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Abstract

The experience of raising children is one that is generally considered to be very challenging for mothers. These challenges often arise as a result of the variety of demands and expectations associated with each passing milestone. For mothers of children with high-functioning Cerebral Palsy (CP) these demands are often more intensive due to the extensive interventions required to help their children actualise their potential. The aim of this study was to report on, and interpret the unique nature of experiences confronted by mothers of high-functioning CP adults. In doing so, the study adds to the deficit of literature that demonstrates how societal judgment impacts mothers' perceptions of their experiences and highlights why it is necessary to cater for high-functioning CP individuals in a mainstream society. Therefore, by providing mothers with the opportunity to articulate their experiences through semi-structured interviews, their lesser-considered voices and subjective perceptions are heard. Participants' responses to the interview schedule were analysed through the use of an Interpretive Phenomenological framework in order to understand the unique and in-depth nature of mothers' personal experiences. These responses were dissected into themes through the use of Thematic Analysis. 'Trauma' and 'loneliness and misunderstanding' were highlighted as prominent emotional responses, and are followed by a discussion of the survival and grief-orientated coping responses mothers reported experiencing. Lastly, mothers' desires for circumstantial control and worries about their adult CP children's futures were identified as integral to understanding their experiences. The study was noted to have implications for socialisation studies as it demonstrated how social isolation can affect maternal emotional well-being. Moreover, the study was noted as having implications in resilience and Humanistic studies as the levels of resolve mothers adopted to cope with their circumstances were highlighted. Lack of generalisability and mothers' inherent biases concerning their children's functional abilities were noted as potential limitations to the study. The impact of raising a high-functioning CP child on mothers' journeys as well as the changing worldviews mothers experience as part of their journey were recommended as noteworthy topics for future research.

Keywords: *Adults, Cerebral Palsy, Experiences, High Functioning, Mothers*

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Chapter 1

Introduction

This chapter presents a brief overview of the various components of the research project. First, the study is contextualised by providing a background that not only provides an understanding of mothering as a historical practice embedded in cultural norms and values but also highlights how personal circumstances can influence childrearing outcomes. This is followed by providing an understanding of Cerebral Palsy (CP) with the help of a historical overview concerning physicians' and doctors' understandings of this disability. Subsequently, a rationale is provided that stands to motivate the importance of studying mothers' experiences in raising high-functioning children with CP to a sufficient level of cognitive and/or physical competence. The former is followed by an outline of the various components of the dissertation concerning the content of each chapter.

Mothering as Historical Practice

The practice of motherhood and mothering has been conceptualised to take on complex and multitudinous meanings throughout contexts and moments in history. While Anthropologists have conceptualised mothering as being crucial to the perpetuation of cultural norms and practices as well as the reproduction of society, Psychologists perceive this practice as being assistive in aiding the formation of children's identities (Hansen, 2020; Spjeldnæs et al., 2014). The former suggests that despite modern-day society's applauding of women who strive to achieve in the arena of work, mothering and how it is practiced remains of keen interest to our society. Evidence supporting the former importance placed on childrearing can be seen in Bowlby's polarisation of the "good enough mother" versus maternal indifference (Buesekens, 2014, p. 57). Such descriptions or categorisations attempt to define the efficiency and effectiveness with which the pursuit of motherhood is practiced and construct motherhood as a form of identity. Moreover, a proliferation of psychological literature has explored mothering practices that practitioners perceive to result in the most desirable or conversely the most undesirable outcomes in a child's personality. Evidence supporting the former can be seen in the debate concerning breastfeeding as a source of emotional support and bonding between mother and infant, the effects of which are believed to provide children with a sense of security or insecurity to function in adult relationships (Benoit, 2004; Gibbs et al., 2018). Here, the extent to which prematurely born infants are often denied this opportunity to bond with their mother stands to be particularly applicable to children with CP who often spend their first

months of life in an incubator due to requiring oxygenation. Consequently, developments in modern medicine have led to Kangaroo Care (KC) which refers to the practice of skin-to-skin contact between mother and infant and can take place during the hospital stay (Jefferies, 2012). However, regardless of whether breastfeeding is demonstrated to lead to a significantly positive attachment outcome in babies, mothering should also be noted as being dependent on the personality of the mother herself (Bahrami et al., 2018). Thus, mothering is not exclusive to the historical-political context in which one lives. Personal circumstances such as having a child with CP can also affect parenting styles and attitudes as can be seen in the literature on overprotective parenting which is discussed in the literature review in the next chapter.

Defining Cerebral Palsy and Its Causes

Cerebral Palsy is the most prominent form of childhood disability (Vitrikas et al., 2020). Evidence supporting the former demonstrates that the overall prevalence is 2/1000 live births (Katangwe et al., 2020). In rural South Africa, the prevalence of CP is estimated to be 10/1000 live births (Katangwe et al., 2020). Known to affect motor functioning as a consequence of injury to the developing brain, CP was previously known as 'Little's disease,' as it was first termed by William John Little in 1943 (Vitrikas et al., 2020). Moreover, CP was thought to develop due to premature birth and birth asphyxia, as well as damage to the brain during infancy (Vitrikas et al., 2020). Many cases of CP are congenital in nature (Shriver, 2013). Birth asphyxia is caused by the interruption of blood flow to the placenta which results in the absence of enough oxygen reaching the bodily tissues to sustain bodily functions (Rainaldi & Pearlman, 2016). Similarly, premature birth leads to a shortened period of utero organ development (Pravia & Benny, 2020). This better explains the former mentioned definition of CP as being the result of a series of neurological disorders of the brain (one of our body's primary organs that transmits messages to other areas and/or limbs of our body). While well-known physicians of the time such as Sigmund Freud and Sach Peterson provided extensive contributions to the nature of the condition, in 2006 an executive panel of experts defined CP as a group of permanent disorders of motor movement (Vitrikas et al., 2020). While Vitrikus et al. (2020) highlight that CP is a condition predominantly resulting in difficulties with movement and posture, the reality that individuals may be affected in a variety of different manners should be mentioned and will be embellished on later in the literature review.

Although CP is denoted as incurable, various treatments have developed over the years which are believed to improve the management of the disability (NINDS, 2023). Certain of these

treatment measures include therapies such as physical and occupational therapy, as well as drug treatments or various forms of surgery (NINDS, 2023). While children with low-functioning capacity may require various forms of equipment to function, children with high-functioning CP can often walk independently without the extensive use of equipment (NINDS, 2023). Similarly, from a cognitive perspective, high-functioning CP refers to individuals who have average levels of cognitive functioning that can enable them to progress into intellectually functional adults. Evidence supporting the former suggests that some children who are severely impaired in a physical capacity, display normative levels of intelligence as well as receptivity to learning language skills (Fluss & Lidzba, 2020). Thus, although Song (2013) suggests that physical and cognitive functioning are strongly related in children with CP, the former suggests that not all instances of CP affect functioning to an all-encompassing extent. Further evidence of the former can be seen in the diagnoses of Monoplegia and Hemiplegia as variants of CP (National Health Services (NHS), 2023). While Monoplegia refers to one limb being impacted by CP, Hemiplegia refers to one side of the body being impacted (NHS, 2023). Spastic Hemiplegia is a form of CP that often affects individuals who are of a highly cognitive or functional level (Riad et al., 2008).

However, despite the formerly mentioned variations of 'high-functioning presentations' within the CP spectrum, the literature review to follow this chapter will demonstrate that many mothers contend with an incredibly tiresome and demanding journey to enable their children to function at such a highly capable level. In addition, the formerly mentioned medical or surgery-related difficulties and the need for intensive therapeutic intervention suggest that parenting a child with CP can take on an additional dimension of physical maintenance demands as these individuals navigate their daily lives from childhood to adulthood. Thus, this study intended to investigate how mothers negotiate such difficulties when coming into contact with social and environmental settings that do not cater to their children's realities.

Rationale

While childrearing is renowned for posing challenges concerning accessing resources (Ramnandi et al., 2019), for mothers raising children with CP such challenges are seen to be much greater than for parents with non-disabled children (Ramnandi et al., 2019). Moreover, a study including mothers who have children with CP demonstrated that the levels of distress that these mothers experience are much greater than those experienced by mothers of non-

disabled children (Breslau et al.,1982). Thus, mothers raising CP children experience their circumstances to be emotionally as well as practically intensive in nature.

Cerebral Palsy refers to a series of neurological disorders that occur in infancy and/or early childhood that have a permanent impact on body movement and muscle coordination (National Institute of Neurological Disorders and Stroke (NINDS), 2023). Cerebral Palsy thus impinges on the brain's capacity to regulate movements and maintain posture and balance (NINDS, 2023). Prevailing literature examines the severity of CP according to an individual's physical capabilities (Rosenbaum, 2007). The former definition of CP as a disorder of physically impaired functioning does not account for the non-motor neurodevelopmental comorbidities that may co-exist alongside CP (Rosenbaum, 2007). Such examples may include sensation, cognition, communication, perception, and/or behavioural or seizure disorders (Goldstein et al., 2005). While such co-morbidities are a probable outcome for children with CP, the severity of the child's disability can be perceived as being on a spectrum from mild to severe CP (Sadowska et al., 2020). Research has demonstrated that approximately 20-30% of children with CP have difficulty responding to general intelligence tests (Sigurdardottir et al., 2008). This insubstantial percentage of children with intellectual impairments due to CP suggests that further research on parental experiences of raising high-functioning children into adulthood can be invaluable. This research study aimed to explore how mothers in these circumstances have perceived their experiences of raising their high-functioning children to become highly functional and capable adults in a society that does not necessarily cater for the needs of their children. Thus this study can enable society to better cater to the requirements of parents, and in the case here, mothers particularly, along their journey of raising high-functioning CP children. Offering an understanding of mothers' experiences in raising CP children as well as recognising their contextual influences can ensure the development of intervention strategies that can improve upon these women's daily lives (van der Mark et al., 2019).

In addition, more than half of the population of individuals with CP can walk independently (Centres for Disease Control and Prevention, 2023). Furthermore, the Gross Motor Functioning Classification Scale (GMFCS) demonstrates that mothers of children with high-(motor)functioning CP present with greater levels of distress than children with low-(motor) functioning CP (Ribeiro et al., 2014). The former suggests that there is a significant need to cater to the needs of mothers whose CP children can walk and/or move independently. Hence there exists a substantial need to research the experiences of mothers with physically high-functioning children with CP to better understand and assist these mothers in meeting their own

children's functional demands in everyday settings. While the former mentioned literature considers and defines CP from the perspective of physical functionality, this study will consider the individual's functionality from a physical and cognitive perspective because of the reality that CP is a disability that can affect an individual's cognitive capacity as much as it can affect the individual's physical capabilities (Krigger, 2006).

Additionally, quantitative research has been conducted on the family needs of parents with CP children, stating that family needs may vary based on factors such as the child's functional limitations (Burtule et al., 2014). However, there is a lack of qualitative research on parents' retrospective perceptions concerning their holistic journey in having raised a high-functioning CP adult. This is evident as prior research has tended to focus on specific points in time of the mother's journey in raising their disabled child with CP, such as at the point at which their children are diagnosed (Furgason, 2002). The current study focuses on providing a general overview of the mother's experience of raising CP children from childhood into adulthood.

While mothers and fathers can be involved in the childrearing process, most of the parenting responsibility falls on mothers due to societal expectations (Bornstein & Putnick, 2016). In addition, South African literature on this topic demonstrates that mothers with disabled children are often forced to raise their children alone as fathers are more likely to neglect their paternal duties if their child has a disability (Pelchet et al., 2003). Such neglect may stem from the stigma associated with diagnosis of a 'disability' and the implications of what this word means to parents as well as to society at large (Barnett et al., 1999). Parents often struggle to come to a level of acceptance of their own and their child's reality (Barnett et al., 1999). Such difficulties experienced by parents in accepting their child's diagnosis are usually embedded or implicit in the discriminatory language that society uses to reference and make sense of disabilities on an ongoing basis. Thus, the reality demonstrated in the literature (Plechet et al., 2003) which shows that mothers are often abandoned and/or culturally expected to take care of their CP children alone makes the experiences of women in such circumstances unique and worthy of study.

The American Psychological Association (APA) (2021) differentiates between first-person and third-person language use when talking about disability. Such examples of first-person language include a 'Cerebral Palsy person,' while third-person language would reference a 'person with Cerebral Palsy.' However, there is insufficient literature available to demonstrate how such phrasing of language can have a significant impact on parents of CP children by

affecting how parents feel about, and adjust to, the reality of their child's diagnosis. Thus, while existing literature acknowledges the phenomenon of 'stigma by association,' which is directed toward individuals affiliated with a disabled child (Jansen-van Vuuren & Aldersey, 2020), there is little literature available to demonstrate how such affiliative stigma affects the perceptions and experiences of mothers raising highly functional disabled children. Moreover, this study will add to the deficit in literature available that distinguishes between children with CP that have high- versus low-functioning capacities. This study will thus demonstrate that CP is not a homogeneous disorder. Thus this study will make use of language that can encapsulate the nuances embedded in how each individual with CP may present. Similarly, there is an insufficient quantity of literature available that makes use of the interchangeable terms 'high-functioning CP' and/or 'mild CP.' Nevertheless, this thesis will use both first- and third-person language in accordance with the APA which supports both language use. Hence, the respect of disabled people, specifically CP people here and their families, is hopefully upheld.

Research Aim

The aim of this research study was to explore and interpret the reported experiences of mothers who have raised their high-functioning CP children into adulthood. Such reported experiences may refer to the positive experiences and the challenges that mothers have confronted in social settings as well as in an emotional, psychological, and practical capacity.

Research Questions

1. What are mothers' reported experiences of raising their children with high-functioning CP across the child's lifespan and into adulthood?

1.1 What are the emotional experiences of mothers raising a child with mild CP into adulthood?

1.2 How are mothers reportedly impacted by the practical challenges that come with raising a child with mild CP into adulthood?

1.3 How do mothers raising a child with mild CP experience their social world while raising their high-functioning CP child?

Outline of the study

This chapter (chapter 1) focuses on the aims and objectives of the study, delineating the rationale behind the study as well as the research questiones asked. A concise background to

CP as a diagnosis and disability is provided in addition to a conceptualisation and understanding of 'motherhood' as a socio-cultural practice throughout history.

The next chapter (chapter 2) provides a discussion of the relevant literature surrounding the experiences of mothers raising children who have CP. The former experiences are discussed concerning the social, emotional, physical, and practical experiences of mothers as well as their experiences with their children in early infancy, looking at how such experiences can influence parenting styles. Moreover, the importance of early education intervention is articulated as a central component of helping children with high-functioning CP reach their optimal potential in adulthood. Here, this chapter will demonstrate how high-functioning children with CP can be helped to navigate the academic world in the event of being diagnosed with comorbid learning disabilities. The study's theoretical framework is highlighted and provides a firm basis to analyse mothers' experiences and literary knowledge with.

Chapter 3 focuses on the methodological approach to acquiring the data needed for this study. This includes a discussion of the research design and the tools used for data collection, as well as the method(s) employed for data analysis. Additionally, the sample chosen is described in detail and sufficient justification is provided for the chosen demographics of the sample and the sample size. The ethical considerations pertaining to the conduction and analysis of the study and its subsequent data are delineated in the ethics section of this chapter. Lastly, the measures taken to ensure the trustworthiness and credibility of the study are provided and a reflection on my positionality in relation to this current project is emphasised and methods for mitigating the effects of any resulting biases are stipulated.

This methodological outline will be followed by Chapter 4 which will be the findings and discussion component of the study. Here, mothers' experiences of raising a high-functioning CP child into adulthood will be reported and analysed to capture the most salient aspects of their experiences. These aspects of their experiences, namely emotional and circumstantial and their behavioural responses and reactions, will be presented into distinct but sometimes interrelated themes to determine patterns or trends that emerged within mothers' experiences. Furthermore, identifying such similarities or trends among mothers' experiences will be noted as important not because everyone's experiences should be considered identical by any means but so that further research can be conducted on ways to improve how mothers handle their circumstances and/or mitigate some of their adverse emotional and practical experiences while still ensuring the most favourable outcome(s) for their highly-functional CP child.

Lastly, chapter 5 will focus on the implications of the current study and how it can be applied to academic fields beyond psychology and psychological research. This will be followed by a detailed synopsis of the research study's respective limitations and shortcomings as matters such as generalisability and maternal bias will be discussed. Moreover, recommendations for future research will be provided as useful suggestions will be made of matters that could improve our understanding of mothers' experiences.

Chapter 2

Literature Review

This chapter provides an overview of existing literature on the experiences of mothers raising children who have high-functioning CP. First, the term 'highly functional' is provided as a means of referencing the children examined in this study. Here, the importance of early educational intervention in helping such children reach their full academic potential is discussed. The extent to which the necessity for the former can pose a significant challenge to mothers is highlighted. Second, the stage of early infancy is reflected on as a precursor to the parenting choices and emotional experiences of mothers raising children with CP. A delineation of the emotional experiences that govern parenting styles such as overprotectiveness follows. Lastly, an overview of the practical and physical challenges that mothers experience in helping their children with CP is provided.

High-Functioning CP and Educational Intervention

A disability refers to any condition of the mind or body that imposes difficulties on a person's capacity to perform certain activities and/or interact with their surrounding world (National Centre on Birth Defects and Developmental Disabilities, 2020). As formerly mentioned in the rationale, CP is measured on a spectrum from mild to severe. The Gross Motor Functioning Classification System (GMFCS) is one of the most commonly used scales to measure the severity of CP (Palisano et al., 2006). By contrast, standard intelligence tests are often used as a means of testing a child's level of functioning and/or eligibility for remedial schooling placements in the educational system (Sherwell et al., 2014). For this study, individuals with any variant of mild CP are termed "highly functional" (Papageorgiou et al., 2020, pg. 5). Although such individuals are seen to possess a considerable level of cognitive normalcy and/or physical independence, for mothers of these children, however, as previously mentioned, the emotional, social, and practical components of the journey toward ensuring that their child acquires such capabilities are often extremely strenuous. The strenuous nature can be seen as early intervention is essential to minimise the onset or effect of possible learning disabilities (Fluss & Lidzba, 2020). The literature demonstrates that this is the case even for mothers whose children are identified as being cognitively high-functioning early on in their developmental journey (Rosenbaum, 2003). Although many children with CP who walk independently and attend mainstream schools have high-functioning CP, these children often show signs of having a form of learning disability, such as dyscalculia (Fluss & Lidzba, 2020).

