Mothers Who Listen with More Than Ears

The Phenomenological Experience of The Non-verbal Communication Between Mothers and their Child with Complex Cerebral Palsy.

Submitted to the New School of Psychotherapy and Counselling and Middlesex University Psychology Department in partial fulfilment of the requirements for the Degree of DCPsych in Counselling Psychology and Psychotherapy

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Abstract

In England, every 1000 babies born 1 will be left with complex cerebral palsy affecting all limbs and internal organs. Of those children by age 12, 43% will have no consistent way to communicate with the world. Empirically, many mothers of these children self-report that they can communicate effectively with their children in these cases in a way that possibly only the mother understands. Understanding the mother's experience of living with a complex cerebral palsy non-verbal child is important for professionals and the society that supports them.

The aim of this research is not to prove or disprove this phenomenon but rather to explore the lived experience of mothers with disabled non-verbal cerebral palsy children, validating and giving a voice to an otherwise isolated abnormal form of mothering.

A homogenous sample was collected made up of 8 mothers who had non-verbal complex cerebral palsy as a result of Hypoxic Ischemic Encephalopathy at birth. The age range of the children was not > 3 and not <16. Interviews took place on a video link, semi-structured interviews were done and the six stages of a Heuristic Inquiry were used to analyse the transcribed data.

The results produced 7 universal themes: 'The Choice to Communicate,' 'Communication Over Time', Impediments to communication', 'Certainty and Uncertainty', 'Embodied Communication', 'Being Towards Communication', and 'Being in the World with Others'. These themes capture the essence of the experience that mothers have when confronted by a baby that is diagnosed with multiple disabilities and unable to verbalise. The findings that emerged are fundamentally existential and they are examined through an existential lens.

A Brief Note On Researching During Covid=19

The COVID-19 pandemic has brought about challenges to student and career researchers, changing initial plans for face to face interview’s to online. This was especially significant for phenomenological qualitative research as the experience of interviewing on Zoom has an impact on research whether we acknowledge this or not. There are always challenges when faced with having to adapt research plans to the current circumstances. Going forwards perhaps there will not be clearance to conduct interviews via Zoom but for the pandemic years this was the only safe way to keep research interviews going. My participants actually found this easier for them because getting out the house and organizing carer’s for a disabled child can be a logistical nightmare. Zoom offered my participant mothers more flexibility. I was cognisant that I did not get to see the whole physical body of my participant as I only saw what the screen allowed me to see. I was aware that instead of being in an interview room purposely hired for the interview we were both in our own private spaces. Yet there is something joyful about persevering and carrying on the work no matter what and the ability to use Zoom allowed for.

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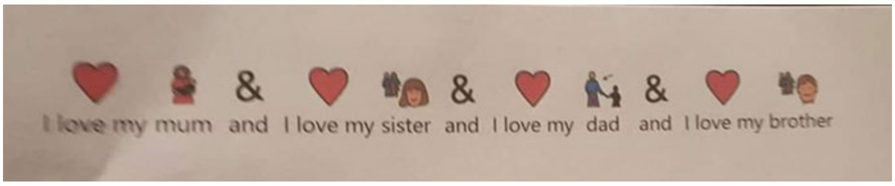
Chapter 1 Introduction



I love my mum and I love my sister and I love my dad and I love my brother

Overview of the Chapter

The chapter begins with by setting the work firmly in an existential setting. The reason for this is that it was through facing my own existential crisis when my son was brain injured at birth and being told he would never speak that the seeds for this research were sewn. There was a real drive inside of me to find out how what I was experiencing was being experienced by others. I had the benefit of having a psychology education and I wondered how other mothers with their complex cerebral palsy children coped with the their feelings and existence around the experience of having a child that does not speak.

Moving on from the existential work on motherhood I introduce non-verbal communication in children as a concept. I explore with the reader what challenges it brings and the way that it is understood in current health, social and educational settings. I explain the aetiology of cerebral palsy and I situate myself and my personal interests in this research.

This is a Heuristic Inquiry, which means that the research starts with my own knowledge of the experience and moves outwards to learn more about the lived experiences of others who are mothers with complex cerebral palsy non-verbal child. I reflect on how my professional and personal voice have informed the research and its evolution from an idea to a credible topic worthy of exploration. Finally I present the research question, the research aims and the research objectives. As I invite the reader to move through the thesis and discover the powerful findings and conclusions that this has exploration produced.

Introduction to Motherhood through an Existential Lens

This thesis explores motherhood from within the framework of an existential philosophical approach to motherhood. The transition into motherhood is a significant life event researched from various disciplines exploring pregnancy, birth and the early period of motherhood as a period of life in which a woman might experience disturbance and gain new outlooks in a bodily, psychological, social and existential way (Prinds, 2015). This may be even more relevant for women who have given birth to unwell babies since research suggests that mothers of babies who have post birth complications undergo an experience of loss of the perfect child, crisis and unpredictability (Shulman, 2020). This research explores the motherhood transition actualises considerations on how to make meaning of life existentially beyond the prognosis and how mothers grapple with existential issues (Hall, Kronborg, Aagaard, & Brinchmann, 2013), Existential motherhood research suggest that motherhood transition is considered a pivotal yet paradoxical life event both bodily, psychologically, socially and existentially (Arnold-Baker, 2020). Motherhood it would seem gave meaning and purpose in life, presented the mother with her and her child's vulnerability of life. Furthermore motherhood brought about a sense of responsibility, thoughts about life and death and 'something bigger than myself' (Garland, 2019). Past research indicates that when motherhood transition is reduced to a medical event then it reduces some of the authenticity of the experience and reduces down the meaning mother find in the miracle that is motherhood (Arnold-Baker & Donaghy, 2005). Throughout the thesis the existential ideas of meaning, responsibility, embodiment, authenticity, identity, power, freedom and autonomy present themselves. These ideas and human issues are expanded upon in the literature review, the theoretical underpinning of the methodology, the findings, the discussion and conclusion. Firmly situating this work within the already growing body of research on motherhood linked to existential ideas and philosophy.

Introducing Non-verbal Communication

The term non-verbal communication spans many conditions. What sets cerebral palsy apart as a non-verbal condition is that it is accompanied by severe physical disability from birth (Bax, 1990). Unlike many adults who lose the ability to speak and function as part of neurological illnesses there is no established proof of cognitive ability (Kavčič & Vodušek, 2005). Other childhood conditions that have well documented and very defined cognitive diagnoses can pinpoint a child's abilities. Hypoxic brain injuries that lead to cerebral palsy occurs to healthy babies, which is a phenomenon in of itself that would seem to create its own narrative around communication. Much of what gets decided for the child with cerebral palsy , with regards to ability, is often down to the perseverance of the primary care givers, which in many cases is the mother (Landsman, 2005). There is much mediation between the mother and others on behalf of her child to establish the child's level of intelligence (Green, Brightman, & Kassner, 2012).

Children with severe speech, language and communication deficits make up less than 2% of the population (Royal College of Speech and Language Therapists, 2018). These children may have no verbal language, be completely unintelligible, and therefore, unable to indicate their basic needs, wants and desires (Lindsay, 2011). They are likely to need life-long intensive help which can be described as a 'low incidence/high needs' condition (Rosenbaum & Rosenbloom, 2015).

However, many of these children's needs are met, and a number of these children go on to achieve a good quality of life (Green, 2003a). This would therefore suggest that these children do have a way to communicate, albeit in a non-verbal way which the child's mother and care givers discover as relationships develops with the child (Green et al., 2012). A common misconception is the assumption that children with cerebral palsy will also have learning disabilities. Children with cerebral palsy may have severe to moderate learning disabilities, but it is also possible for them to be extremely intelligent (Mercieca & Mercieca, 2014a).

It seems plausible to suggest that mother and child learn to communicate in a more embodied way to build a relationship (Merleau-Ponty, 1973). Mother's may be using other senses such as smell to know their child. Changes in smell so subtle that only the mother would notice and attribute to illness (Vaglio, 2009). Additionally many mother's admit to licking their new-born babies skin and noticing if the taste changes when their new-born is ill (Stechyson, 2018). Yet, as the mother experiences this unfolding communication she may face many challenges by those who refuse to see what she sees in her child (Wyn, 2007). Motherhood is regarded as something akin to a mystical rite of passage for many women and many mothers will describe motherly intuition (Stadlen, 2011). This may be laughed at by those who do not feel that such a bond exists (Mercieca & Mercieca, 2014b) yet the mother will experience the uncanny by being accurate in knowing what her child is asking for (Van Buren, 1993). Many mothers are possibly deeply burdened by the responsibility to accurately communicate on behalf the child (Brunson & Loeb, 2011). This gives rise to the question of what support is in place to facilitate and improve communication through communication aids and when is such support offered (Cockerill & Carroll-Few, 2001). All these issues feed into the experience of the mother as she navigates through her ability or inability to communicate to forge a relationship with her complex care child (Rosenbaum, 2003).

