the student.
3. Will be prepared for meetings with the student. This includes being up-to-date on the latest work in his/her area of expertise.
4. Will expect written work as jointly agreed, and will return that work with constructive criticism within a timeframe (a suggestion of 2-4 weeks) jointly agreed at the outset of the research.
5. Will provide advice that can help the student to improve his/her writing. This may include referrals for language training and academic writing. The supervisor will provide guidance on technical aspects of writing such as referencing as well as on discipline specific requirements. Detailed correction of drafts and instruction in aspects of language and style are not the responsibility of the supervisor.
6. Will support the student in the production of a research report, dissertation or thesis. Provision should be allowed for adequate, mutually respectful, discussion around recommendations made.
7. Will assist with the construction of a written time schedule which outlines the expected completion dates of successive stages of the work.
8. Will ensure the student has the opportunity to present work at postgraduate/ staff seminars/national/international conferences as appropriate.
9. Will assist with the publication of research articles as appropriate.
10. Will discuss the ownership of research conducted by the student in accordance with the University guidelines and rules on intellectual property, co-authorship and copyright.
11. Will ensure that the research is conducted in accordance with the University's policy on plagiarism.
12. Will ensure that the student is made aware in writing of the inadequacy of progress and/or of any work where the standard is below par. Acceptability will be according to criteria previously supplied to the student.
13. Has a duty to refuse to allow the submission of sub-standard work for examination, regardless of the circumstances. If the student chooses to submit without the consent of the supervisor, then this should be clearly recorded and the appropriate procedures followed.

THE STUDENT:

1. Undertakes to work independently under the guidance of the supervisor. This includes reading widely to ensure that the literature pertinent to his/her chosen topic has been identified and consulted.
2. Is obliged to make appointments to see the supervisor and will arrange meeting times well in advance.
3. Will think carefully about how to derive maximum benefit from these contact sessions by planning what he/she wants in these sessions.
4. Should submit written work for discussion with the supervisor well in advance of a scheduled meeting. The kind and frequency of written work should be agreed with the supervisor at the outset of the research.
5. Undertakes to submit written work that is relatively free of basic spelling mistakes, incorrect punctuation and grammatical errors. Responsibility for the accuracy of language, the overall structure and coherence of the final research report, dissertation or thesis rests with the student.
6. Undertakes to heed the advice given by the supervisor and to engage in discussion around suggestions made. Ultimately the student has to take responsibility for the quality and presentation of the work.
7. Should strive, within reasonable bounds, to maintain a focus on his/her research area and to work within the agreed time schedule.
8. Will prepare material for presentations at seminars and conferences.
9. Undertakes to submit papers for publication.
10. Agrees to honour agreements about ownership of the research and in accordance with the University's guidelines and rules in relation to co-authorship, copyright and intellectual property.
11. Will ensure that the work contains no instances of plagiarism and that all citations are properly referenced and that the list of references is accurate, complete and consistent.
12. Agrees to work in accordance with the criteria of acceptability as supplied by the supervisor.
13. Undertakes not to place the supervisor under undue pressure to submit work for examination until the supervisor is satisfied that it has reached an acceptable level of quality.

I confirm that I have read and understood this statement and agree to be guided by its principles

Name of student : Nicole Soames

Student's signature : NSoames

Name of Supervisor : Clare Harvey

Supervisor's signature : [signature]

Name of Co-Supervisor : n/a

Co-Supervisor's signature : n/a

The broad area of study is: Mother's perception of relationship between Cchild & sibling

Provisional submission date is: Feb. 2017

Degree : Educational Psychology Masters

School : Human & Community Dev.

Faculty : Humanities

Date : 11/03/2016

Specific agreements pertaining to: ownership and joint publication, funding, etc. may be attached and signed.

GRIEVANCE PROCEDURES. It should be acknowledged that during the course of the research, both students and supervisors can feel aggrieved. In this event, matters should be dealt with as swiftly as possible by the parties involved and, if necessary, the appropriate Postgraduate Coordinators and Committees. There is, in addition, a University Grievance Policy to help guide deliberations. It is available on www.wits.ac.za/prospective/postgraduate.

Appendix 5: Ethical Clearance Approval Letter

University of the Witwatersrand, Johannesburg

Faculty of Humanities – Postgraduate Office

Private Bag 3, Wits 2050, South Africa • Tel: +27 11 717 4002• Fax: +27 11 717 4039• Email: Sarah.Mfupa@wits.ac.za

Student Number: 859968

Miss Nicole Janet Soames
P O Box 1686
Fourways
Johannesburg 2055
Gauteng South Africa

19 May 2016

Dear Miss Soames

APPROVAL OF PROPOSAL FOR THE DEGREE OF MASTER OF EDUCATION IN EDUCATIONAL PSYCHOLOGY

I am pleased to be able to advise you that the readers of the Graduate Studies Committee have approved your proposal entitled "*The relationship between cerebral-palsied children and their siblings: A maternal perception*". I confirm that Ms Clare Harvey has been appointed as your supervisor in the School of Human and Community Development.

The research report is normally submitted to the Faculty Office by 15 February, if you have started the beginning of the year, and for mid-year the deadline is 31 July. All students are required to RE-REGISTER at the beginning of each year.

You are required to submit 2 bound copies plus 1 CD in pdf (Adobe) format of your research report to the Faculty Office. The 2 bound copies go to the examiners and are retained by them and the CD is retained by the Faculty Office as back up.

Please note that should you miss the deadline of 15 February or 31 July you will be required to submit an application for extension of time and register for the research report extension. Any candidate who misses the deadline of 15 February will be charged fees for the research report extension.

Kindly keep us informed of any changes of address during the year.

Note: All MA and PhD candidates who intend graduating shortly must meet your ETD requirements at least 6 weeks after your supervisor has received the examiners reports. A student must remain registered at the Faculty Office until graduation.

Yours Sincerely

SD Mfupa

Sarah Mfupa
Postgraduate Division
Faculty of Humanities
Private Bag X 3
Wits, 2050