The former demonstrates that despite the fact that a CP child may present as cognitively sound, this may not translate into having a sufficient level of academic ability to navigate a mainstream schooling system. Further evidence of this can be seen, to continue the example mentioned above, in the fact that CP children with a learning disability, who attend mainstream schools, may underachieve academically (Fluss & Lidzba, 2020). Therefore, the literature emphasises not only intervention but early parental detection of developmental delays being crucial to minimising long-term developmental discrepancies (Choo et al., 2019). This suggests that an extensive level of input, responsibility, and parental astuteness is required from mothers to ensure that their children can manage their learning difficulties to reach a reasonable academic level. Such intervention can aid in ensuring that CP children can one day pursue a career in their adult lives. Thus, it is understandable that mothers in these circumstances experience overwhelming levels of distress and anxiety (Seroke & Mkhize, 2023).

However, aside from the stress and anxiety related to improving their children's educational prospects, mothers of CP children also have positive experiences relating to how their children have overcome or compensated for these educational difficulties along their journey. Evidence of the former can be seen despite the fact that CP children may take a longer than average amount of time to learn to stand, walk, and/or use their hands, these outward obstacles may conceal great intellectual abilities (Kerekovsky, 1992). This suggests that in the case of high-functioning children with CP, once mothers start working on educational therapies, they become privy to their child's true intellectual potential. The former is evident as providing therapeutic intervention can enable children to catch up to developmentally typical peers (Choo et al., 2019), and ensure that such delays do not become permanent disabilities (Filler & Xu, 2006).

Initial stages of infancy

However, before the child reaches school-going age, mothers of CP children have initial concerns about whether or not their child possesses other difficulties or disorders in the form of comorbidities. This is especially relevant as children who are born with CP and/or developmental complications have often spent their earliest moments of life in the Neonatal Intensive-Care Unit (NICU) due to premature birth having resulted in oxygen deprivation (Jiménez-Palomares, 2021; Zhang et al., 2020). As mentioned previously, children with CP may possess a series of difficulties in addition to physical limitations. These were defined by Goldstein et al. (2005) as including sensation, cognition, communication, perception, and/or

behavioural or seizure disorders. The former suggests that during their child's earliest stages of life, mothers have a considerable reason to worry as doctors try to discern the exact nature of their child's CP diagnosis. Further evidence supporting the former can be seen in a study conducted by Minocha et al. (2017) which concluded that epilepsy was the most common comorbidity alongside CP. In these formative stages, before the outcome of the child can be determined, the mother often experiences trauma upon hearing about their children's diagnosis. Evidence of this can be seen in a study conducted on Taiwanese mothers of CP children which found that mothers tend to experience a sense of loss and grief upon hearing about their children's diagnosis (Phumudzo et al., 2021). The former suggests that mothers tend to prepare themselves for raising a child that has an extremely low functional capacity as they believe this to be the most likely outcome.

Thus, despite the previously mentioned literature which states that most children born with CP respond well to standard intelligence tests (Sigurdardottir et al., 2008), mothers of CP children experience feelings of uncertainty concerning their children's potential outcome as the extent of a CP child's functional capabilities are only able to be determined as a parent progresses along their child's developmental journey. The former is due to the fact that, as mentioned previously, CP is characterised by various developmental delays. Fluss and Lidzba (2020) note that signs of intellectual proficiency may vary depending on what area of the child's brain has suffered the most injury. Thus, despite the availability of tools such as Magnetic Resonance Imaging (MRI) to identify a diagnosis of CP in the earliest stages, doctors are often reluctant to reveal the extent of possible brain injury (Williams et al., 2021). Such reluctance may be due to the fact that the clinical expression of the initial brain injury may change over time as the brain matures (Stavsky et al., 2017). This suggests that brain scans to reveal the extent of a CP infant's brain injury may not be necessary. Neuroplasticity can allow the brain to eventually repair or compensate for potential harm (Zotey et al., 2023). While the former is to be considered a positive outcome, this can leave mothers in a constant state of fear and anxiety.

Furthermore, mothers' emotional distress is often exacerbated by the birth trauma that mothers of CP children have often experienced. This is evident in a study conducted on women in Tanzania which demonstrated that a limited proportion of women can access adequate care at birth (Mselle et al., 2013). However, this occurrence is not exclusive to low-income and under-resourced countries. A study conducted by Khan et al. (2023) tested the impact of neonatal care interventions on high-income countries. Although this impact was noted to be unclear, the former demonstrates that poor neonatal care is not exclusive to low-income countries. This

need to implement neonatal care interventions in high-income countries suggests that neonatal care in these countries is not sufficient as it stands. Thus, the former highlights that mothers of children with CP may have received insufficient care during the birthing stage which will leave them with various emotional experiences.

Emotional Experiences

Mothers of high-functioning children with CP are not only forced to deal with the trauma of a traumatic birth but are also thus put into a situation whereby their children's delayed development causes them extreme emotional distress. The former is evident as mothers struggle to help their children adapt to educational settings that do not cater to their disability-related needs. A study assessing the factors that affect the quality of life of children with CP demonstrated this as many schools were reluctant to accommodate CP children due to the system's lack of competence in helping children with disabilities (Savage et al., 2021). These mothers tend to experience emotional and behavioural dysfunction, including depression (Sajedi et al., 2010). This suggests that mothers often contend with the brunt of the childrearing burden as a result of societal expectations that position women as primary caregivers for their children (Smith & Blamires, 2022). For instance, in the family context, mothers often experience the most guilt concerning their child's circumstances in comparison to other family members (Sajedi et al., 2010). Thus, mothers with CP children tend to exhibit the most stress out of all family members as they are the individuals who - second to their CP child - are perceived as being the most responsible for their children's outcomes. Here, the formerly mentioned construct of 'parental astuteness' is seen to be unfairly applied to and expected of mothers as they adapt to the daily challenges and struggles of childrearing (Meeussen & Van Laar, 2018).

The injustice of the former is further revealed as mothers of CP children do not necessarily have the experience and/or knowledge to identify indicators of developmental delays (Wise & Gellasch., 2022). Wise and Gellasch (2022) further demonstrated in their study on mothers of children with CP, that healthcare providers dismissed possible indicators of developmental delays, saying that the mothers should just be patient. Despite the former mentioned delayed diagnosis being the fault of doctors' negligence, a study conducted on mothers of children with a disability such as CP demonstrated that mothers in such extenuating circumstances experienced a more pronounced sense of guilt than mothers with typically developing children (Sedova et al., 2022). The former was noted to be because these parents are more emotionally

affected by their children's difficulties and limitations (Sedova et al., 2022). Hence, mothers with disabled children tend to perceive their children's capacity to meet developmental milestones as reflective of whether they (as mothers) are making the best or most informed choices to assist their children in getting ahead in life.

In addition to the aforementioned sense of guilt, mothers contending with disabled children are often forced to contend with stigma and discrimination (Jansen-van Vuuren & Aldersey, 2020). In a schooling context, such experiences can be attributed to teachers' misunderstanding of disabled children's capabilities and needs (Gyasi et al., 2020). This is specifically the case for mothers whose children have discrepancies in certain areas of learning. Children with CP often perform poorly in mathematics. Thus, these children are often diagnosed with dyscalculia (de Freitas Feldberg et al., 2021). For mothers of CP children with this mathematical disability, gaining a level of understanding from teachers in mainstream schooling environments poses a stressful and significant challenge that causes great anxiety. This may be because dyscalculia is an understudied learning disability (Bulthe et al., 2019). However, research also demonstrates that children with dyscalculia are often very proficient in languages. Evidence supporting the former denotes that despite mathematical deficiencies in individuals with dyscalculia, their language skills and memory for written words may be at a highly advanced level (Scully, 2014). Thus, the deficit in research conducted on dyscalculia and discrepancies in areas of learning can result in mothers with cognitively high-functioning CP children experiencing undue discrimination and a lack of assistance. Educators tend to believe that children cannot be highly gifted and capable while struggling with disabilities simultaneously (Klinger, 2022). Thus, despite evidence that suggests that the mothers' levels of emotional distress are dependent on the severity of their child's disability, there is a prevailing lack of understanding regarding high-functioning disability (Yilmaz et al., 2013). This results in intense levels of depression and distress among mothers of children with mild CP (Yilmaz et al., 2013).

This feeling of helplessness and despair is exacerbated as mothers are forced to contend with the emotional toll that 'not being catered to' by the educational system has on their children. Evidence supporting the former can be seen in a study conducted on disabled children from rural mainstream primary schools in Guyana (Lashley, 2023). The results of the study revealed that these children experience loneliness and perceive themselves to be undervalued as members of their school (Lashley, 2023). Thus, despite the former mention of the isolation that mothers of highly functional CP children experience, the former highlights the reality that

second to their grief and disappointment, mothers of high-functioning CP children feel acutely impacted by the distress of their children. Here, the aforementioned reality that mothers of CP children feel that they are responsible for their children's success and/or failure causes dysfunction as mothers perceive themselves as being responsible for the educational system's actions that are not in their control. Evidence of this can be seen in a study conducted by Ryan and Cole (2009) which demonstrated that advocacy and activism are seen as being implicated within the roles of mothers with disabled children, as mothers tend to adopt this role collectively or on their own accord. Consequently, mothers of disabled children are noted as experiencing higher levels of stress, anxiety, and depressive symptoms than mothers of typically developing children (Parkes et al., 2011), as they feel obligated to fight harder for their children's rights than mothers of typically developing children. Such persistence can be explained by the previously mentioned sense of guilt that mothers tend to experience upon witnessing their disabled children's difficulties. Such frustration can be resultant from mothers' awareness of their child's potential to achieve if provided with the right concessions (Ntinda, 2015).

In addition, the sense of emotional dysfunction that mothers experience is often exacerbated as mothers of CP children often feel the urge to overprotect their child from experiencing further hardship in addition to the difficulties they have already been experiencing since birth. Evidence supporting the former can be seen in a study conducted by Gagnon et al. (2020) which demonstrates that overparenting has a greater behavioural presence in parents of disabled children in early adolescence. This parenting style can be defined as a series of behaviours by parents that are well-meaning but are carried out at an obsessive level (Ganon & Garst, 2019; Segrin et al., 2012). Here, the previously mentioned behavioral dysfunction caused by emotional disturbance present in mothers of CP children is further exemplified. However, such dysfunction and presenting frustration may feed into 'helicopter mothering' that discourages independence through overinvolvement (Miller et al., 2024).

Moreover, the reality that mothers of CP children may develop an overprotective parenting style as a result of their having experienced trauma should be highlighted. The former is especially the case with mothers who may have almost lost their CP children to stillbirth and/or prematurity. Evidence supporting the former suggests that parents who are placed in the NICU witness their children being subjected to intensive medical care in a strange setting (Shaw et al., 2023). Thus, overprotective parenting may emerge as a coping mechanism for parents who wish to help their children avoid further difficulties and trauma. Evidence supporting the former

suggests that pre-term birth may have long-lasting effects that manifest themselves as symptoms of Post-Traumatic stress disorder (PTSD), affecting the mother-child relationship (Suttora et al., 2014). The former suggests that mothers of children born under such extenuating circumstances grapple to acclimatise to their way of living, even after several years. Further evidence supporting the former suggests that as the demands of taking care of a child with a disability increase, mothers can feel increasingly helpless, depressed, and incompetent (Crnic et al., 1983). Such mothers may display overprotective behaviours toward their children to disguise feelings of being out of their depth when it comes to helping their children. Evidence supporting the former can be seen in a study conducted by Jankowska et al. (2015). The study demonstrated that despite being accepting of their children's CP, many mothers tended to display overprotective and demanding attitudes toward their children.

Furthermore, the literature suggests that mothers' personality traits influence emotional experience. Evidence supporting the former suggests that mothers who displayed higher levels of neuroticism tend to be more overprotective and demanding of their children (Jankowska et al., 2015). Such overprotectiveness and expectations that result from a neurotic personality type can be seen to influence the overall outcome that mothers are willing to accept, as well as the extent to which mothers are happy and/or accepting of their children's end prognosis. Evidence supporting the former can be seen in a study conducted by Naletilić et al. (2017). The study found that mothers who exhibited higher levels of neuroticism were reported as having a lower quality of life. Gambhir et al. (1993) suggest that parental attitude is influenced by the severity of the child's disability, however, Naletilić et al. (2017) suggest that this is not the case. Thus, although Gambhir and colleagues suggest that the severity of CP is an essential influencer of parental attitudes, Naletilić et al. adopt a more optimistic stance by suggesting that with the right attitude and enough effort, CP children's functional capacities can improve. Furthermore, a study conducted in the United States of America demonstrated that the extent to which mothers believe that their interactions and parenting practices can influence the outcome of their child is noted as a significant factor that motivates/deters parental involvement (Bramesfeld et al., 2013). While this study specified their sample as being children under the age of 5 years, I suggest that the importance of a positive attitude is paramount to childhood progression with age. In favour of the latter is literature that suggests that mothers' attitudes can have a significant influence on the attitudes of their children (Rudebeck, 2020). Thus, the former not only highlights the importance of parental involvement to achieve progression. The value encompassed in adopting an overtly positive attitude regardless of their feelings of self-

doubt is demonstrated. This can set a precedent for their children's cooperation in advancing functional prospects.

Furthermore, positive beliefs held by mothers concerning their children's potential can significantly influence the extent to which parents pursue high-functioning possibilities in raising their children. Evidence supporting this suggests that it is not just parental involvement that is important for the adjustment of children and adolescents, but also the parenting strategies adopted (Ridao et al., 2021). While the former discusses adjustment from the psycho-social perspectives of children, the literature suggests that parental strategies are important to all circumstances concerning childrearing. An example of such a strategy may refer to careful planning to ensure that children's physical therapies do not interfere with their university or school learning. Evidence supporting the former suggests that fatigue is already present at a young age in adults with CP (Russchen et al., 2014). Such levels of fatigue are known to equally affect focus depending on its severity. The former highlights the importance of engaging in academic activities before exercise to maximise focus. Thus, decision-making about the most effective and efficient amount of therapy, as well as the time of day at which therapy is conducted are important (McCoy et al., 2019; Verschuren et al., 2021). Thus, despite the seeming insignificance of such minutia, these details can impact the abilities of children with CP to engage in and absorb the information obtained in therapy. This impacts the outcome of such interventions and can aid in improving upon the child's prognosis and informing the subsequent lifestyle to which mothers have to adapt.

However, despite the importance of such careful planning and continued effort, adopting such an optimistic attitude while raising a child with CP is easier for mothers if their children are high-functioning. This is evident as, despite the aforementioned uncertainty that mothers of CP children experience due to delayed milestones, these children do tend to develop the required abilities to precipitate independent daily functioning. Evidence supporting the former suggests that efforts to stand and the ability to sit independently at 2 years of age have been associated with future walking (da paz Junior et al., 1994; Molnar & Gordon, 1976; Wu et al., 2004). Thus, despite evidence that suggests that mothers of CP children are forced to adjust their expectations of their children upon receiving a diagnosis (Guimareas et al., 2023), mothers of high-functioning children tend to gain a feeling of emotional equilibrium as they watch their child start to complete expected milestones. Evidence supporting the former can be seen in a study conducted by Schuengel et al. (2009) suggesting that resolution in parents of older children was demonstrated through more focus on interventions to improve their children's

lives as opposed to passive fixation on their children's existing outcome. Similarly, such resolutions toward diagnosis were presented as being more evident in parents of high-functioning children (Schuengel et al., 2009). Thus not only are mothers' emotional experiences influenced by their feelings of guilt and the need to overprotect their children, but the personality traits, attitudes, and belief systems of mothers are noted as impacting their experiences of raising children with high-functioning CP into adulthood.

Physical and Practical Challenges

Moreover, depending on the manifestations of the high-functioning individual's CP, accessibility issues can remain a relevant obstacle with which mothers have to assist their children with. Evidence supporting the former can be seen as the obligations of taking care of a child with CP are noted as being strenuous and adversely impacting the mother's physical as well as their socio-emotional well-being (Davis et al., 2010). Thus, the intensive levels of physical therapy that a child with CP requires, in addition to their required early educational interventions, can be particularly overwhelming for mothers. Despite the reality that many children with high-functioning CP can walk independently, strength training and stretching are often required to maintain this level of functioning (CDC, 2023; NINDS, 2023). Evidence supporting the necessity of such interventions can be seen in a study conducted on mothers in Zambia. The Zambian study demonstrated that mothers with CP children experienced accessibility problems in town relating to architectural structures without elevators or ramps (Singogo et al., 2015). This suggests that physically independent children with CP may still require support structures such as ramps or elevators to help them navigate difficult terrain or structures. Thus, for mothers, the uncertainty as to whether these prerequisites will be met can cause a significant amount of distress. Evidence supporting the former can be seen in mothers of children with Developmental Coordination Disorders (DCDs) who have observed their children's struggles in navigating stairways (Kaufman & Schilling, 2007). This suggests that mothers of children with motor-coordination disabilities such as CP, have significant reason to worry about whether or not there are additional support structures in place to help their children navigate to different areas.

Furthermore, individuals with CP not only find simple movements such as walking and balancing to be more challenging than individuals who are non-disabled but, as mentioned previously, they may also struggle to negotiate long distances (NINSD, 2023). Balance and endurance presents as the primary factors that limit the walking abilities of individuals with CP

(Nelson & Boyer, 2021). Therefore, the distances with which disabled children have to contend are a practical difficulty that may cause mothers of children with mild CP considerable levels of stress. Evidence supporting this demonstrates that mothers tend to experience difficulties relating to physical access or transport challenges and/or terrain that is unmanageable for their children to navigate (Singogo et al., 2015). The former suggests that although the severity of CP should be considered when applying for social benefits (Alriksson-Schmidt et al., 2021), recognition of the benefits of providing social benefits regardless of severity should be noted. Evidence of this can be seen in a recent study conducted in Saga concerning the necessity of the appropriate width of parking spaces for disabled individuals with vastly differing severity levels (Lu et al., 2015). The former study has implications for mothers raising high-functioning CP children who require the availability of disabled parking bays without question or speculation by other community members concerning their needs and/or motives. While attending physical therapy has been noted as a possible means of improving CP children's physical stamina and strength to better perform basic activities, this does not guarantee better gait functioning that would make walking distances easier to manage (Maltais et al., 2014). Further evidence supporting this suggests that the effects of physiotherapy are inconsistent (Das & Ganesh, 2019). Thus, despite the reality that mothers of children with high-functioning CP can aid their children's physical abilities through the help of physical therapy, this does not mitigate the uncertainty these parents feel as a result of living in a society that does not cater to many of their basic physical limitations.