Aetiology

CP is a term that incorporates a spectrum of disability (Bax, 1968). Ways of acquiring cerebral palsy are varied, therefore the focus here is only where cerebral palsy was the result of Hypoxic Ischemic Encephalopathy (HIE) at birth (Chao, Zaleski, & Patton, 2007). The patterns of damage in these cases of cerebral palsy are quite specific, therefore increasing the possibility of the emergence of commonalities within the experience between myself and my participants therefore, an emic rather than etic approach.

Although this research is focusing on the mother-child communication, this phenomenon does not have to be limited to just mothers. It is likely that fathers and nurses who spend considerable time with such a child will develop a deep connection and means of communication. The use of the word mother within this research is more of a signpost to the reader. Using the word mother also allows for cohesiveness within the literature which uses the terminology mother rather than primary caregiver. Primary caregiver would be a more correct and all-encompassing phrase yet so many research papers still use the word mother (Rothbaum, Rosen, Ujiie, & Uchida, 2002).

Personal Interest

I always knew that I would research the lived experiences of living with a child who has complex cerebral palsy, because I live with such a child and I saw the need for more social awareness. Less obvious was which aspect I was going to research. Through self-reflection and a reading of the literature on cerebral palsy I saw that raising a child that does not communicate in a normative way is a unique phenomenon within mothering (Green, 2003b).

In my experience, there was no support to mitigate or explain the lack of a normal bonding experience or to help me establish a mode of communication with my child. This informed my decision to do a Master's degree in Cognitive Neuro-rehabilitation Psychology. I did this to better understand my son's condition and because I wanted to heal his cerebral palsy (Wyn, 2007). Learning how to evaluate interventions objectively, including the administering of neurotropic drugs, possibly saved his life and enabled me to make decision that improved his quality of life. I became an expert in my field, out of love; I became the expert mother knowledgeable in all things pertaining to her child's condition out of necessity (Mercieca & Mercieca, 2014b).

Professional Interest

Prior to entering psychotherapy as a career I was a primary and secondary school teacher. This was work I loved but left after my son with Cerebral Palsy was born as life changed for me. Having that deep interest and knowledge of child development added an extra dimension to the thesis as my experience made me look at the development of communication from the perspective of child development psychologists. I was then able to critically appraise these theories in the context of Cerebral Palsy that does not follow a linear developmental pattern. My knowledge of the key stages and education rubrics also laid a foundation on which to structure some of my thoughts and ideas of cognitive and social development in children as being a teacher I knew that these areas are separated so a child can be stronger in one area and weaker in another.

As well as putting the spotlight my own experience as a mother of a complex disabled child. I am a counselling psychotherapist within an IAPT. Service. I have a wealth of experience in peri-natal care and parents who are full time carers. I can demonstrate something of the personal and contextual circumstance from which these women and parents come to parenthood based on my general experience of working with this group professionally. I highlight the individuality of each parent and the unique issues faced within the context of a child that has cerebral palsy and complex care needs. This is to propose that counselling psychotherapists might adopt a bespoke phenomenological approach towards the care and needs of each mother. Using my existential counselling psychotherapy training I have undertaken, to implement the different existential approaches based the different philosophies when interviewing participants. I used my clinical training to skilfully afford each participant mother space to share her story with me.

This Research As an Exploration:

The research question is: What is The Phenomenological Experience of The Non-Verbal Communication Between Mothers and their Children with Complex Cerebral Palsy? There is, simply a quest to explore the lives of these unique mothers in the context of their experience. To create a narrower question for the phenomenon might limit the exploration in some way and therefore limit the findings. In this way the findings for this phenomenological experience should evolve more organically because the research question allows enough scope for it to do so.

Another way to understand the way forwards is as follows. As the researcher I hold a compass (A knowledge of the phenomenon as I experienced it) that points North, I know how to move towards North but I do not know what I will find at North (the experience of others who have experienced this phenomenon), or what I will discover on the way to North. A Heuristic Inquiry is similar to holding the compass, it is a method of genuine not knowing to find knowledge. To authentically explore the phenomenon it has to be done in a way that allows for all the knowledge to unfold around the researcher. There can therefore only be a compass, a knowledge of the way but there cannot be a predetermined knowledge of the destination as that would not be in the spirit of finding a new discovery.

Focusing on:

Where mothers of children with complex cerebral palsy face limited or no responsiveness from their child how do they explain the presence or absence of the meaningful two-way communications?

What communication evolves between the infant and the mother with a child who misses key developmental processes and how does it leave the mother feeling?

Aims and Objectives.

This research aimed at exploring what the internal world and life experiences of the mother is like, in relation to the complex non-verbal communication with her cerebral palsy child. The key objective was to explore the experience of communication from the time that the mother takes over the care of this child first in the hospital and then at home. The rationale for this research was to give voice to unheard mothers who are full-time communicators for their children who are not verbal. It was hoped that with enough focussed research, professionals, including psychotherapists, can learn how to better understand those mothers who are caring for the most vulnerable children in our society. This work gives a view into the complex communication of these mothers and children in order to develop an understanding of the lived experiences of the mothers who communicate in this way. Ultimately this research hoped to enlighten professionals who work with these mothers to insure they are adequately supported. The findings might be expanded to include other complex medical conditions with similar implications.

Thesis Structure

Chapter 2 is a narrative review of the literature critically exploring the material to form a basis for this research building on the established theories and ideas. Chapter 3 explores the heuristic method as a phenomenological approach it addresses the ethical issues of gathering data. Chapter 4 shows the individual depictions as the emerge from the transcripts. Chapter 5 is the discussion and findings linking the findings to the theories and existential issues that the participant mothers confront. Chapter 6 critically reflects on the research and states the conclusions that have come out of the findings and what this research brings to Counselling Psychotherapy as a profession. The conclusion also looks ahead to the areas for further research.

At the start of each chapter I use a quote linked to either non-verbal communication or finding meaning. These quotes act as bridges through the chapters to inspire the reader as I have been inspired by the people I have quoted. I also have the quotes to remind myself that a Heuristic Inquiry is not just a theoretical process but a holistic approach that draws upon art and literature to encapsulate as much of the real world phenomenon as possible.

Chapter Breakdown

Chapter 2: Presents the literature starting from the historical roots of cerebral palsy in the 19th century and then looks at the social model of medical care of children from the 1950s to date. The literature also examines in depth the theories of reciprocity, attachment and mothering. Followed by the literature on how existential literature approaches motherhood. The literature review then proceeds to critically appraise mothering in the context of disability finally exploring non-verbal communication and its links within the psychotherapeutic encounters of client and therapist.

Chapter 3: Delineates my research method and the philosophical basis of my methodology. I opted for the heuristic research method because it is a well-recognized method that uses the personal experience of the researcher as well as participants. I provide a comprehensive account of my data collection and analysis before concluding with some considerations on research validity and reflexivity.

Chapter 4: This chapter gives an account of each participants individual depiction and showcases the individual voice of each participant. Within the participant depictions is my own individual depiction putting my voice amongst the voices of my participants. These individual depictions are in the first persons participants own words accompanied by the artwork that the participants produced as part of the interview.

Chapter 5: The findings and discussion have been placed together to facilitate the links between the theoretical underpinnings of this research and the transcript verbatims brought to demonstrate the phenomenon of non-verbal communication between mothers and their complex cerebral palsy children. Once again verbatim from my own transcript is among the findings and the composition of these findings synthesises into a harmonious exploration of the lived experience of the mothers. At the end of each finding there is a focus on how the mother grapples with the existential issues she faces as she confronts the world of childhood disability, illness and non-verbal communication.

Chapter 6: Reflecting on the entire process of the research and each chapter as it was experienced as the researcher. This chapter shows the impact of the research on the researcher followed by the implications of the research on Counselling Psychology, Existential issues of motherhood, the social implications of this finding and the conclusions of how mothering a child that does not develop physically beyond the stages of new-born keeps the mother in the preoccupied state. This chapter also reflects on further research beyond this thesis.