Social Experiences

Lastly, mothers of children with high-functioning CP also experience social difficulties alongside the abovementioned challenges. In a study conducted by Singogo et al. (2015), mothers experienced social isolation from members of their community. This social isolation was partly noted as being a consequence of mothers' fears that people would not accept their children or blame them for their children's disability and is seen to be partly self-inflicted. However, the social experiences of mothers who have disabled children cannot be perceived to be a product of the mother's internality to the exclusion of other factors such as social support, even for mothers of highly functional disabled children. Evidence supporting this demonstrates that the attitudes of the broader public toward children with CP and their families can contribute to the experience of psychological trauma (Olawale et al., 2013). In contrast, a study conducted on the effects of social support on depression of mothers with CP children demonstrated that continued social support was effective in reducing depression (Park, 2023a). Not only is social

support effective in improving mothers' mental health and well-being, but the extent to which social support is sustained can have a significant impact on mothers' overall experiences. Despite the importance of social support, the former demonstrates that the social exclusion of mothers with CP children can take place through intentional discrimination, such as excluding mothers from social events (Smith & Blamires, 2022). However, phenomena such as "stigma-by-association" suggest that mothers may be discriminated against inadvertently because they have children who are disabled (Pryor & Reeder, 2011, p. 9). This suggests that many mothers of CP children may be exposed to social exclusion even if this is not intentional. Thus, despite their children's high-functioning status, mothers of CP children are often perceived as having an anomalous circumstance that others find difficult to relate to in social situations. Moreover, the social experiences of mothers with disabled children are not only hindered due to stigmatisation. In addition, mothers of CP children often have an imbalanced lifestyle as a result of the aforementioned demanding responsibilities with which mothers have to contend (Nazi et al., 2017). Parents of disabled children tend to be more involved in their child's transition from high school to university, as this transition often poses greater difficulties for individuals with a disability (Lane, 2017). This suggests that the social experiences of mothers raising children with CP are often negative as raising high-functioning disabled children continues to be demanding and all-consuming even when their child has reached adulthood.

In addition, the socialisation of mothers with high-functioning CP children can also impact the less obvious social engagements or interactions that mothers experience on a day-to-day basis. Such interactions may include mothers' opportunities to bond effectively with their spouses and/or other children. This is evident as although a study conducted by Olawale et al. (2013) found that none of the participants reported marriage difficulties as a result of having a child with CP, the literature suggests that being required to meet the various needs of CP children can harm marital relations (Davis et al., 2010). Further evidence supporting the former suggests that even though mothers of CP children contend with the brunt of caregiving duties both parents are equally affected by their child's disability (Seroke & Mkhize, 2023). However, the literature does not specify how or in what regard fathers are impacted by their children's CP leaving us to believe that much of the marital strain that occurs between parents of CP children is due to mothers feeling overburdened. Evidence supporting the former suggests that marriages involving CP children may suffer due to factors such as stress, guilt, and blame (Vijesh & Sukumaran, 2007). Although interventions such as couple's therapy to work on a co-parenting alliance are noted as being a significant and helpful solution (Darwiche et al., 2022),

such forms of mediating difficulties in relationships caused by the hardships of raising disabled children are not always effective.

The 'glass-child' phenomenon suggests that the vulnerabilities and needs of siblings of disabled children are often overlooked (Rainbow Trust, 2018). Such circumstances in which siblings of disabled children are overlooked may be because, as mentioned previously, assisting disabled children to become as functional and independent as possible often involves an extensive amount of input from parents, leaving little time to nurture other relationships. Furthermore, siblings of disabled children are often expected to help their parents by adopting a nurturing role and therefore are expected to help in raising their disabled sibling(s) (Hanvey et al., 2022). Thus, the siblings of disabled children may be provided with the impression that their needs come second to those of their disabled siblings. Further evidence highlighting the impact of being raised alongside a disabled sibling highlights that being asked to fulfill excessive caretaking responsibilities and neglect are often struggles faced by the siblings of disabled children (Rossiter & Sharpe, 2001). The former demonstrates the extent to which mothers caring for children with CP, despite their disabled children's highly functional level, often struggle to attend to the entire family's needs. Here, the extent to which the mother has a partner to whom she can look for support is noted as being incredibly assistive in helping the mother along her journey (Song et al., 2015). This suggests that mothers of CP children who have more than one child tend to experience significantly less guilt if they are aware that they have a dependable partner to co-parent with. Evidence supporting this denotes that biological, married parents tend to make greater investments in their children regardless of their financial status (Berger & Font, 2015). The former suggests that in modern-day contexts, fathers are perceived as being capable of stepping in to assist in the childrearing process. Evidence supporting this can be seen in a study conducted by Pelchat and colleagues. The study found a positive outcome emerged in which parents united in their common goal to help their child gain independence (Pelchat et al., 2009). Thus, the aforementioned demonstrates that the extent to which mothers of CP children are provided with adequate assistance has a significant impact on how mothers experience raising a child with CP.

Moreover, of crucial significance to the mothers' experiences of raising a high-functioning disabled child is the bond or level of closeness that mothers develop with their disabled child. Evidence supporting the former can be seen as emotionally available parents promote their child's ability to grow and develop healthily (Barfoot et al., 2017). While there are studies available that suggest that mothers tend to develop a mental representation of their child during

pregnancy (Karstad et al., 2023), these studies tend to suggest that once mothers are aware that their children are at risk of developing untypically, these mothers disengage from their reality (Vreeswijk et al., 2012). The former studies, although depicting the trauma mothers often experience at the prospect of raising a child with developmental delays, portray mothers of high-functioning CP children in a less capable light than they turn out to be in bonding with their children and fostering their children's trust. Such trust and rapport can be noted as instrumental in helping CP children reach a highly functional level. Evidence supporting the former suggests that harnessing a relationship between parents and their infants is essential to ensure the effective application of early interventions (Harniess et al., 2022). This suggests that although the process of helping CP children reach a highly functional level is often very strenuous and the quality of the bond between mother and child is crucial in influencing the child's outcome. Furthermore, mothers who perceive their children as providing them with a source of comfort and companionship tend to experience the journey of raising their children more positively. Evidence supporting the former suggests that mothers can draw inspiration from their children (Davis et al., 2010). Furthermore, despite evidence that suggests that parental bonding may be delayed due to the physical condition of premature infants at birth (Robson & Kumar, 1980), the reality that mothers of CP children spend an extensive amount of time with these children due to the need to rehabilitate them suggests that this 'chasm' can be rectified. Evidence supporting the former suggests that the companionship of parents has been seen to result in closer connections between parents and children (Chi et al., 2019). Thus, the aforementioned demonstrates that the social experiences of mothers of children with high-functioning CP are multifaceted and intricate as they are exposed to discrimination and the unique opportunity to form an indescribable bond with their disabled children.

Conclusion

In conclusion, the experiences of mothers with disabled children are unique in the levels of emotional, practical, physical, and social strain that childrearing of this nature brings. Such experiences place the depression and anxiety that these mothers contend with in context. The concerns that mothers experience regarding their children's cognitive competency are highlighted as a significant obstacle with which mothers are forced to contend at the start of their motherhood journeys. Moreover, high-functioning individuals with CP are generally only considered to be on the lower end of the severity spectrum once they have reached a considerable point of advanced functionality. Although CP is not a progressive disability, the clinical expression of the initial brain injury may change over time as the brain matures

(Stavsky et al., 2017). This leaves many mothers in an anxiety-exacerbating predicament whereby they have to endure a considerable length of time before they are provided with perspective or closure to witness the prognosis of their child's disability. Thus, greater research should be invested in understanding this maternal experience to assist in improving the well-being of mothers on the path toward raising their child to conquer adulthood.

In addition, this study intended to explore the practical challenges that mothers with high-functioning CP children face. Such challenges have been demonstrated as having a prevailing effect on the emotional well-being of mothers. Further evidence supporting this can be seen on the GMFCS scale which demonstrates that mothers of children with high- (motor)functioning CP present with greater levels of distress than children with low – (motor) functioning CP (Ribeiro et al., 2014). Such distress may be as a result of the effort involved in helping high-functioning children to navigate terrain that is not disability friendly. Thus, despite the relative levels of independence of high-functioning individuals with CP, the lack of support and assistance provided to disabled individuals in this context is seen to exacerbate the already strenuous realities with which these mothers live.

Lastly, mothers of children with CP often find their journeys to be time-consuming and isolating. These mothers find that their children, despite being highly capable and high functioning, continue to benefit from parental involvement into adulthood (Lane, 2017). Simultaneously, many mothers tend to isolate themselves due to fear of the stigma and blame associated with having a disabled child (Singogo et al., 2015). This suggests that despite the formerly mentioned advanced capabilities of high-functioning disabled children, mothers of these children often experience blame. Such blame is directed towards these mothers by members of the broader community who believe them to be the cause of their child's disability. Thus, despite the aforementioned importance of support, many mothers with CP children are not provided with adequate levels of socio-emotional support. Hence, continued research should further explore how mothers of CP adults can be assisted in managing their own as well as their adult children's lives while maintaining a lifestyle that is not detrimental to the mental health of themselves or their children.

Theoretical Framework

The theoretical framework for this study will refer to the medical and social models of disability. The medical model differs profoundly from the social model in how it conceptualises disability (Hogan, 2019). These models refer to ways of thinking about disability and our

approaches to disability as a phenomenon that we need to contend with in our society. The medical model perceives disability as a form of functional impairment relating to the body that is inherently pathological in nature (Olkin, 2022). This model emphasises intervention to correct the individual's disability as its main objective (Olkin, 2022). However, this model and way of thinking about disability has endured extensive criticism for its pathologisation of disability and its objective of helping disabled individuals become 'normal' through treatment (Olkin, 2022). The social model, however, considers the individual's environment that can either impose or mitigate the individual's experience of disability (Guccione & Elrod, 2012). Thus, the social model was developed in response to the medical understanding of disability and proposed that disability is a label conjured into being by an unaccommodating and oppressive society rather than being the fault of the compromised individual (Hogan, 2019). I suggest that both models will be useful in conceptualising the experiences of mothers raising children with CP because mothers with CP children often struggle to navigate social settings due to stigma (Whittingham et al., 2011). While the former denotes the importance of the social model of disability, mothers often experience premature feelings of loss and grief as they assume the worst concerning their child's prognosis (Phumudzo et al., 2021). This highlights the applicability of the medical model to these mothers' experiences.

Chapter 3: Methodology

Research Design

This study employed a qualitative research design, examining personal experiences as the phenomena of interest. Qualitative research refers to a method that highlights experiences, perceptions, and, behaviours as an area of study (Tenny et al., 2024). It thus enables inquiry into unquantifiable human experiences (Cleleland, 2017). Such unquantifiability and complexity pertained to the experiences of mothers with adult children who were born with CP. This was evident as each parent had highly nuanced and intricate interpretations of their journey of having raised a disabled child. In such a context, qualitative analysis provided a means of amplifying the emotional depth and nuances present in mothers' interpretations of their experiences (Sakwape et al., 2023). These perspectives were gathered using an interpretivist paradigm to provide insight into the participants' subjective understandings of their realities as opposed to having explored a definitive and universal understanding of the social world (Greener, 2008). This approach not only denotes reality as being based on an intimate and personal construction (Salice & Schmid, 2016), it highlights the former mentioned reality that there are different permutations of high-functioning CP as a phenomenon that may impact the journey of mothers in vastly differing ways. The form of phenomenology most relevant to this study was Hermeneutic Phenomenology, which tries to encapsulate the complexities embedded in individual experience (Dangal & Joshi, 2020). An example of an individual experience would include mothers of children whose CP presents as Spastic Hemiplegia. As was mentioned in the literature review above, Spastic Hemiplegia is a form of CP that often affects children who are of a highly cognitive or functional level (Riad et al., 2008). The former suggests that a mother's construction or interpretation of her experience of raising her child may vary depending on what aspect of her child's functionality has been most affected by CP.

Moreover, the importance placed on individual experience extends to the emotional internalities of the mothers. Thus, despite generalised evidence that states that mothers of children with developmental disabilities contend with considerable levels of stress (Feizi et al., 2014), the matters which cause these mothers emotional distress may be dependent on the areas in which their children require the most assistance to function. Thus, accessing the emotional internalities of mothers who are have raised CP children into adulthood is central to understanding their individual experiences and realities. Furthermore, this accessing of

emotional internalities and perspectives is in line with the epistemological assumptions upon which the current research was based. The epistemological underpinnings of research refer to the means via which a form of knowledge is accessible or discernible to whoever intends to study it (Al-Ababneh, 2020). This study assumed that the perspectives and experiences of mothers who have children with CP were accessible through the use of semi-structured interviews. In addition, the ontology of a research study examines how phenomena under question are conceptualised by individuals, as well as whether these phenomena are socially constructed or exist independently (Reman & Alharthi, 2016). In this study, the ontology of childrearing experience and disability was conceptualised as being dependent on a myriad of factors that can exacerbate or alleviate the difficulties mothers experience.

Such factors may include social, emotional, and practical support and acceptance. This is evident as looking after a child who has CP involves extensive practical and emotional investment (Phumudzo et al., 2021). Mothers in these circumstances may confront various circumstances that harm their ability to function socially (Phumudzo et al., 2021). Here, the appropriateness of a phenomenological study to illustrate and describe the essence of an individual's experience was highlighted (Teherani et al., 2015). Hermeneutic Phenomenology thus enabled the researcher of the current study to understand how participants make sense of their experiences as mothers of CP adult children. The study can also potentially provide insight into how mothers understand their respective roles as important members of their child's journey. Thus, developing a knowledge of how and why mothers of disabled adults may have reacted to and influenced their surrounding environment in different contexts is critical. The former can be assistive in developing a holistic understanding of how the mothers who formed the participants in this study experience or may have experienced their extenuating circumstances.

Sample and Sampling

The sample for this study consisted of a minimum of eight and a maximum of twelve participants who have had personal experience in raising a child with mild CP into a highly functional or capable adult. Such functionality may present in either a physical and/or cognitive capacity. The children that were in question must have received a diagnosis of mild CP at some point along their journey to adulthood, and this must have been made by a medical specialist such as a doctor or physiotherapist. Moreover, the mothers of these individuals must have had a considerable level of involvement in aiding or supporting their child along their journey and

were willing to share their experiences of their social, emotional, and practical challenges, as well as their interpretations of their experiences in assisting their child. Only the mothers who had a child with CP that were at least 20 years of age or older were chosen. This is because I was exploring the experiences of mothers across their son's or daughter's childhood. Furthermore, the participants had to be the biological mothers of the children in their care because these mothers would have a measure of their child's development from birth until the present moment. Moreover, being the biological mothers of their children could make the experiences of their journey more intimate due to the emotional investment that mothers have with regard to the success and wellbeing of their children. Exclusionary criteria pertained to mothers of individuals under the age of twenty, individuals whose presentation of severe CP means that they are unable to function at a high level in cognitive and/or physical domains and are thus considered low functioning. Moreover, mothers who are not the child's biological mother were to be excluded.

The study used purposive sampling methods. Following the understanding of Braun and Clarke (2013), this sampling strategy was effective as the participants comprised a targeted sample who met specific criteria and characteristics necessary to the research questions. Thus, individuals were selected based on whether they have adult children with high-functioning CP. These individuals were assistive as their circumstances enabled the mothers to purposefully inform an understanding of the research problem (Creswell & Poth, 2016). Thus, although the formerly mentioned strategy and sampling size did not enable generalisability, the former was effective in gathering data for a qualitative study that intended to uncover and illuminate the emotional depth in mothers' interpretations of their experiences (Patton, 2002). I intended to gather participants through means of making personal contact with certain participants from my WhatsApp/Facebook contact list and requesting written permission to interview them about their journeys. Moreover, I contacted organisations such as Therapyworx Physiotherapy Centre to gather participants who were willing and interested in participating in the study. Furthermore, I requested that the participants gathered from this therapy practice inform other suitable candidates about the study, thus making use of a snowball sampling technique in this regard. This sampling method is commonly employed in qualitative research and refers to the collection of research participants through the help of another participant who passes on information concerning the research study to other suitable volunteers or participants (Kirchherr & Charles, 2018). The table below outlines the demographics of the participants.

Table 1: Demographics of Participants

Mom Psuedonym	Child age	Daughter/Son	Child Pseudonym	SES	Other children	Other children Age	CP child currently doing	Diagnosis	Prog-nosis
Linda	27	Daughter	Nicole	Lower-middle	1 daughter	23	Uni	Yes(6-9 months)	Bleak
Janet	21	Son	Brian	Middle class	1 son	22	Comm pilot license	Yes(6-8 months)	Can't remember
Michelle	33	Son	Wayne	Pref no	1 son, 1 daughter	Son (31) Daughter (28)	Runs business	Yes(in infancy)	Mild-left side affected
Alison	33	Son	Eric	Upper middle	1 son	36	Data Processor	Yes (1 and a half yrs)	Mild quad-raplegic
June	20	Son	Ron	Middle-upper	Triplets (2x girls and CP child)	20	Studying to be a pilot	Yes (2 and a half/3)	Di-aplegic
Amanda	41	Son	Harry	Pref no	None	None	Un-employed	Yes 3 mnths	Bleak
Lisa	35	Daughter	Sally	Middle class	3-Son, daughter, daughter	41, 39, 31	Un-employed	Yes 8 mnths	Spastic quadraplegic
Jessica	20	Son	Steven	Middle class	3 other children	16, 14, 10	Studying	Yes 2 yrs old	Hemi-plegia

Table 2: Demographics of Participants Continued

Mom Psuedonym	Child age	Daughter/Son	Child Pseudonym	Spectrum	High Functioning	Walk/move independently	Extra therapies
Linda	27	Daughter	Nicole	mild	Yes	Yes	Yes
Janet	21	Son	Brian	mild	Yes	Yes	Yes
Michelle	33	Son	Wayne	mild	Yes	Yes	Yes
Alison	33	Son	Eric	mild	Yes	Yes	Yes
June	20	Son	Ron	mild	Yes	Yes	Yes
Amanda	41	Son	Harry	Mentally High Functioning, low physical Functioning	Yes	No	Yes
Lisa	35	Daughter	Sally	Cognitively High functioning, in wheelchair to leave house	Yes	No	Yes
Jessica	20	Son	Steven	mild	Yes	Yes	Yes

Data Collection Method and Procedure

Once ethical clearance was obtained from the Human Research Ethics Committee (Non-medical) at the University of the Witwatersrand, a letter of participation was drafted and sent to all participants (please see Appendix B). This participant information sheet was drafted either via email, given that the participants consent to provide their email address, or in print form if preferred. This letter of participation included a summary of the purpose of the study as well as an explanation of how the data collected from the study was to be used. All data was collected through the conducting of semi-structured, one-on-one, in-person interviews. This form of interview requires participants to answer pre-set and open-ended questions (Jamshed, 2014). This form of interviewing enabled the collection of data that is in-depth enough to capture the nuances of individual experiences, while still maintaining focus on the overall research question that was being studied (Creswell, 2007; Longhurst, 2009). Evidence supporting the effectiveness of this method of data collection for this particular study suggests that CP is a heterogeneous disability with differing clinical presentations and variations (MacLennan et al., 2015). Thus, semi-structured interviews were a suitable means of encapsulating the uniqueness of each mother's reported experience as part of an interpretive, phenomenological research study. This interview method enabled mothers to make sense of their child's capabilities and/or their diagnosis for the researcher to interpret. After reviewing the literature, I drew up an interview schedule (please see Appendix A), which refers to a schematic representation of questions or topics that the interviewer intended to investigate (Dicicco-Bloom & Crabtree, 2006). The interview schedule was not to be too prescriptive and thus allowed for flexible answers that reflect each participant's understanding(s) and interpretation(s) of their personal experiences. Interviews were held in person as far as possible at the University of the Witwatersrand's Emthonjeni Centre at a time suitable to the participants. If participants volunteered to participate who were outside of Gauteng, an online interview via Zoom or WhatsApp call was set up. This entailed the arrangement of an agreed-upon date and time at which to conduct the call between the participant and the interviewer. Flexibility on part of the interviewer was adhered to in order to best suit the participant as far as possible. All interviews were audio recorded with participants' consent and then transcribed verbatim by myself.

Data Analysis

According to Braun and Clarke (2006), Thematic Analysis (TA) is a method used for identifying, analysing, and reporting patterns or 'themes' in qualitative data. As part of this method, an interview schedule was created (please see Appendix A), and all interviews were audio recorded and transcribed verbatim. In Braun and Clarke's (2022) latest work 'Conceptual and Design Thinking for Thematic Analysis', TA is considered to require more of a reflexive process. This process requires the researcher to constantly make sense of and engage in choices concerning why he or she has chosen specific themes to answer their overall research question (Braun & Clarke, 2022). Thus, while Braun and Clarke's (2022) perspective on TA continues to praise this method for its flexibility, it argues that the researcher is required to devise an in-depth understanding of the collected data before one can embark on the process of coding. In keeping with Braun and Clake's (2006) directive, I first familiarised myself with the collected data. This process was followed by the previously mentioned step of generating initial 'codes' or identifying interesting features across the data set (Braun & Clarke, 2006). Moreover, to make better sense of the features identified, I was reflexive in collating the various features found in the collected data into overall themes (Braun & Clarke, 2006). The themes identified were semantic as well as latent in nature as I reported on and interpreted the experiences of participants. Such practices are in keeping with the principles of the Interpretive Phenomenological approach to research (Smith & Osborne, 2015). Under the branch of Phenomenology, as previously mentioned, hermeneutics was implemented as this enabled me to discern unique features embedded in each participant's experience (Nigar, 2020). Lastly, the final report on the study was compiled and produced once the former process had been completed (Braun & Clarke, 2006).

Credibility, trustworthiness, and reflexivity

Qualitative analysis is generally considered to be lacking in empirical value and rigorous conclusions (Cope, 2014). The former is considered to be because the central objective of interpretivist, qualitative research is to make sense of subjective (and thus unquantifiable) human experiences (Guba & Lincoln, 1989). Moreover, it is believed that the criteria for judging validity in instances of personal and social construction are not absolutist (Bradley & Schaefer, 1998). This means that there is no tried and tested method that one can trust against which to measure the accuracy with which one recalls and/or interprets human experiences. However, Guba and Lincoln's (1985) points towards trustworthy qualitative research were

considered to ensure that the study conducted garnered results that were as close as possible to mothers' actual experiences by ensuring Confirmability. Moreover, the method of Triangulation was adhered to as discernable patterns were emphasised, reinforcing that identified phenomena were present in the data (Stahl & King, 2020). Furthermore, dependability was ensured through continuous communication with my supervisor. The former consistent dialogue, in addition to subjecting my research to peer scrutiny through internal and external evaluation of the finished thesis, ensured that the findings presented were trustworthy (Stahl & King, 2020). The results and findings of my research study cannot be considered easily transferrable as not many mothers of CP children have adults who operate at such a highly functional level (Lincoln & Guba, 1985). Thus, several precautionary measures were taken by myself and my accompanying supervisor to ensure that the research conducted and conclusions drawn were as trustworthy and reflective of each participant's experience as possible. The participants were under no circumstances coerced to participate in the study through the use of incentives, thus ensuring that the experiences gathered were not the product of manipulated data and were as close to each participant's 'truth' as possible. Concerning the latent component of this study, no information that was inferred about the participants and/or their children portrayed them in an unflattering manner. Furthermore, the data collected was stored on a password-protected computer. Braun and Clarke's (2006) steps for the completion of rigorous data analysis were implemented in the process of analysing all collected data. My research proposal was reviewed by the University of the Witwatersrand's Human and Research Ethics Committee (non-medical) and data collection only took place once I had received ethical clearance. Only myself and my supervisor have had access to the data.

As a female Masters student in the field of Research Psychology, I have a keen interest in the emotional experiences of women with disabled children. Moreover, my experience as a child with mild Cerebral Palsy who has developed into a highly functional adult reinforces my interest in this subject matter. However, I am aware that as a result of this topic's personal relevance, and my positionality as a Psychology student studying toward a Masters degree, I may possess some inherent biases concerning matters of childrearing. Such biases may refer to a preconceived notion of the 'correct' way of raising a child with CP to achieve the most functional outcome. Such preconceived ideas may also pertain to the age at which mothers are supposed to start taking their children to physical therapies (9 months in my mom's experience), as well as the amount of time and energy mothers should invest in addressing any learning delays or difficulties the child may have. In addition, I acknowledge that my race and

class as a white, middle-class female in South African society have impacted the financial and social privileges I have been able to access in a neo-colonial, post-Apartheid society. Consequently, my perception of what constitutes the most necessary resources to assist mothers in raising their disabled children might be unrealistic. I am further aware that my mother's educational background of having received an Honours degree in Psychology at the University of the Witwatersrand may have provided her with a certain depth of knowledge and access to resources that many mothers may not possess. These difficulties posed as a result of my positionalities were mediated by the practices of reflexive note-taking and journaling after each interview. These practices helped me to be more aware of separating my preconceived ideas from the beliefs and opinions of the participants that I interviewed. Similarly, I consulted with my supervisor to gain a more objective perspective on the data I collected.

Ethical Considerations

When conducting research, researchers are obligated to not harm their participants (Varkey, 2021). Similarly, we are obligated to ensure that participants are in no manner exploited or at risk of being subjected to any form of exploitation (Barrow et al., 2022). To ensure that the study remained within the ethical boundaries applicable to semi-structured interviews, several measures were implemented. The anonymity and confidentiality of all participants were maintained in the instance of publication. As such, no information that could identify the mothers partaking in the study (or their children) was revealed. First, an application for the current study was submitted to the University of the Witwatersrand's Human Research Ethics Committee (non-medical) so that a review of the researcher's intentions for conducting the study could be conducted. This review ensured that the study proposed remained within the parameters of a Masters level research dissertation and that the research questions did not address matters beyond the student's scope. Simultaneously, the practical methods through which the researcher intended to gather a sample and the accompanying data were also up for review by the formerly mentioned ethics committee before any activity was carried out by the researcher. A participant information sheet (please see Appendix B) was handed out or emailed to the study's intended participants if individuals were willing to provide such personal details. These details were stored on the student's computer and were not used for any other purposes other than making contact with the participants for the interviews. As mentioned previously, this document provided a summary of the objectives of the intended study in which individuals

were invited to participate and served to avoid deception. Participants were notified that should they feel the need to withdraw from taking part in the study, they were welcome to do so at any point without any repercussions or consequences. Thus, the participants were notified that no incentives were being given to compel them to participate in the study. Moreover, participants were asked to fill out a consent form (please see Appendix C) that provided the researcher with certified permission to conduct the study. All participants' identities as well as the identities of their children remained anonymous in the write-up and publication of the study's results. This was ensured by storing the data on password-protected computers as well as the use of pseudonyms in the write-up of the study so that all participants' true identities as well as their children's identities remained anonymous. Questions provided at the end of the interview questionnaire were used to gauge each participant's experience of the interview. In the event of any distress caused during the interviews due to the possibly sensitive nature of the topic(s) being discussed, the contact details of the free counselling services at the University of the Witwatersrand's Emthonjeni Centre were provided.

Chapter 4: Findings and Discussion

Introduction

In relation to the aims of the study, the table below is divided into four superordinate themes and two subthemes maximum, all of which were identified in the interviews conducted. All of the themes have a distinct relationship to how mothers of high-functioning CP children experienced raising their children from the timespan of childhood into adulthood. How these mothers felt about and navigated the challenge of raising their children who have a unique presentation or manifestation of CP was reported. The former can be identified in the below Table 3 entitled "Summary of Superordinate Themes and Subthemes." The themes and subthemes identified throughout the eight transcripts have been summarised in the table below. After the table, a discussion of each theme and its relevant subthemes will follow.

The first theme noted in the data was 'The Emotional Experiences of Mothers.' This theme will detail the psychological impact of the childrearing journey for mothers with CP children. This theme will examine what the researcher perceived as the most salient depiction or description of mothers' experiences. As such, 'Trauma' will be the first subtheme discussed in the data. Moreover, the internal emotions of mothers will be revealed as they look back on their feelings of 'Loneliness and Misunderstanding' that they endured due to negative interactions with individuals in their environment, as well as their personal perceptions of how others view them and their children. Secondly, how mothers coped with their trauma and responded to the unfamiliar demands of raising a child with high-functioning CP into adulthood will be discussed as another factor that provides insight into mothers' emotional experiences. Here, how mothers responded to and contended with the demands of their daily lives as parents of children in extenuating circumstances will be explored through the subtheme of 'Survival.' This will be followed by an explanation of how grief-related responses enabled mothers to process or come to terms with their lifestyles and their children's difficult journeys. Lastly, the fourth theme 'Worries about the Future' will discuss the concerns that mothers have felt and/or continue to feel about their children's futures at various stages along their journey from infancy to adulthood and beyond.

Table 3: Summary of Superordinate Themes and Subthemes

Themes	Subthemes
Emotional Experiences of Mothers	Trauma
	Loneliness and Misunderstanding
Emotional Coping and Behavioural Responses	Survival Coping-Behavioural Response
	Grief Emotional-Coping response
Compensatory Behaviours and Circumstantial Control	
Worries about the Future	

Theme 1: The Emotional Experiences of Mothers

In order to understand how mothers experienced raising a child with high-functioning CP from childhood into adulthood, it is important to understand how mothers make sense of their experiences on an emotional level. This is evident as emotions are known to play an essential role in the development of an individual's consciousness or awareness of their experiences over time (Izard, 2009). Thus, 'the emotional experiences of mothers' have been identified as a prevailing theme within the interviews. The theme emerged from mothers' reflections on various phases as well as specific instances along their journeys that influenced their perceptions of certain aspects of their experience, or which influenced their perceptions of their experience as a whole.

Subtheme 1: Trauma

Throughout the interviews, mothers reflected on their emotional experience of raising a child with high-functioning CP as being traumatic. Here, trauma is conceptualised not just as an external behavioural reaction to a traumatic event but as an internal emotional experience that consumes an individual on a cerebral level by affecting that person's thinking patterns as well as impacting the individual's affect and emotional stability. Evidence supporting this suggests that trauma can profoundly impact an individual's sense of self on somatic and cognitive levels (Lanius et al., 2020). And while according to Weigmann (2013) a *sense of self* can refer to the process or practice of being able to distinguish oneself from others in our environment, the

latter will first be discussed as encapsulating an individual's internal traumatic thoughts and feelings of trauma that make up the subjective experiences of mothers raising children with high-functioning CP from childhood into adulthood. Evidence supporting this understanding of trauma or rather an 'emotionally traumatising experience' refers to the subjective wound that the event causes for the individual (Oxford Dictionaries, 2013). Similarly, Amanda described how hearing about her son's diagnosis of CP left her feeling emotionally shattered and enraged:

> Amanda: *"I think [I felt] devastation, total devastation. And then anger came in quite quickly. It's like, you don't throw away your child. It's not a dog, not that you would even throw a dog away, but it's your child. Doesn't matter what's wrong. You don't put it into a home and forget about it."*

The former suggests an influx of intense emotions of despair and resentment toward the doctor for proposing that she discard her son by placing him in an out-of-home care facility. These emotions that Amanda recalls feeling suggest that her experience of having heard the news of her child's CP diagnosis was emotionally traumatic and harrowing. Furthermore, it also indicates that the experience left her feeling tormented by the idea of forfeiting her child. The validity of this thought process suggests that parents of disabled children often feel pressured by society to place their children in an out-of-home care facility (Llewellyn et al., 1999). Here the significance of the social model of disability is demonstrated as stereotypical prejudices surrounding CP are seen to inform how medical practitioners approach mothers concerning their children's potential prognoses. Evidence supporting the former can be demonstrated in the likewise implicit bias of doctors specialising in prenatal care who only convey negative information to their patients (Meredith et al., 2024).

Furthermore, disability does not only impact the individual with the disability but also has a significant effect on that individual's caregiver (Tigere & Makhubele, 2019). Thus, mothers are often confronted with the option of out-of-home care unwillingly by mothers with non-disabled children or individuals who try to advise or suggest they place their child in such a care facility. However, such advice is only noted by grieving mothers to exacerbate their emotional trauma as Amanda recalls:

> Amanda: *"So I never went back to that doctor. It was a lady doctor, and I cannot. Maybe you don't remember people who you think are evil. Maybe she was just forceful, I don't know, but I think to say something like that to new parents who have tried a long time to have a baby, and you telling them: "Throw your baby away?"*

Here, not only does Amanda suggest that her experience with that doctor traumatised her and thus made her feel reluctant to remain a loyal patient, but she also demonstrates how such a careless bedside manner and traumatic experience caused her to harbor resentment toward this doctor. Similarly, Michelle highlighted how having been told a similar narrative about her son's diagnosis had a significant overall impact on her experience. The former is evident as she notes feeling regretful about her choice to seek treatment at a child healthcare center. The former is evident as Michelle explains "*If I'd known some of the things that I would never have gone to that Transvaal Memorial Institute, that was a very bad place for me for a long time."* The former suggests that Michelle felt uncomfortable and despondent due to her experience at this institute. She further explains why this experience made her feel emotionally traumatised as she recalls "*They were very negative. They told me he would never walk or talk to put him in a home and try for another baby*." This positioning of her child as discardable because of his disability by practitioners not only foreshadows mothers' experiences of being alone and misunderstood in their journey (see subtheme 2) but, it can be argued highlights a prevailing inadequacy within the healthcare system in which doctors and professionals are not well-versed in the practice of empathy. Physician bedside manner can impact mothers' emotional experiences as can be seen in literature which postulates that practitioner behaviours tend to create an experience for patients which is either perceived as positive or negative (Person & Finch, 2008).

Similarly, the abovementioned indicators of betrayal and resentment expressed by mothers in this study suggest that their doctors' bedside manners had a significant impact on reinforcing their feelings of having been traumatised. Evidence of such initial trauma at birth was recalled by Amanda as she noted at the end of her interview how:

> Amanda: "*Doing the interview did make me think of the trauma of the birth experience I had with my son. The doctor I went to was very neglectful and had a particularly bad bedside manner. And they knew the doctor well, he went to their Shul, and he never confronted us about how he said he couldn't help with the birth because he had to go to a bris.*"

Here, Amanda not only expresses the emotional difficulty that she felt in answering the interview questions but she once again highlights how betrayed she felt by her former doctor's lack of accountability for the traumatic birth of her son and his ultimate condition of CP. Literature suggests that an increasing number of plaintiffs who have experienced medical

negligence report experiencing symptoms of PTSD (Bradley, 1998). Such experiences of neglect and an overall unacceptable bedside manner are further noted as causing emotional trauma in a study conducted in Northern Taiwan on mothers' experiences of learning that their child has a diagnosis of CP. The study demonstrated that mothers felt rejected by professionals and tended to mistrust them as a result of learning about this diagnosis (Huang et al., 2010). Such mistrust is evident in Amanda's experience above as she expresses regret at having remained at the Transvaal Memorial Institute stating that *"I would never have gone to that Transvaal Memorial Institute, that was a very bad place for me for a long time."* Furthermore, this experience counters evidence mentioned in the literature review that doctors are often reluctant to reveal the extent of possible brain injury. And while Lisa recalls having been ignored when she states "*But I was very much brushed off by the pediatrician when I said, "What's this?" "Why does she do this?" And he'd say "Agh that could still go away, and so on and so on*," this did not help to prevent her from enduring emotional trauma as she reflected on how such dismissal led her to see a different practitioner who would be honest about her daughter's diagnosis:

> Lisa: *"It was devastating. It was devastating. I sensed something was wrong with her physical development. I had, she was my third child, so I knew I had this nagging feeling the whole time that the way she's doing things isn't the way it should be. But I was very much brushed off by the pediatrician when I said, "What's this?" "Why does she do this?" And he'd say "Agh that could still go away, and so on and so on." But then I went to the neurologist and- but it was devastating, especially when he said she was mentally impaired because ya, I mean who wants to be not functioning in all aspects of life?"*

While being *"brushed off by the pediatrician"* highlights an instance in which a bad bedside manner led to Lisa feeling neglected, being told that her daughter would be *"not functioning in all aspects of life"* highlights how the eventual news of her daughter's diagnosis left her feeling traumatised. The former suggests that while mothers of CP children appreciate a level of honesty when it comes to providing an accurate diagnosis, how the implications of a diagnosis are explained or phrased by the physician can significantly contribute to a traumatic experience. Evidence supporting the former can be seen in a study conducted by Hamai et al. (2024) on the relationship between interpretation accuracy of hospital reports and physician/patient satisfaction. The findings demonstrated that, unlike physicians, interpretation

accuracy was not associated with patients feeling a sense of satisfaction. Here, the importance of a practitioner's bedside manner in treating patients should be emphasised for the role of such behaviours in influencing parental emotional experiences.