Chapter 2 Literature Review

‘The sphere in which the world of relation is built are three…The third our life with spiritual beings, where the relation, being without speech, yet begets it (Martin Buber 1970 p.70).’

Overview of Chapter

The first section of this chapter presents an exploratory piece of research focusing on children with complex cerebral palsy. The work is presented within the context of existential literature building on Claire Arnold-Bakers work how becoming a mother involves a confrontation with existence and can be called an existential crisis (Arnold-Baker, 2021). Finally, a narrative literature review expands the findings of the research into a larger arena and investigates social issues that come with having a child that has cerebral palsy and that is non-verbal. The work then looks at the literature that surrounds motherhood and what the implications of this literature might have on the perception of mothers. It is hoped that this research will raise awareness of the experience of mothers with disabled children, draw interest to the ways in which the world around these mothers shapes and characterises this phenomenon at all levels and how Counselling Psychology can mediate understanding and improvements. The literature review also brings to the fore the power of non-verbal communication and its place in the alliance between therapist and client.

Process of Literature Review

A Boolean search of the literature was carried out using the following databases- AMED, CINAHL, E-Journals, ERIC, Humanities International Complete, MEDLINE, PsycARTICLES, PsycINFO and SocINDEX. A date limitation was used that set the parameters for the search from 1980 to the present. However, earlier studies which were referred to within other studies were also included and dated back to the substantial original papers, for example Bowlby (1958). A broad range of simple search terms were used related to the topic. These are listed (see Appendix 1).

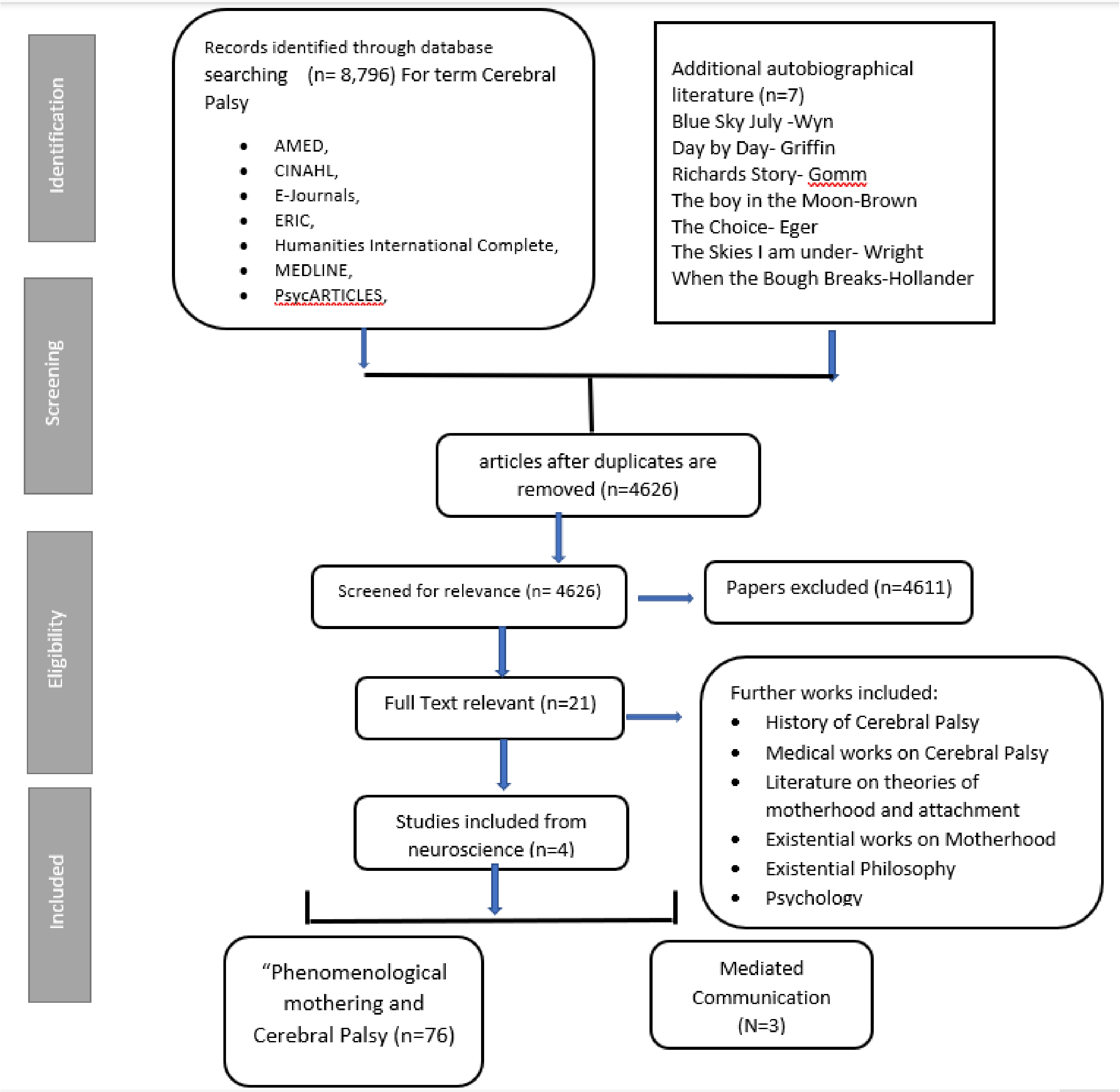
It is at this point that it became clear this literature review would be a narrative literature review that explores Cerebral Palsy and all works written about the topic. Since a more traditional systematic literature review was not appropriate for the limited research papers on the specific subject of complex Cerebral Palsy and non-verbal communication.

The simple search for cerebral palsy generated 8,796 papers, however this number greatly reduced once the search only included peer reviewed journals and more refined terminology was used. Expanding the search with forward and backwards citation searching generated literature that was more relevant. The papers were initially screened for duplicates leaving me with 4626 on the general topic of Cerebral Palsy. These papers were then all screened for relevance and only 15 papers were found to be suitably linked to the topic of Parenting communication, attachment and complex Cerebral Palsy.

Inputting the words, Phenomenological mothering and Cerebral Palsy, generated 76 journals of which 21 had some relevance for this research, although no specific studies were found that were directly relevant to my research question. There was a limited number of studies which explored maternal attachment and cerebral palsy, communication and cerebral palsy mediated communication and cerebral palsy and the experience of motherhood in conjunction to cerebral palsy which, although they had a different perspective added to the understanding of the maternal relationship. Nothing was generated for existential themes for any of the search terms linked to cerebral palsy and mediated and communication. 3 papers were generated for the search term Mother and Existential. A repository search of past theses generated 4 which were connected to communication and cerebral palsy.

The British Library Catalogue search produced 7 autobiographic books on parenting a child with Cerebral Palsy.

A flowchart summarizing the literature search is presented in Figure 1:



A general Google search also led to relevant websites containing helpful information such as recent statistics and educational policies on Cerebral Palsy. When multiple searches using varied search terms began generating the same articles I felt a saturation point had been reached.

The mushrooming method was useful for accessing relevant articles from reference lists in related articles and literature reviews. I read those articles or books that were relevant to my research topic, such as the book Blue Sky July by Nia Wyn which I saw in the references of Mercieca and Mercieca (2014b) ‘Reading with love: Reading of life narrative of a mother of a child with cerebral palsy’. which I have included in my literature review. The searches have been periodically repeated to ensure awareness of new studies. Since the ethical approval of my proposal in 2018 several new studies have been published on parenting and disability most notably, Griffin (2020), Supporting Parent Carer’s . This is positive, as it shows that there is indeed a rising exploration in this area of knowledge across a diversity of disciplines, including psychology.

While I was reflexive throughout the review and I showed how I was drawn to the literature I selected, It was important for me to highlight aspects of my process through this narrative literature review. I was inevitably motivated by my own ideas on this phenomenon, to some extent because I have experienced it myself and in part because I had already read widely on the topic of cerebral palsy and begun creating my own awareness of the wider research area. I had therefore already established some ideas, such as knowing that reciprocity does not happen if a child cannot move independently see or hear. Therefore I had already recognized certain concepts, such as reciprocity attachment theory and child development, that I thought were vital to bring to this study. Consequently, I did not want to lead the research in a predetermined direction, which would have undermined its phenomenological aim. Holding this in mind, I went ahead and researched the history of cerebral palsy, theories of maternal attachment and child develop, communication and literature on an integrative approach to communication in psychotherapy, careful to use loose search terms that would generate broader findings, to keep the literature review balanced.