However, the traumatic emotions experienced by mothers in the current study were not related to instances of diagnosis and insensitive bedside manners to the exclusion of other scenarios. Evidence supporting the former can be seen by Alison's recollection of having experienced emotional trauma due to an adverse social experience with her CP child:

> Alison: *"Well, in the earlier years, you mean at the beginning… so say, I would go, I mean I remember once I went shopping and everybody looked at us and made me feel very uncomfortable, and I just came home and I was like a nervous wreck, (crying)."*

This explanation not only demonstrates how emotional trauma can be experienced in social settings but also highlights the evidence from the study by Singogo and colleagues (2015) mentioned in the literature review which demonstrated that mothers' socio-emotional experiences of raising a child with CP are often based on societal feedback. The former is evident as Alison expressed how *"everybody looked at us and made me feel very uncomfortable."* Further evidence supporting how such social scrutiny can be considered emotionally traumatic suggests that 'trauma' is not only likely to constitute a threat to life but is also likely to constitute a social threat (Bjornsson et al., 2020). Bjornsson continues to explain that such examples of social trauma can involve humiliation or rejection in social situations. For mothers of children with high-functioning CP, however, the reactions or responses of others that comprise their internal experiences of emotional trauma can be far more subtle. Evidence supporting the former can be seen as Alison recalls how her perception of being negatively judged by people at a shopping center made her feel emotionally vulnerable and helpless: *"and I just came home and I was like a nervous wreck (crying)."* Her crying during the interview not only highlights the extent to which she felt traumatised by the incident but it speaks to the psychological phenomenon that intrusive thoughts and memories can easily illicit strong emotional and behavioural reactions as if the trauma were occurring in the present (Center for Substance Abuse Treatment, 2014). And although the thoughts recalled by the participant were not intrusive as they were recalled intentionally to explain how she perceived the responses of the people in her social environment(s) to her child's CP, the extent to which she felt traumatised by the event was evident as she exhibited intense emotions while

discussing the matter even though she was in a calm and unthreatening environment. Further evidence supporting the former can be seen as memory reconsolidation has been proposed to preserve and strengthen existing memories (Bonin & De Koninck, 2015). Similarly, June became emotional during her interview as she reflected on how her challenging family dynamics exacerbated the emotional trauma she was already dealing with due to her son's CP:

> June: "*Because of the being triplets, there were other things happening with the girls as well. So my other one daughter was diagnosed with bipolar. She was suicidal in her teen years. So it's always been very much about, okay, cool. How do we, you know, just get past this next hurdle? How do we cope with this part, etc? The hardest part has actually been now the teenage years, and I think it might be, maybe… I'm going to get emotional. (crying/tearing up)*."

This not only demonstrates the formerly mentioned impact of memory recollection and emotional reactions, but it also highlights how mothers' emotionally traumatic experiences can be heightened by potentially unrelated circumstances. Ponnamperuma and Nicolson (2018) explain that daily stressors tend to impact how an individual experiences the aftermath of a traumatic event as trauma can impact an individual's mental health indirectly through the effects of ongoing stress. Further evidence supporting this reality suggests that trauma advocates tend to over-emphasise the impact of direct exposure to war on mental health but fail to emphasise how daily stressors add to individuals' traumatic experiences of wartime conditions (Miller & Rasmussen, 2010). Similarly, June suggests above that the emotional trauma she experienced while raising her CP son was potentially exacerbated by having to contend with a daughter who struggles with Bipolar Disorder (BD). Evidence supporting this reality that raising a child with BD can impact a mother's emotional well-being and coping capacities suggests that these mothers often display signs of maladaptive coping and chronic stress (Nadkarni & Fristad, 2012). And while June's coping strategies were not necessarily maladaptive she revealed that the level of focus and resilience required to face the task of raising a child with high-functioning CP along with a vulnerable teenage daughter left her without the time to process her stressful experience and feelings of trauma:

> June: *"It's been very, you know, head on and we just do it. But like, when it's, I think my depression comes into it, you know, I suffer with depression. So then it's like, okay, them first and everything else, then, you know, sorry (cries/holds back tears)."*

Moreover, while June admits that *"I think my depression comes into it, you know, I suffer with depression"*, which she highlights as influencing her emotional or tearful response during the interview, the initial emotional response she displayed while recalling how she coped with raising a son with high-functioning CP (alongside her daughter who has BD) suggests that her overall experience was traumatic. Further evidence supporting mothers' experiences as emotionally traumatic can be seen as Jessica remembered the ordeal of consulting with her son's teacher about his educational needs:

> Jessica: "*I remember his grade two year was the worst year, because the teacher that he had then obviously didn't understand him that much, and she had called a meeting with the school and said that he needs to be placed in a special needs school because he doesn't understand what's going on and things like that. So it was a fight for us to keep him there*."

Here, she recalls the traumatic experience of finding out that her son's teacher was not attuned to her son's needs as she highlights *"So it was a fight for us to keep him there."* The former not only alludes to the subtheme of 'Loneliness and Misunderstanding' as Jessica felt that his teacher was not willing to consider or accommodate her son's needs, but it also highlights the reality that mothers who are not kept up-to-date with their children's presenting difficulties and are not notified of the educational system's inability to assist these needs are left unduly traumatised. Evidence supporting how the former can be construed as an emotionally traumatic experience can be seen in the literature review which suggests that learning disabilities are a common co-morbidity of children with high-functioning CP (Fluss & Lidzba, 2020). And while the example mentioned in the literature review highlights an instance in which CP children can navigate the mainstream educational system despite Dyscalculia, June's experience of trauma and feelings of concern can be attributed to the fact that it would have been too early in her son's developmental trajectory to determine his education capabilities. Evidence supporting this can be seen in a study conducted on the concerns of mothers with CP children. Although the study was conducted on a sample of mothers with preschool children, the study found that information about their children's current and future educational trajectories was a concern for 85% of mothers (Bertule & Vetra, 2014).

Moreover, the legitimacy of Jessica's experience as being emotionally traumatic is evident as the former not only brings attention to the previously mentioned reality that advocacy and activism are often implicated in the roles of mothers with disabled children but also highlights

how the educational system fails to work with mothers and chooses to rather work against them, thus making mothers' lives more stressful and complex. Indeed the many possible areas for disagreement between parents and teachers concerning a disabled child's needs can act as a barrier to facilitating parental involvement in educational matters (Hornby & Lafaele, 2011). The former suggests that although mothers' experiences of emotional trauma are subjective in that they are based on mothers' perceptions, mothers tend to feel that their feelings of being emotionally traumatised are dependent on circumstances out of their control. The former is explained by Jessica as being dependent on "*the therapist that you have, the teacher that you have and their ability to understand the disability*" which either exacerbates or mitigates feelings of emotional trauma. This suggests that parents who feel unsupported by teachers in the schooling system often face the burden or pressure of having to *"take matters into their own hands"* to assist their children academically. This reality exacerbates mothers' emotional distress and feelings of being traumatised as the attitudes of unempathetic mothers with non-disabled children often influence schools to adopt discriminatory policies that deprive CP children of educational opportunities (Olawale et al., 2013). The former highlights an additional cause of emotional and psychological trauma experienced by mothers to the distress caused by events such as receiving their child's diagnosis. This is evident as mothers were having to contend with practical obstacles that were noted as having the longest-lasting impact on mothers. These obstacles, however, were not limited to the former demonstrated educational challenges. Lisa recalls how the difficulty that she anticipated her daughter would experience once her daughter's diagnosis was confirmed remains an emotionally traumatic memory for her. She also describes feeling pained by the specific challenges she has had to confront to assist her daughter with daily living:

> Lisa: "*Look, I'm a very realistic kind of person, so once the word was out, I knew that we were up against, it was going to be a battle for her. And the pain of that will never go away. I mean that you don't want to see your child suffer like that*."

Despite having triumphed over the most challenging period of their journey, mothers of adults with high-functioning CP can still be profoundly impacted by the difficulties they experienced. Evidence supporting the former can be seen in studies conducted on mothers of disabled children which suggest that parenting stress remains a constant variable throughout the child-rearing process and can often result in depression (Park, 2023b). An example of one such study by Mbatha and Mokwena (2023) on the stress levels of mothers raising children with developmental disabilities in South Africa found that stress levels were significantly high. And

while the literature review suggests that mothers' stress levels are often dependent on the severity of their children's disability (Yilmaz et al., 2013), the former does not account for the reality that mothers of children with high-functioning abilities are more prone to the difficulty of re-experiencing trauma and not just contending with ongoing stress. This is evident as Lisa reiterates how her daughter's struggles to gain independence have caused her to *"relive"* the emotional pain she was exposed to at the beginning of her journey:

> Lisa: *"But the pain, it never goes away. Nobody wants to see them, and it's like it never goes away. Every time it's all over again when she doesn't go to university, when she doesn't have a job, when she doesn't have a life that seems meaningful for her. It stays painful."*

Here, similar to mothers who displayed intense emotions during their interviews highlighted above, Lisa suggests that the emotional trauma she has experienced during her journey is re-confronted. The former draws attention to the reality that the effects of emotional trauma cannot always be erased for mothers of high-functioning disabled children. Raising a child who has CP is often associated with additional challenges to those experienced by mothers without CP children (Guimarães et al., 2023). The long-lasting impact of emotional trauma contradicts the formerly mentioned premise of the medical model that conceptualises disability as a "sickness" that can be "cured" (Braathen et al., 2015; Olkin, 2022). However, the medical model, although mentioned earlier to not be the prime focus of this study, can be noted as having relevance to mothers' experiences. This can be seen in Linda's mention that her daughter *"doesn't go to university"* and that she *"doesn't have a life that seems meaningful for her"* due to her difficulty with physical abilities and lack of independence. Linda thus suggests that she cannot heal her emotional trauma of watching her daughter live an unfulfilled life. Evidence supporting the former indicates that the inability to access assistance to aid independence can exacerbate the problems of caring for children with CP and increase caregiver stress (Seroke & Mkhize, 2023).

Subtheme 2: Loneliness and Misunderstanding

Mothers' traumatic emotional experiences concerning their children's circumstances were seen to be exacerbated by a sense of loneliness and misunderstanding as they felt isolated and unable to relate to others. Evidence in the literature review suggests that the attitudes of the broader public toward children with CP and their families can contribute to the internalised emotional

experience of psychological trauma. Similarly, this subtheme emerged as mothers expressed how they remembered or experienced interactions with the public concerning their children. Such experiences of feeling publicly scrutinised and thus alone and misunderstood are evident in Amanda's recollection below:

> Amanda: *"As he got older and he moved into a wheelchair to go to, like the shopping center, and I've put- people would never talk to him, because they'll talk to me, because anybody in a wheelchair is mentally challenged."*

The former thus suggests that the stereotypes and assumptions relating to CP lead to Amanda's son being unfairly discriminated against and judged as being incapacitated and therefore incapable of holding a conversation. Evidence supporting the former suggests that in America, people with disabilities are far less likely to be employed (Annual Disability Statistics Collection, 2024). Furthermore, the reality that such assumptions continue to impact the treatment of and opportunities provided to individuals with CP adversely can be seen in the schooling context where children with CP who are cognitively high-functioning but have more severe levels of physical and/or speech impediments are at greater risk of missing out on cognitive assessments due to assumptions being made about their cognitive abilities rather than being assessed (O' Regan et al., 2022). Here, the extent to which this underestimation of their children makes mothers feel helpless can be seen as Jessica recalled how her son was denied acceptance into the mainstream schooling system because of his CP diagnosis:

> Jessica: *"The schools would just see the application form and the diagnosis Cerebral Palsy and immediately say "Sorry, they can't accept him."*

While the former experience will be discussed under theme four as causing Jessica to feel as though she lacked control of her circumstances, the reality that such displays of hasty judgment and discrimination would have made both mothers feel frustrated and alone suggests that stigma can harm mothers' emotional well-being and social circles (McLean & Halstead, 2021). Further evidence supporting the former can be seen as Jessica explains how the stigma attached to CP made her feel alone and misunderstood within her Indian community:

> Jessica: *"And also in our Indian society, there's quite a lack of knowledge about that [Cerebral Palsy], or a stigma that's attached to it."*

Such a lack of awareness is not only noted as reinforcing stereotypes and stigmas that are generally associated with disabilities such as CP but the phenomenon of 'stigma by association,' mentioned in the literature review (Jansen-van Vuuren & Aldersey, 2020), as being under-researched can be noted as a relevant factor in making mothers feel alone and misunderstood. Misconceptions about people who have a disability contribute to stigmas, discrimination, and abuses they experience (Rohwerder, 2018). Similarly, Jessica further explains how even having a disabled child resulted in her experiencing scrutiny and discrimination as the people in her environment did not have an understanding of what she was dealing with:

> Jessica: "*So like I said previously, in our Indian culture, it's not something that's very much understood. So, some people felt that maybe it's a test. Some people felt maybe it's a curse, because nobody really understood*."

This implies that Jessica was being punished through her son's CP. The former not only highlights the extent to which her social circles had made her feel alone and misunderstood, but it also emphasises the role that societal norms can play in influencing mothers' emotional experiences. Here, the relevance of the social model of disability should be reiterated. This can be seen in Jessica's reality, which stands as a concrete example of how a community's (mis)understanding of disability can influence mothers' real-life experiences. Evidence supporting the former suggests that how we understand disability influences the way we treat people with disabilities (Braathen et al., 2015). Braathen's article refers to the medical model of disability that conceptualises treatment of a person with a disability as a means of curing them of an 'illness' (Braathen et al, 2015). However, in a social context such as the above, as well as in the literature review, 'treatment' refers to a social approach and behaviour toward members of our society or social circles. Further evidence supporting this understanding of treatment as a social approach towards others suggests that people with disabilities are more affected by the cultural implications that society attaches to disabilities than by the physical and practical challenges that are caused by the disability itself (Groce, 1999). Similarly, mothers suggested that during social situations they were also treated with disrespect which reinforced their feelings of being misunderstood and alone. Amanda expressed frustration that none of the people she encountered would acknowledge her son or his circumstances:

> Amanda: *"And they would never -"What's wrong with your son," "What's he doing?" "What's-" but they would look at me. They wouldn't look at him. And I understand*

people are maybe scared. People don't know how to handle people with disabilities of any sort."

The former reality was further noted by Amanda as making her feel as though her son was an anomaly as she explained her feeling that *"People don't know how to handle people with disabilities of any sort,"* thus suggesting that her emotional experience of feeling alone and misunderstood was significantly influenced by societal approaches of the public toward individuals with disabilities (in this case, CP). Further evidence supporting the former can be seen in a study conducted by Madi et al. (2019) on mothers living with a CP child in Saudi Arabia. The study found that community attitudes and behaviours such as blame-directing and shaming had a significant impact on making mothers feel stigmatised and discriminated against. And although the literature review suggests that CP is one of the most common childhood disabilities, further evidence suggesting that nearly 1-4 per 1,000 live births are born with CP (CDC, 2022), the current study highlights that mothers' emotional well-being was affected due to their children being treated as an anomaly.

This is further evident as June explains *"You know, people look very differently at somebody with CP or with any disability because they don't understand it,"* thus suggesting that June felt as though her son may have been perceived as an anomaly in social situations. This trend within the data continued to emerge as Alison also recalls feeling like she and her son were made into a spectacle:

Alison: *"But it was difficult (pause)… if I would take my other child to a birthday party and take this child, everybody would look at this child, and this child just sat motionless on my lap. And you know they would, I knew they were skinnering [gossiping] behind my back. And it was, it took maturity to be comfortable with that."*

Such public scrutiny and humiliation which mothers experienced at the hands of people in their communities and social circles suggest that in fact, despite the formerly mentioned evidence that CP is one of the most common childhood disabilities (CDC, 2022), mothers of non-disabled children do not have frequent contact with children with CP. Evidence of this to be the case can be seen in a study that demonstrated that young adults with CP showed limited levels of participation in all areas of life (Guyard et al., 2024). Prevailing literature suggests that such a lack of participation can be due to the physical barriers experienced by disabled individuals that are not accounted for (Cooper et al., 2023). However, regardless of the reason

for the former, mothers noted that they felt emotionally islolated and lost in their experiences of raising a child with high-functioning CP. This is further evident in Jessica's statement, *"It was quite a difficult journey for me because I felt quite alone in it."* Such feelings of loneliness experienced by mothers, however, were noted as not only being exacerbated by discrimination. Rather, mothers' emotional experiences of loneliness were also contingent on the fact that they did not share the same experience as mothers' of non-disabled children:

> Michelle: *"I don't think that until you have any kind of problem, whatever it is that you can understand what someone else is going through. I think also like my son was very prem [premature], he was in hospital for a long time, I didn't have the same experiences as other mothers."*

Here, Michelle made it clear that by *"other mothers*" she is referring to "people who get to take their babies home straight away", thus suggesting that she never came in contact with other mothers who had premature babies. Similarly, a study that took place in London, United Kingdom on the experiences of loneliness by adults with mental health difficulties suggested that a lack of meaningful connections to others and not feeling a sense of belonging to valued groups and communities were instrumental components that contributed to adults' feelings of loneliness (Birken et al., 2023). Although this study was not conducted on mothers of children with CP or any developmental disability, its results reflect what can be seen as a factor contributing to mothers' experiences of loneliness in the current study. This is evident as Michelle says *"I don't think that until you have any kind of problem, whatever it is that you can understand what someone else is going through,"* highlighting how having camaraderie with another mother who has a child with CP would have helped mitigate her emotional experience of loneliness. Support groups can be essential in assisting mothers of CP children with their emotional and social needs (Phumudzo et al., 2021). Furthermore, peer support can have an instrumental impact on mothers' emotional well-being, making it necessary for therapists to facilitate connections between mothers of CP children in similar situations (Prest et al., 2022). However, the findings of this study contradicts the former as is evident when Linda expresses that while she was able to obtain useful information from support groups initially, she once again felt alone and misunderstood when her daughter was developmentally progressing while the children of other mothers were not:

> Linda: *"I must say that when Nicole was a baby, I joined a support group for mothers with children that have CP. But as I mentioned to Nicole, you know, I felt very uncomfortable there, because Nicole was very mildly CP in comparison."*

The former situation in which Linda felt alone and misunderstood was noted as being contingent on the fact that her environment was not suited to her daughter's specific functional needs. Here, attention is drawn not only to the value and significance of providing mothers with generalised types of support strategies and systems such as psychological therapy and useful medical information but also to the importance of catering to mothers of high-functioning CP children. Evidence supporting the former as being relevant to helping mothers feel less alone and misunderstood can be seen in the literature review which highlights that although the severity of mothers' stress levels may not necessarily differ due to the reality that each mother may find their circumstances equally stressful despite the discrepancies in their children's levels of functioning (Yilmaz et al., 2013). Linda's experience of having outgrown the need to remain part of her formerly mentioned support group suggests that emotional support and intervention are most effective in making mothers feel less misunderstood and alone when it caters to each mother's unique circumstances. Evidence supporting the former proposes that the milder the severity of a CP child's diagnosis the more likely it is that parents will experience a form of emotional resolution (Krstić et al., 2015). And while the former experience of emotional resolution will be discussed under the subtheme of "Grief" as being typically never fully realised, the former provides reason for why mothers may need case-specific emotional support to feel less alone and misunderstood.

Similarly, Michelle not only suggested that receiving her son's diagnosis was traumatic but she recalled that *"So it was very like probably the first year that he was diagnosed, was very hard. I used to go to a place called the Transvaal Memorial Institute [mentioned under subtheme 1] that was where they diagnosed like very severe problems."* Here, the trend of mothers feeling alone and misunderstood due to not being in the correct system to cater to their children's specific and advanced needs was demonstrated as making them feel alone and misunderstood. Here, the importance of resource availability and accessibility is not the only factor acknowledged as being important to helping mothers feel understood and supported. Rather, the nature or *type of available resources or in this case, the topics being addressed* are essential in making mothers feel less isolated. Here, Linda notes that *"They were talking like serious wheelchairs for life, hyperbaric pressure chambers, whereas with us, it was obvious that Nicole*

was going to walk at some stage." The former thus demonstrates how not being surrounded by mothers whose children were on a similar level of the CP spectrum can contribute to mothers' feelings of being alone and misunderstood. Evidence supporting the former can be seen in Social Identity Theory and self-categorisation theory which suggests that the degree of identification with a group is based on perceived shared characteristics (Burholt et al., 2023). Therefore, the aforementioned demonstrates that mothers' experiences of raising children with high-functioning CP were emotionally traumatic as they were insensitively informed about their children's diagnosis and felt lonely and misunderstood by people who were judgemental and prejudiced within their surrounding environments.

Theme 2: Emotional Coping and Behavioural Responses

Aside from the emotional experience of feeling traumatised and the sense of being alone and misunderstood that mothers endured, how mothers coped with their trauma and responded to the unfamiliar demands of raising a child with high-functioning CP into adulthood is another factor that provides insight into these mothers' experiences. Evidence supporting the former can be seen in Waisviz and Verstappen's (2022) 'Understanding the Role of Emotion in Behaviour: An Evaluation of Influential Definitions' which highlighted that while emotions occur internally, their expression occurs through measurable linguistic and/or behavioural responses that vary in nature. This theme emerged as mothers described their respective behavioural and emotional responses and approaches to the demands and practical difficulties associated with raising their CP children who all possessed 'normal' levels of intelligence from childhood into adulthood despite various challenges that were practical, social, and/or emotional in nature. Such strategies included survival-based coping behaviours and/or responding via a process of grief-related feelings and emotions to their child's difficult circumstances and respective outcomes.

Subtheme 1: Survival and Attitude

Despite their initial and/or prevailing emotional trauma, throughout the interviews, mothers expressed that they adopted a practical or logical approach to the tasks involved in raising a child with high-functioning CP:

> Jessica: *"I think I also put myself in an autopilot mode. So I knew, 'Okay, I do physio, OT, speech all of that,' and just went through those motions of that. And I just went*

through those motions of just being in autopilot mode doing what's needed to be done, basically."

Jessicas's behavioural strategy for coping with the challenge of raising a child with high-functioning CP was to remain task-orientated. Such a response can be likened to the fight-or-flight response to perceived threat which is a reflexive nervous phenomenon and has an evolutionary survival advantage (Sherin & Nemeroff, 2011). The former demonstrates remaining productive as a coping mechanism that enabled Jessica to divert her attention from fixating on the depressive nature of her circumstances. Rather, through keeping busy and being productive Jessica was able to focus on helping her son to hone skills and abilities that would make him achieve his functional potential. Furthermore, according to van der Kolk (2000), when people are confronted with dangerous or traumatic experiences, one of their primary focuses aside from self-preservation is survival. While a diagnosis of CP does not place individuals or their family members in any form of physical danger, contemporary evidence validating this reaction to stress can be seen in the Survival Optimisation System (SOS), which explains how threats to survival are cognitively appraised. A modulatory system of this model is Fanselow and Lester's Threat Imminence Continuum which selectively controls and regulates survival strategies along an abstract-concrete continuum (Mobbs et al., 2015). Thus, despite mothers' circumstances not posing any form of physical danger once their children were home from the NICU, mothers responded by displaying behaviours that were reflective of their need to preserve their children by improving upon their children's functional abilities (as demonstrated above) or making sure they stayed emotionally strong to continue raising their children.

Evidence of the latter can be seen as June suggested that she applied the same practical or rational approach to how she dealt with her emotional trauma of raising her CP son as she recalled that she and her husband:

June: "*Were at a point where it was good to get an answer on what was happening, as well as guidance on how to take it further. That is where the physical came in. So it was like, Okay, now we know what we need to do. So now we need to go to physio. And now we need to go in and, you know, do Botox injections. Now we need to go and get, you know, special you know, those little thingies, those costs that he did, that he wore, etc.*"

This proactive response to hearing about her son's diagnosis can somewhat be considered a contrast to the formerly mentioned expressions of devastation and betrayal. However, such

behaviours can serve to conceal or maintain functioning in and after moments in which individual experiences traumatic devastation. This is evident as survival refers to the practice of continuing to function despite a traumatic ordeal or difficult circumstances (Maniadaki, 2022). However, such a survival-based stoic reaction does not mitigate the feeling of having been traumatised by an experience but is rather a method of coping with a traumatic experience by maintaining high levels of functioning (Hochschild, 1983). Indeed, June explains how, despite feeling emotionally traumatised she felt compelled to remain emotionally stoic to focus on her challenge(s) at hand:

> June: *"So it was a very physical reaction to all of it mentally, I think maybe possibly, because we were so busy with all three kids, it was, it wasn't an emotional, I think if it was just one child, it possibly would have been a lot more emotional because we had to carry on. We had another two girls the same age that we had to just really help to carry on."*

This behavioural and attitudinal approach was taken by June due to her family circumstances rather than being chosen out of the desire to appear emotionally robust. Evidence supporting the former approach can be seen as the literature review highlights the difficulties that mothers of high-functioning CP children often experience in prioritising the needs of their non-disabled children alongside those of their disabled children (Rainbow Trust, 2018; Rossiter & Sharpe, 2001). Moreover, the emotional state of a parent is noted as playing an essential role in the rehabilitation of their disabled child (Strojek et al., 2022). This is because the child's ability to progress toward a high functioning level, or even to reach merely a baseline level of functioning that is most optimal for them is heavily dependent on parental involvement and adaptation to their child's needs and abilities (Wójtowicz et al., 2007).

Here, the reality mentioned in the literature review that mothers are perceived as the carers who are primarily responsible for their children's progress highlights why mothers adopt this approach (Smith & Blamires, 2022). The former is further evident in Alison's statement: *"It's all an attitude; You have to choose how you're going to react."* The former not only suggests that Alison tried to survive her traumatic ordeal of raising a child with high-functioning CP by adjusting her attitude to cope with and focus on daily demands, but it also contrasts the upcoming theme of circumstantial control which demonstrates how mothers were able to redirect their children's outcomes. In this instance, however, Alison was only able to survive

by redirecting her perception of her circumstances as opposed to altering her actual circumstances.

A traumatic experience can profoundly affect an individual's sense of self (Lanius et al., 2020). This method of controlling your reactions can be considered a response to try and restore one's sense of self or to take control in instances where one feels lost. The former psychological resilience can be effective in helping people navigate difficulties while maintaining composure (Yao et al., 2024). Similarly, Michelle's statement *"You know what, I'm a real believer in 'it is what it is' with everything in life, you know, and we've got to make the best of it."* While the former highlights how attitude adaptation was instrumental in helping Michelle remain emotionally strong and able to find happiness in her situation, further evidence supporting the validity of attitude adaptation as a survival mechanism can be seen as acceptance can lead to positive psychological changes as well as growth and success (Farhadi et al., 2022). However, this response when compared to former responses including Janet's response to her traumatic experience suggests that this process of survival can manifest either consciously with deliberate decisions to change one's attitude or unconsciously and thus as a consequence of the formerly mentioned 'fight-or-flight' state of mind. The latter approach was evident as Janet explained how she continued to pursue her son's therapies and treatments despite being in a state of denial concerning her son's diagnosis:

> Janet: *"Um to be honest, I didn't really understand the full meaning of CP. I kind of just thought we could get over it, do what we have to do to get over it. Um Yeah.* ***So, in fact, I think I was in denial about the whole thing um... But yes, we still went to all the um doctors, physios, OTs at the time, we did everything we could to make, to make it better****." **(emphasis by researcher)***

The former demonstrates stark contrasts in survival or coping strategies displayed by mothers as one, Alison, displayed a conscious awareness of her circumstances, while the other, Janet, unconsciously assumed the former mentioned 'head on' or 'autopilot' approach. And while seminal evidence suggests that core personality factors such as neuroticism, extraversion, and conscientiousness are associated with how an individual experiences and copes with stress (Vollrath & Torgerson, 2000), such deductions cannot be made about the mothers in this study without requesting that mothers profile themselves for the researcher. Rather, mothers' survival strategies of 'getting on with it' or attitude changes may have been based on mothers knowingly making subjective evaluations of how well or poorly they felt they were coping at various moments. Evidence supporting this understanding of attitude changes as being based on

conscious decision-making can be seen in research that demonstrates how constructs that individuals actively implement in their day-to-day lives can be reinforcers of resilience. Such examples include spirituality and traditional child-rearing philosophies that have to be actively reinforced (HeavyRunner & Marshall, 2003). By contrast, mothers' survival-orientated decisions may have been based on what they felt was needed from them psychologically and/or emotionally at any given point along their journey and thus related to unconscious cognitive processes as indicated by the formerly mentioned explanation of fight-or-flight processes by the sympathetic nervous system. Evidence from the data supporting the latter can be seen as Linda reflects on how her attitude and the feeling that she was able to cope was heavily dependent on her daughter's medical state or difficulties at given moments in her journey:

> Linda: *"Gosh, I think I know that when Nicole was about four months old, and because of her vision, she hadn't smiled yet, and she only started smiling after four months because she couldn't do- there were still blood clots in her eyes so she couldn't see us. I remember feeling quite depressed about it. But then, as the blood clots went away, and we got excellent advice from OTs and physios, and we went to every possible place that we could. And we started working with her. And as I said, we began to be much more hopeful than that. I think my lowest point was at that four-month point where she, there was no response at all, except for the crying. But then once she started seeing and she then she smiled, and then, yeah, hope sprung eternal."*

Here, the former suggests that Linda's sense of being able to cope with raising a child with high-functioning CP was based on momentary circumstances and thus not formed due to conscious deliberating. Further evidence supporting this perspective suggests that most survivors of traumatic events exhibit certain immediate reactions such as blunted affect (Center for Substance Abuse Treatment, 2014). Such an initial reaction not only correlates with the retrospective depression that Linda recalled feeling but such a blunted emotional affect can also be reflective of an overall sense of vulnerability and helplessness which will be discussed in theme three below.

However, regardless of whether mothers' attitudes toward their experiences were based on conscious thought training or momentary influences that resulted in emotional fluctuations, the 'survival mode' remains a significant coping mechanism demonstrated throughout the data to have formed part of mothers' experiences. This can be seen in the words of Lisa who detailed

how she coped with the difficulties of raising a child with high-functioning CP through making the best of her situation:

> Lisa: "*But you make the best of your situation with what you have and had. We try to do that."*

The former demonstrates resourcefulness and adaptability as part of mothers' survival experiences, but it also suggests this process of survival and adaptation is ongoing even when their children have reached adulthood. Evidence supporting the former can be seen in a study conducted by Rentnick et al. (2007) on how mothers adapted to the experience of raising a CP child. The findings demonstrated that adaptation strategies may change as a function of their child's development and the changing family dynamics over time. Contemporary evidence that aligns with this study suggests that while CP is not a progressive disability, its symptoms can change over time (NINDS, 2023). Thus, despite the current study aiming to explore the retrospective experiences of mothers who have raised their highly functional CP children into adulthood, the latter suggests that mothers' journeys are never truly over as the needs of CP individuals can continue to evolve or change.

Such changing dynamics and natural development with which mothers continued to cope spark debate over whether or not the experience of being in survival mode itself is strictly a conscious or unconscious process. This debate is further brought to light as Lisa contradicts her initial statement of unknowingly doing the best she could with the resources she had in each moment by recalling how she was aware that she was entering or going to enter survival mode."*Look, I'm a very realistic kind of person, so once the word was out, I knew that we were up against, it was going to be a battle for her."* Similarly, evidence supporting this idea that an individual can either be aware or unaware that they are in survival mode highlights that survival circuits can be harmful *when beyond conscious control*, thus implying that there is a possibility of being aware in the moment you are in survival mode (Hayes & Hofmann, 2018).

The former contrasts the majority of evidence that suggests that awareness of being in survival mode can only occur upon retrospective analysis, as during threatening circumstances our nervous system takes over which leads to logical thinking and strategising that is largely unconscious (Bailey et al., 2023). This awareness or conversely unawareness is not only significant in providing insight into the state of mind mothers may have been in while they were raising their CP children, but it also determines the extent to which mothers felt they were

unable to take the time to process their experiences and regroup emotionally. This is evident as June suggests that her experience was:

> June: *"Very physical compared to possibly if I had only had the one child, where then it would have been a little bit more time to have the emotions play through. At that time, we were very much about just getting things done, doing the best that we could for him, as well as for his sister."*

The former not only demonstrates a conceptualisation of survival mode for mothers as referring to a state of being unemotive and therefore unfocused on processing emotions to remain focused on practical tasks, but it also highlights that such methods of coping were essential in order for mothers to follow through with what they perceived as being the best course of action for their children at the time. Similarly, Amanda states: "*What could you have changed? I did what I did, and I did everything to the very best*," thus supporting the idea that stress-related survival responses are automatic and unconscious as she did not have time to ponder her decisions but took immediate action with the knowledge at that moment. Further evidence supporting this reality suggests that in response to challenges and/or threats to our survival individuals experience cognitive changes that coordinate with other aspects of the brain's stress system to cope with difficult demands (de Kloet et al., 1999). The surprising agility with which this process happens indicates that mothers would not have taken a long time to think through their behaviours or attitude changes as the operational level of neurological processing allows little time for compensation (de Eslinger et al., 2013). Therefore, the aforementioned stoic reactions and attitude changes that occur with remarkable cognitive speed highlight 'survival mode' as being a typical coping response displayed by mothers who have consciously and/or unconsciously struggled or continue to struggle with therapeutic interventions, mobilising disability resources, and managing the demands of raising a family at the same time as navigating the traumatic experience of raising a child with highly functional CP into adulthood.

Subtheme 2: Grief Response

While the formerly mentioned reality of whether mothers were conscious of their survival mode reactions in the moment of their journey can be considered debatable, the fact that the mothers felt a sense of grief when analysing their experiences retrospectively is certain. Evidence supporting the validity of such retrospective feelings of grief as a coping mechanism for trauma suggests that coping mechanisms are critical in helping individuals deal with daily long-term developmental outcomes (Costa et al., 1991). Similarly, this subtheme emerged in

the interviews as mothers expressed feelings of sadness about their children's current difficulties as well as curiosity about what life would have been like if their children had not been born with CP in the process of coming to terms with their children's realities.

The sadness and inquisitiveness that mothers expressed upon reflecting on their feelings about having adult children with high-functioning CP suggest that mothers coped with their experiences of raising CP children by grieving the hypothetical loss of what their children could have achieved if they were not disabled or were able to be more independent. This is evident as Lisa expressed dismay at her daughter's lack of independence:

> Lisa: "*So it's easier in a way, but ja it's still sad, and ja and as I say, she doesn't have a job so she will always be dependent on everybody around for a lift somewhere, or she can't do things independently. So in a way, she never grew up really*."

The former, however, highlights that Lisa continues to process her experience of raising a child with high-functioning CP by allowing herself to feel grief is related to her daughter's current circumstances or levels of progress. Here, the reality that grief is a coping response is demonstrated in evidence that suggests that grief is not necessarily a stage-like, sequential, predictable, or even linear process as not everyone goes through all of Kubler-Ross and Kessler's (2005) phases of grief, nor do they necessarily go through these stages in the proposed order. Further evidence supporting this can be seen in a study conducted by Wittingham et al. (2013) on the shared experiences of mothers with CP children. The results found focus groups participants spontaneously identified feeling an *ongoing* sense of loss and feelings of sadness, frustration, and guilt concerning their CP child's difficulties.

The former erratic and unpredictable nature of grief thus suggests that this process does not help an individual "cope" with their circumstances and therefore heal completely but it helps them to make sense of their experiences and acclimatise to their reality. Evidence supporting the former can be seen in evolutionary theories which suggest that grief allows individuals to reassess their plans and priorities concerning their loved ones (Freud, 1914/1915). Michelle explained that "*he's just a normal part of the family, treated the same way. I mean, I do wish that, you know, a lot of people would look past certain things*." Thus, although Michelle feels grief concerning how others perceive her son's disability, she expresses the level of acceptance toward him displayed by immediate family members as being a more important factor in defining her experience. Furthermore, formerly mentioned evidence under the theme of survival-orientated coping responses discussed how the sympathetic nervous response of

survival mode is not at the forefront of individuals' consciousness and is often only acknowledged retrospectively (Bailey et al., 2023; de Eslinger et al., 2013). The former can be noted as delaying the opportunities that individuals have to recognise and thus cope with or process trauma by grieving. Evidence supporting the former reality can be compared to the consequences of a complex grief scenario which suggests that prevailing circumstances derail or delay the natural course of the grieving process (Shear, 2012). This is evident as Michelle states "*He still does have this thing that "I'm walking funny, so someone's looking at me." I think that's kind of sad for me…*" Thus, her son's self-consciousness about his gait is a remaining hurt or form of grief that she still has to process. However, such feelings of grief concerning her child's difficulties with feeling accepted cannot be minimised. Evidence that supports the former as a legitimate source of grief suggests that a sense of self-consciousness suggests that there is no relationship between self-concept and functional motor status in individuals with CP (Roostaei et al., 2021). This thus explains why her son may feel self-conscious despite his highly functional level of CP as reported by her below:

> Michelle: *"He still does feel it, so even though he runs a business, he's got a girlfriend. He's been living on his own for a long time. When he first moved out, he moved out totally on his own."*

Moreover, this delayed experience of grief supports the premise that although grief is considered a natural and universal response to loss, some forms of grief cannot be openly acknowledged or publically supported such as perinatal losses (Mughal et al., 2023). Similarly, the general public may not be able to comprehend or apply gravitas to such hypothetical losses or matters of grief experienced by Michelle due to her child's highly functional outcome. This reality provides further context for the delayed grief response experienced by Michelle as she attempts to cope with leftover/ less understood concerns of mothers with high-functioning CP children. However, the grief that mothers expressed having to process in response to their children's diagnoses of CP was not limited to, or only concerned with their child's current circumstances and difficulties.