Of course I wanted to always be impartial but I did make choices throughout the process, selecting journals to incorporate that I considered applicable or significant, based on my own understanding and perceptions. However impartial I was as a researcher, subjectivity was inevitable. To mitigate my own subjectivity I read extensively, regularly checking my choice of journals and articles to confirm that I bringing as comprehensive and truthful a perspective of the current literature as possible.

The Autobiographical Literature

Blue Sky July (Wyn, 2007), was included because it demonstrated the phenomenon of enmeshment, motherhood and communication through the authors voice. Day by Day was not included as academic work by this author was used instead (Griffith, 2011). Similarly The Skies I am under was not referenced as the authors blog was more relevant to issues around social care and the fights parents experience to get support (Wright 2015). Richards Story was an account of using assistive technology before there was the possibility of eye-gaze it was one mothers discovery of cognitive ability and her sons journey through university. This biography showcases the misconception that lack of ability to communicate is often seen as lack of intelligence (Gomm, 2007). The Boy on the Moon looks at mediated communication and the struggle of the father who is communicating for his child, it was directly relevant to the phenomenon but from the father's perspective (Brown, 2009). The father offers an insightful evaluation of society's beliefs about the disabled. The Choice was a book I was reading and it became hugely important to my clinical approach as a psychotherapist but also supported the concepts of growth beyond trauma. In this book Eger (2018), recounts how in the 1950/60s she gives birth to a son who is diagnosed with Cerebral Palsy. Her account of early intervention from 1960 is really interesting as it shows historical evidence of the drive to support a child with Cerebral Palsy so that it should gain his/her autonomy. Finally I included When the Bough Breaks because of how honest, raw and authentic Hollanders (2009), voice in this book is also the only one of its kind where a mother depicts her struggle to communicate with her child and her difficult decision to give her child up for fostering.

An Outline of the Literature

I started my literature review providing context for the reader to establish and understand the medical and social significance of cerebral palsy as a condition. I then explored motherhood from both the traditional theories of child development this included looking at attachment, maternal responsibility the preoccupied state of being a new mother. This naturally was followed on by exploring complex care and mothering using existential ideas to fully shine a light on a number of key themes that are relevant to this experience, although there was no specific existential work on motherood and mothers of complex cerbral palsy children who are non-verbal. It became important to explore communication broadly and then specifically for the reader to understand the context of what communciation means for this research, this naturally led on to exploring reciprocity as a foundation for communication, mother and child eye contact as a mode of communication and touch as a means to commuinicate.

As I perviously stated there was not much direct research pertaining to non-verbal communication beyond the child being a newborn. It was therefore necessary for me to bring literature that did address non-verbal communication and I looked to psychology and existential philosopy for inspiration. I brougth the psychodynamic non-verbal communication perspective leading to philosophy of language as a premis for mother's to create language between herself and her child. It was at this stage that I encountered the term mediated communication and it encapsulated some of the phenomenon that I was exploring. I then thought about metaphisical communication and this brough me to transpersonal non-verbal communication in theraputic encounters. As this research is from an existential perspective I read extensively to see what aspects of non-verbal communication could be explained by existential philosopy.

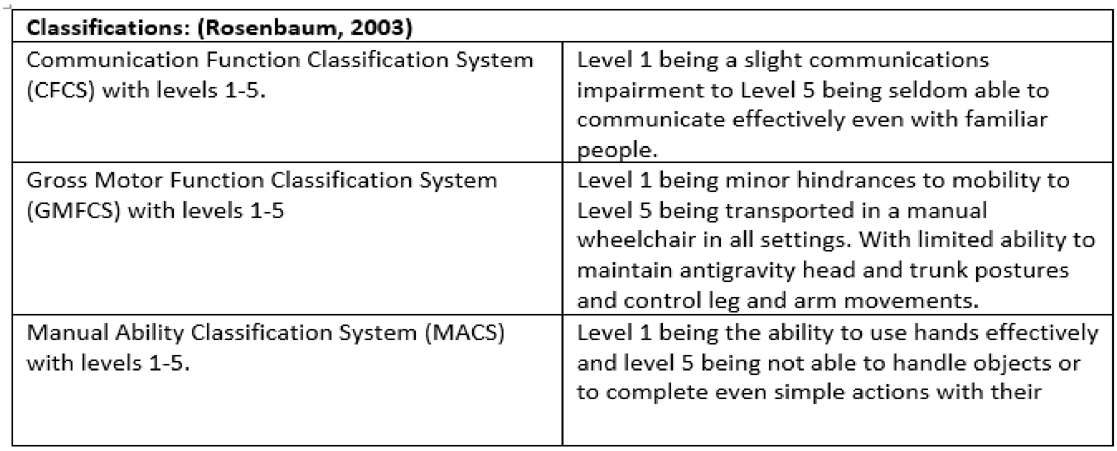
Finally I felt it was important to explore child development as the development of a child with cerebral palsy must surely be impacted by the disadvantages this condition creates. Explaining theories of development acted as an oritientation for the reader of what development posibly should look like but does not look like for the mother's and their children being focused on for this research.

A Brief History of Cerebral Palsy

In the mid-1800s, Dr William John Little pioneered the study of cerebral palsy, followed by Sir William Osler in 1889 who wrote the first book on cerebral palsy (Snow, 2008). In 1891 Sigmund Freud (1987), co-authored a Clinical Study of the Unilateral Cerebral Paralyses of Children, followed by his book in 1893 On the Knowledge About Cerebral Diplegias of the Childhood Age (in connection with Little's Disease). Freud, in 1897, writes that cerebral palsy might be caused by foetal development instead of oxygen starvation at birth in infantile cerebral paralysis (Longo & Ashwal, 1993). Although Freud was not entirely accurate in his definition of cerebral palsy, his work is considered a milestone in the understanding of cerebral palsy (Kavčič & Vodušek, 2005). His ideas opened the possibility of understanding brain damage effecting motor and cognitive development in young children. Freud differed with Dr Little by being the first to understand that the patterns of movement seen in children was a product of brain damage. Freud's use of the term cerebral palsy encompassed too many childhood deficits and modern medicine can now differentiate between different brain diseases (Egan, Tannahill, Petticrew, & Thomas, 2008). Additionally, although Freud commented on cognitive deficits, there are currently no ways to prove that cognitive deficits are present in the category of cerebral palsy being researched here. There is an issue regarding educational psychologists who diagnose these children with cognitive deficits using standardized tests due to a lack of evidence i.e., that the child has no way to communicate is not evidence to rule out cognitive abilities (Gabis, Tsubary, Leon, Ashkenasi, & Shefer, 2015)

Cerebral palsy is an incurable but not degenerative disorder of movement and posture, appearing in the early years of life due to brain injuries (Bax, 1990). The result is interference during brain development (Bax et al., 2005). cerebral palsy is classified into categories of severity, based on central data information on over 6000 children with cerebral palsy from 13 geographically defined populations in Europe (Cans et al., 2002). The classifications of severity is made by assessing three areas of function:

Table 1: Classifications of cerebral palsy

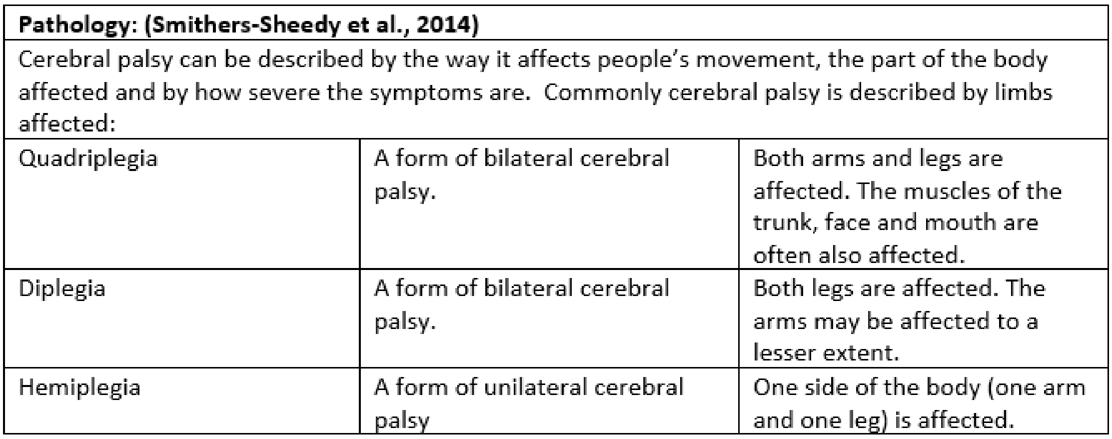


Classifications: (Rosenbaum, 2003)	
Communication Function Classification System (CFCS) with levels 1-5.	Level 1 being a slight communications impairment to Level 5 being seldom able to communicate effectively even with familiar people.
Gross Motor Function Classification System (GMFCS) with levels 1-5	Level 1 being minor hindrances to mobility to Level 5 being transported in a manual wheelchair in all settings. With limited ability to maintain antigravity head and trunk postures and control leg and arm movements.
Manual Ability Classification System (MACS) with levels 1-5.	Level 1 being the ability to use hands effectively and level 5 being not able to handle objects or to complete even simple actions with their