Rather, mothers coped with the trauma of giving birth to a CP child by mourning the hypothetical possibilities that they believe their children would have had available to them if they had not been born with a disability. The former was made evident as Linda stated that she feels "*Often a lot of grief for the person she could have been, you know, if she hadn't had the brain injury*." This expression of curiosity and indulging in retrospective reflections of what

her daughter would have achieved in the absence of a disability contradicts studies such as the one conducted by Fernández-Alcántara et al. (2015) on mothers of children with infantile CP which suggest that such hypothetical thinking only takes place in the earlier years of their child's life and is eventually replaced by a full sense of acceptance. The latter experience was noted to be true for Janet who initially stated *"I think I was in denial about the whole thing"* and later explained that "*I've come to accept it, because Brian is not a serious case*." However, most mothers in the study did not demonstrate this eventual complete sense of acceptance. This reinforces the reality above that grief is not a linear coping process. Thus, mothers of high-functioning CP children not only coped with their infant or adult children's realities by adopting a stoic attitude and survival-orientated behaviours but also processed their feelings by allowing themselves to feel a delayed sense of grief caused by having to forego their expectations and desires for their children to deal with their children's present realities.

Theme 3: Compensatory Behaviours and Circumstancial Control

Although mothers adopted survival and subsequently grief responses to cope with their traumatic experiences, mothers reported feeling that they had lost a sense of control over their lives. Evidence supporting the former as a typical emotional response when confronted with unexpected circumstances suggests that a traumatic experience can erode an individual's general perception of being 'safe' in the world and lead to them adopting compensatory behaviours (Center for Substance Abuse Treatment, 2014). Such behaviours aim to make up for the fact that a traumatised individual feels vulnerable in the outside world as they cause the individual to start fixating on areas of their reality that they can control (Kay et al., 2009). This theme emerged as mothers not only described instances during their journey in which they felt like they lacked control, but they described the behaviours they adopted that made them feel as though they could still assist their children to become successful. However, this theme should be noted as being separate and different from the theme of 'Emotional Coping and Behavioural Responses' (Theme 2). Such distinctions can be made as theme 2 reflects how mothers experienced and responded to the non-negotiable journey and external demands of raising a child with high-functioning CP into adulthood. By contrast, theme 3 will discuss how mothers attempted to alter or improve their experiences by obtaining a sense of control over their circumstances.

Throughout the study, mothers expressed feeling like they lacked a sense of control over their circumstances. Evidence supporting the former suggests that an individual typically has to

respond with intense helplessness, fear, or horror to an event for the circumstance to be considered a trauma (Center for Substance Abuse Treatment, 2014). Such a sense of helplessness and fear was evident as Amanda recalled how she wished she had asked someone else to accompany her to her consultation where the doctor revealed her son's diagnosis:

> Amanda: *"And you know, you remember things and you forget things. I couldn't remember something, but I can remember her words. And I always vow when you're going for an issue with somebody with a doctor, or somebody try and take a friend with and because you hear something, and they will hear something, and they will remember what you don't remember a friend or your mother or your father or your husband, because you're getting traumatic information poured at you, and you go into like a traumatic state, you don't remember. So I always, I always say to anybody, you take somebody with you, because you need them to say, 'Don't overreact.'"*

This retrospective regret at not having allowed someone to accompany her to the appointment, and/or advice for future mothers not only re-emphasises how traumatic Amanda's experience of receiving her son's CP diagnosis was for her, but it also conveys the extent to which she felt helpless and lacking in control of her circumstances. And while Maier and Seligman (2016) define 'learned helplessness' as a typical neurological response that exhibits a person's emotional failure to escape shock that has been induced by uncontrollable and aversive events, the current study demonstrates that mothers' feelings of helplessness while raising a highly functional CP child were momentary or periodic. This is evident in Amanda's description of the lengths she went to to help her son integrate socially into university:

> Amanda: *"I went to Belfour Park long ago it was beautiful, and it was over Christmas. He was starting in the January. It was Christmas time where they had all the Christmas things out, and they had young girls, students, helping the children and doing the little things. I know I sound terrible when I say this, but I'm not. I went there and I looked for the prettiest one, I know. And you can rub me out on that. I didn't and I said to her: "Please, will you help me? Would you, would you take like a helper", because they were helping there "Would you be a helper to my son to go to Varsity College?" And why I did that? A), she was gorgeous. B), I knew the people, the people there would, the guys would love her, because she was gorgeous."*

The former further demonstrates that as Amanda's journey progressed she became more and more capable of engaging in compensatory behaviours to improve upon or better her son's

circumstances as she was able to mobilise assistance to improve the ease with which her son would socially integrate into university. Moreover, evidence supporting the validity of this desire for control suggests that feeling in control can be seen as a measure of satisfaction and quality of life (Hwang, 2020). Similarly, mothers of high-functioning CP children demonstrated that they felt satisfied with the compensatory behaviours they implemented as is evident when Janet explained: *"I do feel that I was quite pushy with him, I pushed him to do things, and if it weren't for that fact, maybe, maybe he wouldn't be the same person that he is now."* This apparent sense of self-assuredness Janet demonstrated concerning how she approached raising her son not only suggests that she feels grateful and accepting of her child's overall outcome, but it also indicates that she feels proud of how proactive she was in confronting the challenge of raising a child with high-functioning CP. Evidence justifying such feelings of pride and a lack of regret suggests that higher levels of mastery are oftentimes associated with lower levels of stress (Weinberg et al., 2023). This is further evident as Janet concludes "*So I'm not regretting any of my things that I did,"* indicating that she feels that the proactive behaviours she implemented were beneficial to her son.

Furthermore, this transition from feeling out of control to feeling proactive and in charge demonstrates how mastery acts as an important buffer against the effects of traumatic stress (Miller et al., 2022). The former further reveals itself as a useful tool for mothers who have prevailing fears surrounding their perceptions of their children as being susceptible to harm. Evidence supporting this can be seen in Linda's explanation of why she feels she adopted the behaviour of overprotectiveness towards her daughter:

> Linda: *"I think my overprotectiveness stems from my fear that she would be harmed in some way. This was mostly because she was in ICU for 5 days during which we almost lost her twice, and that her vision was so poor and she had some developmental delays."*

While this reality in which Linda had to worry about coping with the potential loss of her daughter differs from the aforementioned experience in which she mourned the hypothetical loss of who her daughter could have been, it highlights feeling out of control in any capacity as a significant consequence of psychological birth trauma (Gamble et al., 2002). Further evidence supporting the desire to engage in overprotectiveness and other such overcompensatory behaviours can be seen by parents of children with health disorders. Such parents are noted to report higher levels of parental vigilance compared to mothers of non-

disabled children as they perceive their children to be more vulnerable (Meakins et al., 2015). The former not only suggests that mothers' initial experiences of trauma influenced how they approached the task of childrearing, but it also demonstrates that assuming a sense of agency was an essential reaction for many of the mothers to mitigate the feeling of being out of control. Evidence supporting the former can be noted in Alison's reported experience in which she explains how she took the initiative to protect her son in the event of a robbery:

> Alison: *"(Shaking voice) I used a bit of things to my advantage, like, for instance, we were robbed, and they came in, they hi-jacked my husband, and they came inside and I looked at the guy, which they say you mustn't do. I looked at him in the eye, and I said, "Please don't harm me or any of us, because I said, I have a disabled child. And I said, please look after us." And the guy actually…they robbed us, which was fine, but they, the one sort of looked after me from the other one, so I was very grateful for that. I don't know how that would have turned out otherwise."*

Here, her shaking voice as she recounts her experience indicates that despite her actions of taking control of her situation, Alison felt a sense of desperation. However, as she continues to detail her experience, she reveals that she was able to remain somewhat calm and focused enough to negotiate for her and her son's safety. This experience reflects the reality that a degree of emotional regulation can enable individuals to modify the duration and intensity of emotional expressions to best respond to environmental circumstances (Aldao & Plate, 2018). Furthermore, this instance in which emotional regulation allowed Alsion to *"use a bit of things to my advantage,"* for circumstantial control suggests that mothers were not just passive recipients of their experiences but were also dynamic agents in influencing how they experienced and progressed along their journeys. This is further evident in Lisa's experience who, despite her formerly mentioned dominant experience of struggling to mobilise resources to help her child become more independent, *was* eventually able to be resourceful by contacting a parent at her child's school who was also raising a CP child:

> Lisa: *"But I was also very fortunate because I, at her school, I met a mother, occupational therapist with a disabled child, and she helped me, and we actually imported a book. Can you believe that? I know it sounds funny, a book from England: Nancy Finny "How To Work With A Cerebral Palsy Child In Your Family." So it had lots of practical things in and I let my friend, you know, say "What we need is this, this,*

this, and this. So, ok let's see, this will be a good chair for her. This will be a good way to feed her. This will be a good way to...(Pauses)"

This expression of agency to gain a sense of circumstantial control is expressed in Albert Bandura's Reciprocal Determinism theory which suggests that an individual can influence their environment as much as the environment can influence the individual (Little, 2018). However, not all mothers perceived themselves as being able to harness a sense of emotional control. This is evident as Jessica recalled:

Jessica: *"The only thing is that I think I was immature at that time when I had my son and when I was a young mother, and if I was more confident enough, I would have been able to educate people better when faced with different challenging situations*,"

suggesting that she felt ill-equipped to educate people on her son's difficulties despite being a teacher who specialised in Remedial Education. The former not only contradicts Lisa's perception and the general trend that *"Today, we live in a world with all this knowledge, all this knowledge, and all the research, it's available"* which made mothers feel that that they were more in control of their circumstances as well as their children's futures. Rather, it suggests that mothers' sense of parental self-efficacy was not determined by mastery to the exclusion of other factors such as self-perception (Saether et al., 2023). The former thus reinforces the reality mentioned in the literature review that mothers' experiences of raising CP children are informed by a combination of emotional and practical components that shifted or evolved over a period of time (Findler et al., 2016; NINDS, 2023). Thus, although Lisa expressed her perception that "*There wasn't internet, there wasn't much information. So yes, goodness me, I would rather raise her now and know more*," she, as well as many of the mothers interviewed for the study, were able to gain some semblance of circumstantial control through enormous efforts and compensatory behaviours. Indeed recent technology has proven to be highly beneficial in helping mothers obtain a sense of circumstantial control by allowing mothers to improve their children's physical difficulties and/or academic challenges through devices (Kambouri et al., 2023; Lieber, 1986). However, the mothers in the study tended to adequately harness a sense of control over their circumstances and improve upon their children's realities without such devices, as is evident in Janet's statement "*We did everything we could to make it better."* Thus, although Janet highlights doctors, physiotherapists, and occupational therapists as being essential to her son's improvement as it is not known whether or not she had access to the former mentioned devices, she demonstrated a similar focus on her child's ultimate improvement.

In addition, CP has been noted as a disability that does not have a cure. As such, the applicability of the medical model to disability can be considered to be somewhat inaccurate as it asserts that CP is an illness that can be healed with medical intervention (Braathen et al., 2015). However, the importance of such consistent therapy to improve CP children's functional abilities can once again be noted as a necessary measure implemented by mothers to improve their children's functional potential. Further evidence supporting the former suggests that immediate action is considered necessary to ensure that children reach their full potential as adults (Smythe et al., 2021). While the former fixation on maximising their children's full potential by helping them acquire certain abilities in the earliest phases of growth is noted as an overcompensatory attempt by mothers to rectify their situation, some mothers still displayed a tendency to want to display overcompensatory behaviours as Amanda reflects *"Okay, I see him when maybe he's battling to do okay, something. And then I think, oops, pull back a little bit,"* thus suggesting how she has to refrain from the impulse to take control in situations where she perceives her son with certain physical challenges. Evidence supporting this continued overprotective behaviour despite having desired control suggests that the changes associated with raising a child who has a disability not only evolve with children's changing needs but continue to impact mothers throughout their lives on an emotional level (Findler et al., 2016). Further evidence supporting this suggests that mothers of disabled children may engage in overprotective behaviours to protect their children from perceived threats within their children's environments (Lindhout et al., 2006). The former can be considered understandable as most CP children have a difficult start to life. This was previously highlighted by Linda who provided potential reasoning behind her overprotective behaviour(s). Similarly, other mothers in this study found it difficult to accept the albeit limited level of control that they have had over their situation. This was further evident as Jessica stated: *"And I think having a kid after him, I was so grateful for every small milestone that they had achieved."* This feeling of gratitude highlights how mothers' desire for, but subsequent inability to achieve a subjective sense of control significantly impacted their long-term emotional well-being. Thus, although mothers remained emotionally wounded by their children's difficulties the aforementioned overprotective or overcompensatory behaviours indicated their need to feel in control of their circumstances and highlighted that mothers were not passive in their children's developmental outcomes as they did their best to feel in control and improve upon their high-functioning children's abilities.

Theme 4: Worries about the Future

In addition to lacking a sense of circumstantial control which mothers went to great lengths to try and attain through overcompensatory behaviours, mothers expressed being preoccupied with worries about their child's future. Evidence supporting the relevance of future worries as a theme suggests that mothers of children with developmental disabilities (DD) tend to feel greater levels of pessimism about the future (Cantwell et al., 2014). In the cases of mothers with CP children, such pessimism may be due to the complications at birth as mentioned in the literature review (Jiménez-Palomares, 2021; Zhang et al., 2020) that were also demonstrated to affect mothers' overprotective behaviours in the theme above.

Moreover, mothers' feelings of concern regarding their children's future were all reported to have emerged around the time that they received a diagnosis of CP. Some mothers reported that their concerns arose immediately after birth. Evidence supporting the former denotes that injuries that are derived from birth trauma can be immediately obvious (Geirsson, 1988). Such a reality can be seen in Alison's recollection of how her son's state at birth caused her to have concerns that he may have CP:

> Alison: *"Well, I knew from birth there was a problem, and so it wasn't a surprise to me, because from birth, he was he was blue, so I knew there was some brain damage. So the whole thing was how badly it was damaged, the brain was damaged, so I thought he'd have CP."*

This acknowledgment that her son's appearance at birth caused her to have concern that he may have CP stands in contrast to Cantwell's (2014) understanding of mothers as being purely 'pessimistic' without a legitimate reason. Rather, the reality is that doctors' predictions can cause mothers to prepare themselves to raise a low-functioning child (Phumudzo et al., 2021). This means that mothers' concerns are not merely based on blind pessimism. Whether illegitimate or not, their concerns are often informed by medical practitioners. Evidence supporting the former can be seen in a study conducted on first-time mothers in Tshwane, Gauteng to find out about mothers' lived experiences of caring for their children postpartum. The findings suggested that mothers felt a lack of confidence to take care of themselves and their newborn babies after having been discharged from the hospital (Masala-Chokwe & Ramukuba, 2017). While these findings contradict the noted mistrust displayed by mothers under the theme of 'Trauma,' such a discrepancy can be explained by examining the length of

time that has passed from the beginning of mothers' journeys to their children's current outcomes. Evidence supporting the former can be seen as Linda recalls how *"we were very worried when she was younger about what her future would be,"* suggesting that it was only as their daughter started progressing and displaying signs of not being severely impaired that they began to feel a sense of hope. Evidence supporting this suggests that the daunting nature of raising a child with CP is often because of knowledge that children who suffer from birth asphyxia are at a higher risk of functional impairments that not only include CP but can also be audiovisual-related in nature (Heringhaus et al., 2013). The former demonstrates that mothers' respective levels of knowledge concerning CP had a significant impact on the extent to which they were concerned for their children's futures. This is evident in Janet's statement *"Um, to be honest, I didn't really understand the full meaning of CP. I kind of just thought we could get over it,"* suggesting that the level of concern mothers had for their children's futures was somewhat dependent on their having an understanding of the disability and being provided with a clear prognosis. Evidence supporting this suggests that for children with genetic neurodevelopmental conditions, many parents look to healthcare professionals because they value clear information and understanding (Turbitt et al., 2024).

Moreover, such conclusions are often drawn as a result of the former mentioned reality that practitioners often persuade mothers to assume the worst as they focus on the low-functioning and most expected outcome (Phumudzo et al., 2021). However, the extent to which mothers found prognostic information to be incorrect and thus lacking in value, in the long run, is demonstrated by Michelle who expresses her regret that she did not trust her gut instinct in favour of adhering to assessments made by teachers and/or practitioners:

> Michelle: *"And I think that the only other thing I probably would have done is stuck to my what I thought, like my gut instincts, like occasionally there would be a teacher or someone who would put a lot of doubt in my mind."*

This regret that not having trusted her intuition that Michelle experienced corroborates with evidence from a study conducted by Peng and Lu (2024) which demonstrated that although mothers' feelings about their children's future improved as their children grew older and displayed more capability, they reported experiencing feelings of anxiety in the initial phases of their children's journeys. Further evidence supporting the former suggests that mothers of CP children initially require extensive assistance from family members and organisations to lessen the burden they are experiencing (Phumudzo et al., 2021). Such difficulties that mothers

are confronted with are not only overwhelming but the reality that it is often difficult to provide mothers of CP children with an individualistic prognosis makes mothers feel even more uncertain of what the future holds for their children. Evidence supporting the former can not only be noted in the healing consequences of neuroplasticity with age noted in the literature review but is also highlighted by the reality that delayed development is a typical consequence of CP (Choo et al., 2019; Zotey et al., 2023). The former corroborates with the medical model of disability as it implies that CP children can improve functionally given the right amount of therapy and exercised levels of patience. The mothers in my current study, however, indicated that the right amount of therapy, and patience were enough to alleviate their feelings of concern. This was made evident as mothers highlighted how each phase of their children's development entailed unique challenges and obstacles. This reality caused mothers to experience trepidation about the ease with which their children would reach the next milestone. This is evident as Janet recalled the sense of relief she felt every time her son progressed to the next grade:

> Janet: *"(Laughs) Well, every time he passed a grade, that was definitely a plus. And he never failed a single year. He passed year, not very well. It was always a case of he might have to change schools, go to a remedial school or do the year again but he never did. He actually managed to cope quite well."*

The former not only highlights how mothers never felt at ease with their children's progress but also highlights a clear discrepancy between the respective levels of assistance in remedial versus mainstream schooling systems. Thus, although Janet notes that the main source of difficulty she experienced with her son's development was due to delayed milestones, the former suggests that remedial interventions would have made her experience feel more manageable and caused her less worry for her son's future. Evidence supporting the legitimacy of future concerns highlights how assumptions about the cognitive potential of disabled children tend to result in a lack of effort to implement inclusion measures on behalf of institutions (Wondemu, 2022). This reality demonstrates how, in keeping with the social model of disability, understandings of disability are generally environmentally dependent (Guccione & Elrod, 2012). This is because 'disability' is reliant on public acknowledgment to be considered an important matter worth catering to by educational institutions and is thus often neglected. Consequently, mothers are expected to "make it work" or find ways of coping with challenging aspects of the schooling system without much help from the educational system itself, causing mothers to remain in an ongoing state of concern.