A diagnosis of level 5 of disability might be caused by a grade 3 hypoxic ischemic encephalopathic brain injury at birth (Rutherford, 2005), a few days following a stroke or accident such as drowning, resulting in an inability to use their arms or legs. Swallowing food and saliva is no longer possible, requiring regular suctioning. Feeding tubes are necessary for nutrition. Such an injury would affect language areas of the brain resulting in an inability to speak. In many cases cognitive impairment and global developmental delay is presumed

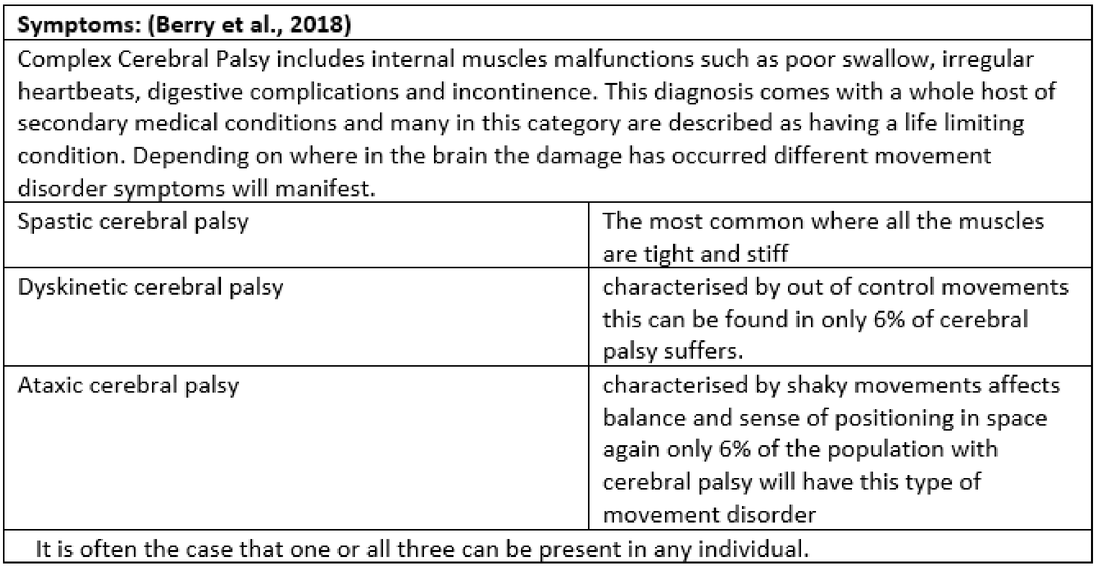
(McClure, Threlkeld, & Fitch, 2006). The child will often experience multiple seizures a day and secondary dystonia (Austin, Lin, Selway, Ashkan, & Owena, 2017), and have cortical visual impairments and problems with their hearing. With new-born brain injuries there will be an inability to cry with sound although this may or may not recover over time (De Vries & Cowan, 2009)

Table 2: Pathology of cerebral palsy



Pathology: (Smithers-Sheedy et al., 2014)		
Cerebral palsy can be described by the way it affects people's movement, the part of the body affected and by how severe the symptoms are. Commonly cerebral palsy is described by limbs affected:		
Quadriplegia	A form of bilateral cerebral palsy.	Both arms and legs are affected. The muscles of the trunk, face and mouth are often also affected.
Diplegia	A form of bilateral cerebral palsy.	Both legs are affected. The arms may be affected to a lesser extent.
Hemiplegia	A form of unilateral cerebral palsy	One side of the body (one arm and one leg) is affected.

Table 3: Symptoms of cerebral palsy



Symptoms: (Berry et al., 2018)	
Complex Cerebral Palsy includes internal muscles malfunctions such as poor swallow, irregular heartbeats, digestive complications and incontinence. This diagnosis comes with a whole host of secondary medical conditions and many in this category are described as having a life limiting condition. Depending on where in the brain the damage has occurred different movement disorder symptoms will manifest.	
Spastic cerebral palsy	The most common where all the muscles are tight and stiff
Dyskinetic cerebral palsy	characterised by out of control movements this can be found in only 6% of cerebral palsy suffers.
Ataxic cerebral palsy	characterised by shaky movements affects balance and sense of positioning in space again only 6% of the population with cerebral palsy will have this type of movement disorder
It is often the case that one or all three can be present in any individual.	

The neuroscience and neurobiological models challenge the medical model of cerebral palsy that puts the definitions into neat categories. Rather, neuroscientists propose that no two brain pathologies are the same, and no prediction of how hypoxia will manifest itself can be made (Quillinan, Herson, & Traystman, 2016) If one factors in genetics and every child's individual set of parents, MRI scans alone do not determine outcomes for that child. Even if a child is put into a category there is a fluidity to this, and even a possibility that a child may move into different categories over his or her lifetime (Austin *et al.*, 2017). Further, this suggests that not only is the mother's experience of her profoundly disabled child possibly a unique phenomenon, but that each child's pathology is also unique.

The Social History of Cerebral Palsy

The historical context of care for children with disabilities in current literature highlights a gap in the knowledge about how society treats complex disability in the Western world today (Dwyer, 2012). During the 1970s and 1980s, the concept of normalization surrounding individuals with disabilities was embraced by society in the Western world (Ouellette-Kuntz, 2005). The normalisation of disabilities marked the ensuing closure of institutions for people with special needs (Lemay 2009). Normalization is the philosophy that those with disabilities should have equal opportunity to live within the community who should provide the required social support services (Heaney & Burke, 1995). There remains an attitude towards non-verbal complex disability with society shying away from this vulnerable group. Complex cerebral palsy sufferers are often left isolated and over-medicated to make carers' lives easier (Egan et al., 2008).

Today, it is predominantly families, particularity mothers, that care for young children with disabilities. Whereas progress concerning human rights for children with disabilities and their families has come a long way (Miller, 1978), the social policies to help these families in caring for their children in the community have not translated into the support needed or promised (Pousada *et al.*, 2013). Inferences regarding this social situation shows the need for long term social support and health services to be available to family caregivers when they take that step to go home from the hospital with their complex need infants (Elder et al., 2003). Currently, homecare policies exist only for those who meet strict and narrow criteria for children with special needs in the UK, with many children being too well for health and too ill for social care, resulting in them getting no support at all (Miller, 2004). Social policy has been affected by attachment research since the 1970s, with a huge impact on budgets and opinions of what mothering should and should not look like.

The Social Construct of Parenting a Child with Illness

An important question one might ask is how did society go from a preoccupation with antisepsis and sterile conditions of children in the early 1900s, where parents were forcibly separated from their children by hospital policies, to modern day society where the parent led care has left parents feeling alone with their duty of care (Karen, 1998)

Two movements between 1943 and 1959 brought about the change to the medical care of children in the UK. Psychologist David Levy (1943), began a study on maternal over-protection by going into family homes to observe this phenomenon. While observing over-protective mothers, Levy found in the control group of orphaned children, symptoms of emotional deprivation from having no mothers in the family home. This control group became the subject of the study as a pattern of behaviour seen in these children emerged. Although these children were polite and compliant, they lacked a depth to their emotions. The adults around these children were disturbed by a lack of affection and love in these children. Questions around the impact of the mother-child relationship began to be asked by psychologists and social policy makers.

Alongside this, the Platt Report, formerly called the Welfare of Sick Children in Hospital (Ruth, 2010), was commissioned by the UK government to observe the needs of sick children (Platt, 1959). The report advocated the parent should be allowed to visit their sick children in hospital. It brought about change in policy that first tolerated parents, then accepted parents, and finally included parents in the nursing care of their children (Ruth, 2010). Social change was slow, and the medical world resisted considering the psychological wellbeing of children (Robertson & McGilly, 2009).