Similarly, the former was also noted as impacting Jessica's initial experience as she explained:

> Jessica: *"We had put him in a mainstream nursery school, Islamic nursery school, and they obviously struggled to understand his needs. He was just left at the back of the classroom to do his own thing. He wasn't really attended to or anything of that sort. So we took him out of that and we put him in ... remedial school which was a huge difference for us because there the teachers were equipped to deal with children like him."*

Here, the reality that such a discrepancy in the levels of accommodation afforded to children with CP in mainstream versus remedial schooling environments is further highlighted as having impacted mothers' schooling choices at various points within mothers' journeys. Evidence supporting the former can be seen in a study conducted on mothers of children with varying types of disabilities to better understand the factors they consider when choosing a school for their children. The findings highlighted that the type of resources such as special education programs, teachers' levels of experience with disability, and facilities available were all important factors that informed mothers' decisions (Mawane & Bal, 2018).

In addition to the above-suggested subjective weight that mothers ascribed to their decisions, the data demonstrated how the prejudice mothers mentioned significantly influenced their levels of concern for their children's futures. This can be seen as Jessica highlights how the reluctance of high school institutions to accept their child due to his CP diagnosis left her feeling concerned about how their son was going to complete secondary schooling:

> Jessica: *"But then when it was time for high school, that was another difficult journey for us, because just finding a school that would accept him. We found that because our son was academically able but physically unable, that was a huge challenge. The schools would just see the application form and the diagnosis Cerebral Palsy and immediately say 'Sorry, they can't accept him.' So even after going to the school and begging and pleading and saying, 'You know what, just give him a trial, give him a week try, see what he's capable of, so you'll be able to understand what we see' lots of schools weren't willing to do that."*

The former not only highlights the abovementioned reality that assumptions about CP children's cognitive potential hold both mothers and their children back from obtaining worthwhile opportunities, but it demonstrates how even in today's supposedly more progressive and politically correct society, misconceptions and prejudices about individuals

with CP still have a significant impact on the experiences of CP individuals as well as their mothers. Evidence supporting the former reality suggests that advocacy and activism are seen as being implicated in the roles of mothers with disabled children (Ryan & Cole, 2009). While such proactivity has been mentioned as demonstrating mothers' need for circumstantial control, it can further be noted as demonstrating the depth of the concern that mothers feel for their children's futures as mothers often contend with the brunt of the childrearing burden as a result of societal expectations that position them as being primarily responsible for their CP children's outcome.

Yet mothers' concerns for their children's futures in the current study were not limited to phases such as the initial stages of development during infancy or concerning child health and diagnosis, nor were they limited to grade school as mentioned above. Rather, mothers' feelings of concern for their children's futures extended to them experiencing worries about what will happen to their children after they die. The former is evident as Amanda reveals:

> Amanda: *"I'm not very sure of as bright as my son is how socially astute he is. So when I've died or am not around, he'll have to be careful about people who might take advantage of him or give him lifts, or if he's living on his own, if he'll cope. And likewise, if he's living on his own, I'm worried about how he will cope concerning the practical side of things."*

While Amanda's son's reported lack of social astuteness may not be related to his CP, there is evidence which suggests that individuals with CP who are highly functional may have had to spend more time focusing on improving their academic and physical abilities, thus leaving them with minimal time to focus on honing their social skills (Myrhaug et al., 2014; Shikako-Thomas et al., 2008). Evidence supporting the former suggests that although early childhood is perceived as being the common window period in which a child's developmental potential is at its highest, the reality that honing such practical abilities and academic skills relies on extreme levels of focus and investment can leave little time for mothers to help and encourage their children to hone social skills (Smythe et al., 2021).

Evidence supporting the latter can be seen in the literature review as mothers of CP children often have an imbalanced lifestyle as a result of the demanding responsibilities surrounding their children's rehabilitation with which they have to contend (Nazi et al., 2017). Moreover, Amanda's concern about *"how he will cope concerning the practical side of things"* suggests that her worries for her son's future without her are not limited to her concerns surrounding his

social abilities but are also evident in her concerns relating to her son's practical capacity to take care of himself.

This is further evident as she expresses worries about when she dies, *"if he's living on his own, if he'll cope."* Such a concern for parents regardless of their CP children's age and level of education can be understood as even though these individuals are seen to possess a considerable level of cognitive normalcy and/or physical independence, the extent to which mothers feel that their children would be able to cope on their own may remain uncertain. Evidence supporting the former suggests that mothers of children with CP often perceive these children as being vulnerable (Pereira et al., 2016). Thus, mothers' experiences of raising children with high-functioning CP were notably characterised by a prevailing sense of uncertainty and doubt surrounding their children's futures as they expressed having felt concern from the moment of their children's birth, during the schooling phase and have even continued to feel concerned as they worry about their children's capacities to navigate the social world as well as practical matters once their mothers have died.

Conclusion

The aforementioned findings demonstrated how mothers raising children who have high-functioning CP from childhood into adulthood were impacted emotionally, socially, and behaviourally by their experiences. Mothers reported that receiving news of their children's CP diagnosis as well as a lack of understanding displayed from practitioners and in daily scenarios, to be emotionally scarring and traumatic. Mothers further noted how their emotional trauma was exacerbated by the intense levels of discrimination and societal judgment that they experienced in social and community settings. Such prejudice was also demonstrated by mothers to cause them to feel alone and misunderstood due to their children being stereotyped as incapable. Moreover, mothers also felt isolated and misunderstood because they struggled to locate other mothers with children who had similar case-specific experiences of CP. The former not only demonstrated how such a journey of raising a child with CP can make mothers feel like they are an ostracised anomaly, but it highlighted the unique experiences of mothers raising children on the high-functioning spectrum. Moreover, mothers revealed how their experiences were defined by and comprised of specific behavioural and emotional reactions which informed or created their experience and influenced the outcome of their journey simultaneously. Here, the coping mechanisms of survival-oriented proactivity and choices as well as grief-related responses were noted as being integral to mothers' subjective and

pragmatic journeys. This was followed by a discussion of how mothers' feelings of lacking control or a sense of agency over their circumstances led them to adopt various overcompensatory behaviours. The former was discussed regarding mothers' strategic social interventions and overprotective behaviours which they exhibited to gain a subjective sense of control. Lastly, mother's experiences of raising children with CP were noted by mothers to pose ongoing worries despite their children's high-functioning abilities and/or mature age. This was indicated as mothers revealed their children's developmental, educational, and independence-related concerns.

Chapter 5

Conclusion, Implications, Limitations, and Recommendations

Introduction

This chapter will examine the implications of the study, identifying how the study conducted can have relevance to other topics of interest within the field of Psychology as well as how it may have relevance to similar but unrelated academic fields. The limitations of the current study are highlighted in detail and recommendations for future research are provided for researchers to consider expanding upon or broadening the existing knowledge on mothers' subjective experiences of raising children that have high functioning CP into adulthood.

Implications of the study

This study was conducted on mothers' experiences of raising children with highly functional levels of CP from childhood into adulthood. Thus, the study has significance in helping readers understand the role that motherhood plays in impacting an individual's opportunities and development. This was demonstrated as mothers' intensive levels of involvement in catering to their children's therapeutic and educational needs were demonstrated as being beneficial in helping their CP children reach a highly capable level of functioning. Furthermore, findings highlighted mothers' experiences of receiving their children's CP diagnosis as being emotionally traumatic and thus having relevance to the subject matter of practitioner conduct and empathetic practice. Thus, how practitioners delivered the diagnosis to mothers was seen as heavily impacting their emotional well-being. Similarly, the study has firm implications in the field of emotional well-being as linked to social levels of social difference and injustice. This was demonstrated by how mothers were treated in social circles and by their communities which had a significant influence in making them feel emotionally alone and misunderstood. Here, the specific nature of children's CP as being high-functioning was also noted as impacting how mothers experienced the social world on a subjective level. Moreover, the themes of survival and grief-related coping not only articulate how trauma can be long-lasting and impactful but they can also be noted as having implications for resilience studies. This is evident in how mothers were able to move forward with their lives and raise their CP children by implementing therapeutic rehabilitation despite having experienced a form of loss. The former themes explained how mothers dealt with the demands expected of them emotionally and practically. However, the findings of the study can even be highlighted as having implications for fields of study such as existentialism and Humanistic Psychology. This was

evident as mothers were concerned with improving their own and their children's realities as they strived for a sense of circumstantial control. Lastly, mothers' respective concerns for their CP children's future suggest that these findings can have relevance to studies on physical therapy and remedial education. The former is evident as the objectives of physical independence for CP adults and educational advancement in CP individuals with developmental delays were highlighted as vital matters that formed a part of mothers' experiences.

Limitations of the Study

The study's qualitative, phenomenological paradigm enabled the opportunity to gain in-depth insight into mothers' experiences of raising a child with high-functioning CP into adulthood. However, this emphasis on the uniqueness of human experience did not allow for the generalisability of findings, and thus its results cannot be attributed to a larger population. Moreover, the reality that mothers were reporting on their retrospective perceptions and experiences of their journeys brings questions of data trustworthiness to the fore. Evidence supporting the former suggests that an individual's retrospective outlook concerning an experience can be markedly different from what they perceived and felt at the exact moment that the experience was happening (Brisudová et al., 2024). The former by no means suggests that mothers' experiences were in any way subject to alteration or inauthentic. However, it does highlight that a consistent understanding of mothers' experiences may not have been captured. The former may be because mothers' perceptions may evolve as their children age and mothers continue to assess or reanalyse their past experiences. Lastly, despite the fact that certain inclusion criteria were instated that enabled the researcher to collect a sample population for the study, inherent levels of bias that mothers often harbour concerning their children and their children's abilities may have lead mothers to overexaggerate their children's functional abilities.

Recommendations for Future Research

The current study focused on mothers' subjective experiences of raising a child that has high-functioning CP, providing detailed accounts of how mothers were impacted on emotional, social, and practical levels as they persevered in helping their children to maximise their potential. However, future research should examine to a greater extent how children's highly functional abilities impacted mothers' experiences of their journeys. The former is of interest as it could determine the role that the children had to play in influencing mothers' experiences.

Moreover, although it was not mentioned in the current study, throughout the interviews mothers mentioned how raising a child with CP changed their priorities and/or outlook on life as well as how they conduct themselves daily. Therefore, I suggest that future research could be conducted to understand how the adversity of raising a CP child into adulthood can impact or change a mother's worldview.

Conclusion

The aforementioned demonstrates that the current study has significant implications for a variety of academic fields as the difficulties mothers experienced in areas such as obtaining social acceptance and acquiring opportunities suggested that the study has applicability to critical social and developmental studies. Furthermore, the relevance of the current findings to Humanistic Psychology, existentialism, and resilience studies was emphasised. The former implications were followed by a discussion of the limitations concerning the study. Here mention of phenomena such as maternal bias and the ever-evolving nature of individual beliefs was made. This was emphasised as it was noted that mothers can re-evaluate their past circumstances long after the completion of this study and thus rethink their current answers to the above interview questions. Lastly, recommendations for expanding on this area of study were provided. Here, the suggestion was made that how children's highly functional abilities impacted mothers' experiences of their journeys should be explored. Moreover, the potential life lessons and changes in the personal values and priorities of mothers should be interrogated as this can have great implications for developmental and attachment studies in the field of psychology.

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Appendix A

Interview schedule: Reported experiences of mothers raising children with CP from childhood into adulthood.

1. How old is your child with CP?
2. Have you got a daughter or a son?
3. What is your socioeconomic status?
4. Do you have any other children? How old are they etc.?
5. What is your child with CP currently doing with their life?

6. Has your child been given the official diagnosis of CP?
7. What age were they when they were diagnosed with CP and what was the provided prognosis?
8. What was your initial reaction to this diagnosis? How did you feel about it and what were your thoughts?
9. How did you continue to cope with and/or feel about this diagnosis emotionally throughout your son's/daughter's childhood?
10. How do you feel about having a CP adult?
11. Where on the spectrum of CP would you place your child?

11.1 What does the term 'high functioning' mean to you? Would you consider your child to be high functioning?

12. What can your child do independently?

    12.1 Was your child in any extra therapies in order to learn how to do these things?

    12.2 Can your child walk and/or move independently?

13. How do/did people in the various environments that you frequent daily respond to your child's CP?

14. Have you experienced any practical challenges in helping your child navigate or adapt to certain environmental settings over the years? For example, schools, university etc. Were these difficulties accommodated for?

15. What are the positive experiences that you can recall with regards to raising your child with CP?

16. Do you feel that your experience is comparable to those of mothers who do not have a child with a disability, yes/no? Explain.

17. Looking at your experience retrospectively, would you have changed anything? Or done anything differently?

18. How have you found this interview?

19. Are you ok to stop now?

Appendix B

Participant Information Sheet

Dear Madam,

My name is Alexa Heyman. I am a Masters student in the Psychology Department at the University of the Witwatersrand, Johannesburg. My supervisor is Dr Clare Harvey. I am conducting a research study about the experiences of mothers raising Cerebral Palsy children. The study's title is 'The Reported Experiences of Mothers Who Have Raised Their High-Functioning Cerebral Palsy Children into Adulthood.'

I am inviting you to take part in an interview. If you decide to take part, your participation in this research study will last about 45 minutes. The interview will take place at a place and time convenient for you.

With your permission, I would like to audio record the interview. This data will be stored on my laptop in a password protected folder. Only myself and my supervisor will have access to the data.

During the research activity, I will need to ask for some personal information about you, including your child's disability and their diagnosis.

The interview will be confidential. When I share the results of the research study, I will not include your name or anything else that could identify you and thus I can assure you remain anonymous to others. With your permission, other researchers may use the data collected from this research study, but your name and any personal information will not be used or passed on.

If you decide to take part in the research study, it should be because you want to volunteer. You do not have to take part. You can stop being in the study at any time. You do not have to answer any questions if you do not want to. You will not get any direct benefits if you choose to join the research study. You will not lose any services, benefits or rights you would normally have if you decide not to join. Taking part in the research study will not cost you anything. You will not be paid for being in this research study.

The risks for this research are that some of the questions asked may make you feel sad or upset. If this happens, I will stop the interview and continue another time. If you need some support or counselling services following the interview, these are available free of charge at the University of the

Witwatersrand's Emthonjeni Centre. The contact name is Paballo Lepota and the contact details for the counselling service are paballo.lepota@wits.ac.za or +27 (0)11 717 4513.

This research study will be written up as a research report. The report will be available on the university library website. If you would like to receive a summary of this report, I will be happy to send it to you. The results may also be used in conference proceedings and publications.

If you have any questions during or afterwards about this research study, feel free to contact me or my supervisor on the details listed below. If you have any concerns or complaints about the ethical procedures of this research study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,
Alexa Heyman.

Researcher:
Alexa Jade Heyman. 2368399@students.wits.ac.za, 0747911236

Supervisor:
Clare Harvey (Dr), clare.harvey@wits.ac.za, 011 717 9999

Appendix C

Consent Form

Title of project 'The Reported Experiences of Mothers Who Have Raised Their High-Functioning Cerebral Palsy Children into Adulthood.'

Name of researcher Alexa Heyman

I, …….., agree to participate in this research project.

I agree to the following:

(Please circle the relevant options below)

The research study was explained to me. I understand what this study is about.	YES	NO
I understand that I can volunteer to take part in the study	YES	NO
I agree that the interview may be audio recorded	YES	NO
I agree that anonymous direct quotations from my interview may be used by the researcher in their research report/publications/conference presentation	YES	NO

I agree that my participation will remain anonymous (my name or other identifying data will not be used by the researcher in their research report)	YES	NO
I agree that other researchers may use the information I provide in my interview (depending on their own ethics clearance being obtained) but my name and any personal information will not be used or passed on	YES	NO

…… (signature)
…… (name of participant)
…… (date)

…… (signature)
…… (name of researcher/person seeking consent)
…… (date)

Appendix D

Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Heyman

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: H24/06/13**
PROJECT TITLE	'Mothers' Experiences of Raising a High-Functioning Child with Cerebral Palsy into Adulthood.'
INVESTIGATOR(S)	Miss A Heyman
SCHOOL/DEPARTMENT	Human and Community Development/
DATE CONSIDERED	21 June 2024
DECISION OF THE COMMITTEE	Approved Risk Level: Low
EXPIRY DATE	27 August 2027
DATE 28 August 2024	**CHAIRPERSON** _____ (Professor J Watermeyer)

cc: Supervisor : Dr C Harvey

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **A SIGNED COPY** returned to the Secretary electronically. Unreported changes to the application may invalidate the clearance given by the HREC (Non-Medical)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved I/we undertake to submit an amendment of the protocol to the Committee. **I/we agree to completion of a regular progress report. For Minimal and Low Risk studies, this is due annually on 31 December. For Medium and High Risk studies, this is due twice annually on 30 June and 31 December.**

Alexa Heyman
Signature

22 /01 /2025
Date

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix E

Plagiarism Report

turnitin

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

Submission author:	Alexa Heyman
Assignment title:	Draft submission (all, regardless of course/programme)
Submission title:	Dissertation copy 1.docx
File name:	Dissertation_copy_1.docx
File size:	293.34K
Page count:	112
Word count:	37,175
Character count:	214,129
Submission date:	05-Feb-2025 02:25PM (UTC+0200)
Submission ID:	2580296742