Ideas of motherhood from the early 1900s changed because of the work of John Bowlby (1958), who formulated theories of childhood attachment. Social workers in the 1940s began to be concerned about children's' home lives. However, they did not think about which aspects of the home life were making a difference to a child's wellbeing. Bowlby (2017) argued that all the material aspects of the home life did not matter. The critical issue for him was the question where is mother? In many instances the mother was not in the home, either because of death or hospitalization. Bowlby's radical findings attempted to prove how children failed to thrive without their mothers. Societies viewed mothers as an integral and important part of a child's well-being.

One would expect that this established innate connection between mothers and their children would naturally carry through to communication, tuning into their children (Winnicott, 1960) even in cases of non-verbal children.

One would think that through the social change and social perception of mothers' key role in child rearing, professionals would take mothers very seriously. The research into parents with complex, chronically unwell children suggest otherwise (Kirk, 2001), with a tension over the balance of power between parents and medical professionals. Barnes (2019), comments that the medical model for disability as an illness has been replaced by a social construct of disability. Oliver (1993), warns that this social construct of disability has started to hold the disabled hostage limiting disability within society.

Attachment

Bowlby's theory of attachment was influenced by Lorenz's study of imprinting (Lorenz, 1970). In his work Lorenz showed how attachment was innate and therefore necessary for survival. Similarly, Bowlby described babies as biologically pre-programed for attachment to ensure their survival (Bowlby, 1958). Bowlby's attachment theory proposed that the child forms one main attachment and for that attachment to become secure it must last for the first two years of life (Bowlby, 2017). Building on this narrative, Bowlby claimed that the child has an innate need to attach to one main attachment figure (monotropy). The child's relationship with its mother is therefore unique (Bowlby, 1988). The long-term consequences of maternal deprivation might include delinquency, lessened intelligence, more aggression, depression, and a failure to show affection. Bowlby's theory of monotropy led to the formulation of his maternal deprivation hypothesis. Looking at 44 juvenile delinquents, Bowlby (1944) created a theory of maternal deprivation. He reasoned that the relationship between the child and its mother from birth to five was the most important to a child's development relationally in the world. Disruption of this principal relationship seemed to indicate an increased likelihood of juvenile delinquency, emotional problems, and antisocial behaviour (Bowlby, 1944).

This research, and similar findings by other psychologists, did not make an impact on the medical world which still held parents at a distance once a child was hospitalized. Bowlby's student and co researcher James Robertson (Bowlby & Robertson, 1953), studied children's behaviour in hospitals. His film, ‘A Two-Year-Old Goes to Hospital’, had the desired impact that psychologists were working towards. In this film Robertson did not claim anything new about young children in hospital. He highlighted what was previously there, what every parent and many professionals knew: that young infants require close contact with their parents, particularly when they are unwell. Broken care from changing medical staff, however well-meaning and warm, is insufficient, leading to distress and possibly avoidable emotional harm. There were 3 phases a small child evolved through because of losing his or her mother where no other attachment with a suitable carer is formed to replace her: ‘Protest, Despair and Detachment’, (Bowlby & Robertson, 1953). The film created a wave of change in medical society.

Bowlby’s work also ignited a social pressure that placed women in a difficult position. With all these new attachment theories pressure about what constituted a ‘good enough mother’, (a phrase introduced by Winnicott (1960), began to build emotionally and physically. Mothers who worked were criticised for not spending enough time with their young children. At the same time hospitals and governments wanting to cut costs began to not just encourage parents to get involved with their children’s medical care, but relied on this parental care (Miller, 2004). Researchers such as Howe (2006), extrapolated that the mothers of disabled children failed to form attachments to their disabled child. Which buys into the current climate of institutionalising parent carer blame (Clement & Aiello, 2021).

Howe’s reasoning, that the parent’s childhood attachment styles are why the disabled mother and child fail to form a normative attachment, is based on Bowlby’s theory. If one were to observe the child’s development, or lack of development, together with the many months this child spends in hospital, the normal pathway to forming an observable attachment is broken. Howe’s (2006), work does not take into consideration fear of loss, which might stop the mother forming an attachment. The mother is possibly experiencing prospective grief or an actual grief for the loss of the perfect child (Ellis, 1989).

Howe does not account for the mother’s fear of the diagnosis and the all-consuming task of the medical care which is not parenting (Dolgin, Phipps, Harow, & Zeltzer, 1990). Ironically, what started out as a way of empowering parents, especially mothers, has now become the rod that is hitting the mothers back (Platt, 1959). In the story, When the Bough Breaks (the bough being the mother), Hollander, tells a story that is goes against social norms and expectations (Hollander, 2009). This mother, after much turmoil, puts her cerebral palsy child into foster care not because she does not love her child but because what her child is, this being too much and too painful to bear. Current research has explored the emotional turmoil of mothers with disabled children in more depth to understand both the physical and emotional life of the mother, describing the mother as feeling both happy and sad at the same time, using the Greek term ‘Charmolypi’, (Griffin, 2019).

Maternal Responsibility

The mother of a baby with complex cerebral palsy in hospital can often be told take your child home and just love them. This declaration can mean anything. It can literally mean take your child home and love your child. Or, it can mean take your child home and you as the mother are responsible to provide the care (Rossiter et al., 2017). It might mean that the doctors have no idea how to manage your child’s symptoms. Consequently, this could mean take your child home and because you love your child you will work out how to manage this child (Stern, & Stern, 2018). Finally, it might mean take your child home as your child will most probably die and anymore interventions will only prolong this child’s suffering (Stern, 1999, p. 12).

Research intimates that for many mothers take your child home equates to take responsibility (Papadatou, Martinson & Chung, 2001). These mothers become full-time specialist nurses proficient in clearing blocked airways, inserting nasal feeding tubes, managing and administering medications, and responding to crises (Kirk, Glendinning, & Callery, 2005). This is on top of the normative time-consuming work involved in bringing home a healthy baby (Arnold-Baker, 2021). These mothers might wrongly extrapolate that taking the child home from hospital meant the child was well (Kirk, 1999). It does not occur to the mother until much later that this child was not expected to live (Kirk, 2001). Do they love their child? Yes, but mothers get tired and the exhaustion of keeping a brain injured baby alive seems to block anything maternal the mother might have been feeling (Landsman, 2005).

Further down the line the doctors might ask a question like, Mum, what do you think we should do? Research indicates that some doctors might disregard any parental input, frustrating the mother, who knows that the doctor is not listening to her (Kirk, 2001). Mothers, it would seem, become experts in medications and their combined effects, telling doctors what might be done to make whatever ailment which had arisen within their child go away (Fisher & Goodley, 2007). These mothers are constantly problem solving and puzzling how they might improve life for their child (Wyn, 2007). Often, a mother's pragmatism comes across as being unloving, however the action of taking responsibility for the life of the child is the mother showing her love (Mercieca & Mercieca, 2014b).

The Preoccupied State

Donald Woods Winnicott (1896–1971) was an English paediatrician and psychoanalyst who informed much of the ethics that surround mothering in the 20th century. Winnicott's studies of mother-infant relationships dating from his clinical work in London hospitals from the mid-1920s show how strongly the two elements of inner feeling and external world are linked.

Winnicott describes the mother's psychic relationship to her infant, Winnicott thought the, starts prior to the child's birth. In the last months of pregnancy, the mother retracts from everyday life, gathering her thoughts and being inward, developing a state of mind that is, uninterested to the world beyond herself and her child, similar Winnicott says to psychosis. A type of protective mental bubble. This preoccupation of mind does not happen to every mother, some avoid this preoccupation; it lasts only a few weeks or months after the baby's birth, becoming weaker as the baby develops, and is not clearly recollected. Winnicott (1988), gives a credible explanation of this state of mind and the relationship formed in the book Human Nature.

When the baby feels hunger; the mother gives the baby what it needs with a signal which allows the baby to root for the breast. Touch and gesture—like integration—are delicate, mixed with powerful feelings and Winnicott describes the mother identifies (or not) with the child. In object relations theory, Winnicott (1960) believed that there was no such thing as an infant, but rather only an infant and its mother. This hints at an enmeshment between mother and child where the post birth separation is not taking palace. This stage seems to last for as long as the child cannot integrate itself into the world and gain independence. All the interactions between the mother and child are non-verbal, with the mother fully holding the child in her newly given birth preoccupied state (Finello, 2005, p. 96). The mother becomes fully attuned to meet the child's every physical and emotional need. Winnicott suggested that the need for this state of preoccupation is to safeguard the infant (Stern, 1998).

Complex Care and Existential Mothering

There are many existential themes that arise when mothering with illness. I bring just a few concise examples here, although there are many more. It is implied that transitioning into motherhood changes the mother's self-identity (Arnold-Baker, 2020). Becoming a mother for the first time signals a major life transition for many women. It seems that even though age at first birth now spans a wider range in the UK, women's' ideas of what mothering will entail can remain narrowly focused (Miller, 2011). The mother goes from existing for herself to existing for another person in the world. It appears that these expectations, and this shift in identity, is part of the experience of motherhood. Yet, everyday experiences of new mothering can feel different from the ways in which it had been anticipated, envisaged, and prepared for, especially when the newborn infant is very unwell (Dolgin et al., 1990).

The commercial world is full of healthy and happy pregnant mothers and babies. This adds to the pressure that babies must be worth it (Landsman, 1998), and mothers think that they can 'choose' the 'perfect child'. The idea of having a potential disabled child is 'othered' (Press, Browner, Tran, Morton, & LeMaster, 1998), and (Miller, 2008), defines the term 'othered' as being in relation to other, to become othered is to be seen as alien or non-conforming to an imposed norm. The concept of other, for the mother of a disabled child, disfranchises her from the central society of motherhood and places her at the margins of her society, for being the other (Staszak, 2009). This social conditioning leaves a mark on mothers who give birth to a child with disability. Not only is the baby 'othered' but so is the mother. Sartre describes it as the gaze of the other that the mother has no control over (Sartre, 1956). Landsman describes mothers of babies with disability in the light of commercialism as mothers of 'defective merchandise' (Landsman, 2005). This form of othering in the commercial world is a reductive action of labelling by exclusion of disability as they are not catered for in an able society (Mountz, 2009). The mother is getting the message that she and her child who is disabled are somehow lesser. This idea is affirmed by the physical struggle for the mother of getting a wheelchair bound child around a non-wheelchair world. Foucault M., (1970), explored social constructionism where othering is the invention and preservation of fictional knowledge of the Other — which in the context of the mother of a disabled child, consist of cultural representations that the mother sees in the consumer world of baby advertising

(Bullock, Trombley, & Lawrie, 2000, p. 620). Webber (Schutz, 1932) critiques the idea that true meanings lie beneath language. Rather, this attitude holds that to name or categorize something is to fix its meaning, often around a few vitalized characteristics; to other through the language of identification. Therefore, the mother of a disabled baby is othered as soon as her baby is categorized as disabled, she does not have a baby, but a prognosis, with a list of identifiable differences between her baby and societies norm of what a baby should be (Schutz, 1932).

The mothers of profoundly ill and disabled children seem to negotiate and grapple with their identity, not just as new mothers, but as a new medical care person (Dolgin et al., 1990). It is suggested that these mothers experience a grief cycle alongside their transition into motherhood, (Mercieca, & Mercieca, 2010), (Papadatou, Martinson & Chung, 2001), possibly oscillating between sadness and acceptance, many times over (Hollander, 2009).

The Thrownness and Dasein of Motherhood and Complex cerebral palsy

Heidegger a German philosopher between 1889 and 1976,brings two terms, thrownness and Dasein to describe our human existence. Heidegger (1962), applied the phenomenological approach to explain the meaning of being calling it Dasein. He studied human being in the world in a way that develops conventional thoughts about the self and psychology. He understood the significance of time, space, death and human relatedness. He also sought to understand how human beings subjectively experiences something when being in the world (van, Deurzen, 2010). Heidegger explains that part of human experience is rooted in thrownness which is the situations one finds oneself thrown into and that one subsequently cannot control. When the mother of a child who has had a Hypoxic brain injury is thrown into motherhood she is being in the world in relation to her child, to professionals, to her extended family to her friends and to herself (Green, 2003a). The only control the mother experiences is her own reactions to all the confusion that is unfolding around her.

There are no parenting givens with chronic illness; the start of a day at home may end in a hospital bed in Intensive care unit. The mother does not know how this child's life will unfold because there is nothing to measure their progress against. Even within all the uncertainty, a fixed way of being starts to emerge and a new way for both the mother and child to exist, despite the thrownness of the situation (Shulman, 2020). Green (2003b), looks at each mother and her unique way of navigating the exaggerated uncertainties and living closely with the anxiety and possibility of death (Griffin, 2019).

Anxiety and depression seem to be a characteristic of mothers who have cerebral palsy children (Griffin, 2020). Manuel *et al.*, 2003 found that the more severely medically ill the child the more anxiety and depression manifested. This would certainly be aggravated by extended sleep deprivation which results from parenting a very unwell child, far exceeding the sleep loss that accompanies a healthy newborn baby. Davis (2014), saw anxiety reduce if mothers were better able to adapt. Existentially, there is a thrownness to having a disabled child which forces one off of the conveyor belt of life (Heidegger, 1962). Finding ways to reshape and redefine life with the cerebral palsy seems key to adapting as a mother (Pelchat, Lefebvre, & Perreault, 2003). Barbosa, Chaud and Gomes, (2008), showed mothers experiencing being-in-the-world in emotional pain. Mothers find themselves anxiously unprepared to deal with a disabled child.

It is suggested that the mother renegotiates the world as she experiences the limitations of going about it with a wheelchair and other medical paraphernalia. Fisher and Goodley (2007) describe a self-imposed isolation with normal seen as suspicious. The mother becomes defensive, always conceptualizing motherhood as identifying with it, and yet resisting her identification. An existential isolation possibly takes hold of the mother of the chronically ill child as she stands apart by her experience from the mothers of well children around her (Papadatou, Martinson & Chung, 2001).

Communication

Reciprocity

In the case of cerebral palsy the mother faces her child and reciprocity does not take place. The mother experiences trying to connect with an infant that is absent in so many of the fundamental ways one expects of a baby (Bax *et al.*, 2005). The mother is impacted by the absences of of the normative movement of baby hands touching the mothers face or a mouth rooting for food (Stadlen, 2011). When there is no eye contact or crying, and just a silence when there are no smiles at 12 weeks (Philip & Dutton, 2014) the mother is faced with the blank face and eyes of her baby. Yet mothers do to keep communicating as the literature suggest so the mothers just take a gigantic ‘leap of faith’ in the Kierkegaardian sense (van, Deurzen, 2010). Because the communication being carried out by the mother cannot be proved to be helping or not. The mother might engage in one way cooing and cuddling having faith that it is reaching this infant trapped inside a malfunctioning body (Murray and Andrews, 2005). Alternatively, are the mothers taking a gamble, a ‘Pascal’s wager’ if you like, where it makes sense according to Pascal philosophy to choose the option that would benefit the child most should the parent be right (Nicholl, 1978). In this case on the off chance that if they invest in the child, the child might eventually respond, but if they do not invest in this child then for sure this child will never respond (Zirpoli & Bell, 1987).

Living in The Four Dimensions When Motherhood Becomes Nursing.

van, Deurzen, (2010), explains that there are four basic dimensions of human existence: the physical, the social, the psychological and the spiritual. On each of these dimensions the mothers in this case confront the world and form their approach out of their individual take on their experience. The mothers focus towards the world describes her reality. The four dimensions are clearly meshed and offer an intricate four- dimensional structure for human existence. Each dimension has aspects of what is aspired towards and aspects that represent human fear.

On the physical dimension (*Umwelt*) the mother connects to her environment and to the gifts of the natural world around her. On the social dimension (*Mitwelt*) the mother connects to others as she mixes with the social world around her. On the psychological dimension (*Eigenwelt*) the mother connects to herself and in this way she builds her own world. On the spiritual dimension (Ü*berwelt*) the mother connects to the unidentifiable aspects of life and thus forms a feeling of an idyllic world, a belief system and a metaphysical attitude towards life (van Deurzen-Smith, 1984) .

Mercieca and Mercieca (2014b), describe the experience of living in the world, when the mothers mitwelt shrinks down to one other person, even if there are other dependents - a husband or other children to take care of (van, Deurzen-Smith, 1984) . Changes might occur within the couple’s dynamics when a disabled child is born into the family. Additionally, extended family members can avoid visiting and keeping in touch once a disabled child is present (Barbosa et al., 2008). Existential thinkers perhaps explain this sudden change parents find themselves in as an existential crisis, or a traumatic event (Stolorow, 2015). The existential significance-emotional trauma crushes the parents' feelings of safety and drops them into an authentic Being-toward-death (Shulman, 2020), where they must confront their finitude and the finitude of all those they love (Yalom, 2008). A re-evaluation of values and priorities must surely follow such an existential confrontation (Arnold-Baker, 2020). Following this, a shift of self might take place where a couple may no longer align in their spiritual Ubervelt dimension, thus creating a divide. However, potentially, they may fully align their values and become closer because of a shared goal to help their child (Deurzen & Iacovou, 2013). Similarly, the couples extended families may no longer understand the couple's new value system and a splitting off from others may play out (Eger, 2018).

Some past research explores early mother-infant reciprocity. Developmental psychologists have looked at the start of the life of a neuro-typical baby and how mother – baby connection happens (Brazelton, Tronick, Adamson, Als, & Wise, 1975). This well laid path of reciprocity does not happen for every mother, as some have babies who are rushed off to Intensive care unit at birth. These mothers sometimes find other ways to develop deep and meaningful connections with an infant that is not responsive (Kearvell & Grant, 2010). For example they will lick their child, touch their child or smell their child in order to bond. Research shows that babies smell lights up reward areas in the mother's brain making the bond between them develop. Furthermore the smeel of the child seems to communicate information to the mother such as illness (Schafer, Sorokowska, Weidner, & Croy, 2020). However, it is well researched that some mothers never develop a deep and meaningful connection with their babies, whether healthy or disabled, so it is important not to perpetuate these myths by encouraging honest and open discussion between mothers about the experiences of motherhood (Maushart, 1999), without the fear of feeling that the mother is a 'bad mother' or failing in some way (Arnold-Baker, 2021).

As the infant grows into childhood what keeps the mother continually investing in this child and this research wants to explore how the mother remains energised to keep mothering. The exploration will also look at whether some mothers do not keep investing in the communication or arrive at a point where they are able to invest less into communication.

Past research has looked at the point of despair and a search for emotional support in the form of psychotherapy that is often not enough, or the mother feels can never be enough (Griffin, 2020). Perhaps as Green 2003a, points out mothers in this circumstance feel misunderstood by the outside world connecting only other mothers in the same situation who understand this world within the world.

Bowlby explained how attachment is formed through reciprocity (Bowlby, 1982). Reciprocity refers to the process in which a behaviour is matched. For example, when someone smiles, and the other person smiles back. According to Feldman (Feldman, 2007), reciprocity in infants begins at three months old, although current research seems to show that new-born babies as young as 12 days old in intensive care show reciprocity. The prognosis for the baby improves because of the reciprocity between mother and baby (Meltzoff & Moore, 1983). However, it is reasonable to assume that children with cerebral palsy who are incapable of achieving reciprocity might experience early attachment difficulties. The emotional bond between a mother and child is likely to be affected by the severity of cerebral palsy. Alternatively, the mother and child adapt to the child's limitations and a unique form of reciprocity develops. A literature search reveals only one non-Western journal that touches on this topic (Quinn & Gordon, 2017).

There is a conspicuous absence of information in the literature about reciprocity and maternal attachment in the context of profound disabilities. Although much is known about reciprocity, not much is done to encourage or help mothers who are not experiencing the expected motherhood experience of reciprocity. This leaves the mother feeling bereft and afraid for the future and what this might mean to them as an individual and their sense of self going forwards (Barbosa et al., 2008). Even many mothers of healthy children secretly feel disappointed that motherhood is not going as they expected, many mothers might project and fantasise about a perfect child (Arnold-Baker, 2015).

The Look of The Mother

Jean Paul Sartre, (1953, p.349.), describes the look of the other, he brings the vignette of a man looking through a key hole watching two people having intercourse. The man looking has no shame until he notices that someone behind him is watching him peeping through the door. Martin Adams (2018 p. 104), in his book an existential approach to human development takes the look further to explain that the child needs the look of the mother to develop its original project (Sense of self). The look of the mother is facilitated by breast feeding and how the mother looks at the child is how the child internalizes itself as a being in the world. This research explores the absences of that mother and child look, the child is tube fed so the face to face contact is not there. Adams explains that it is harder to lie with one's eyes about ones feelings, and research shows that mothers mourn the loss of their perfect child when a child is born with significant health issues. The absent look perhaps allows for a period of adjustment (Barbosa et al., 2008).

The Touch of The Mother

In 75% of cases of children with Cerebral Palsy they have some form of co-morbid cortical visual impairment (CVI), (Rosenbaum & Rosenbloom, 2015). The numbers for cortical visual impairment are much higher in the Hypoxic Ischemic category (Chao et al., 2007). Although, with stimulation, the vision improves over time and Hypoxic Ischemic babies do regain some or all their vision (Philip & Dutton, 2014). Visual impairments challenge reciprocity between the baby and her mother as the baby cannot see its mothers face. Touch becomes an important aspect of communication for mother and child to bond and communicate when a child cannot see. Touch for communication, the speech feeling method, was made famous by Helen Keller (Kirman, 1973). However, cerebral palsy distinguishes itself because the child is unable to see or move its hands accurately to touch (Sherrick, 1974). However, Kaitz, Lapidot, Bronner and Eidelman, (1992), saw that women at birth could recognise their child just by touching them correctly, being able to select their own child from blindly touching a few babies. It would not seem too far-fetched that the child might recognize that touch as their mother. Lavelli, Carra, Rossi, and Keller, (2019). points out that in some cultures touch replaces reciprocity as it seems to teach the child to self-regulate. This idea that touch communicates self-soothing is corroborated by Bytomski, Ritschel, Bierling, Bendas, Weidner, and Croy, (2020). This suggests that touch is one way for the mother to literally reach her child. Psychologists tested the hypothesis that touch improves performance and well-being with basket-ball players (Kraus, Huang, & Keltner, 2010). Beck, Steer, and Brown

(1996) looks at touch specifically stroking by partners during therapy to elevate trauma and re-regulate emotional distress.

Psychodynamic Non-verbal Communication

Alice Millers writes in *The Drama of Being a Child*, 'Sometimes, the client's emotional pain is so great that the only way he/she can communicate to the psychotherapist is non- verbally through transference.' (Miller, 1983, p. 100). This might be linked to the mother-child relationship in the context of severe disability. There is no outward way that the child can show reciprocity or communicate the attachment with the mother. There would seem to be an innate transference from mother to child of attachment and communication (Stadlen, 2011). This is further corroborated in the work of Christopher Bollas who suggested that the client cannot express his conflict in words, so the full articulation of pre-verbal transference evolves in the analyst's countertransference (Bollas, 1987, p. 230). Winnicott's (1960) contribution to this phenomenon alludes to holding the client in the therapeutic space, totally tuning into the client's inner world allowing for non-verbal interaction to take place. This might play out with the therapist synchronising and mirroring client gestures as well as mimicking postural proximity (Davis & Andreasen, 1973). Missing within this literature is a plausible explanation for why non-verbal innate communication might not develop between a mother and child. Howe (2006) pins this absence of communication on the maternal attachment pattern, but his justifications omit to talk about what the mother's experience is in the here and now.

The Co-creation of a Unique Language

In the absence of consistent movement and verbalisation it is possible that the mother and child start to create a unique way of communicating. This transaction can be explained from both a developmental perspective and a social phenomenological perspective. How the mother experiences this creation of a unique language has not been widely explored.

Alfred Schutz (1932), brought together a study of phenomenology in the book *Phenomenology of the social world*. By combining insights from Husserl (Dreyfus, 1982) with the work of Max Weber (Schutz, 1932), Schutz was able to highlight how both actions and intention are the basis upon which social understanding is built. Weber (William, 1973), saw Sociology as a Science, just as Husserl (1969), had seen phenomenology as essentially the science of consciousness. Schutz (1932), was to realize this connection between Weber and Husserl was the emphasis on intention. It is only considered action by Weber (1978), when the acting person attaches a meaning to it. They may misinterpret this and may attribute an incorrect meaning, but, nevertheless, they assign a meaning to a particular action, and it is that meaning that provides an interpretation (William, 1973).

The human need to attribute meaning perhaps opens a window into the mind of the mother. The mother's need to attribute meaning to every leg spasm or head twist perhaps overlays meaning for the child. Imagine the child that has no voluntary movement but that they can twitch from time to time. The mother may interpret that as a 'yes' and henceforth the child uses this involuntary movement to mean 'yes'. This is how both (Schutz, 1932), and (Merleau-Ponty, 1973) described pre-verbal language developed, from gestures that are given meaning which is then agreed upon by two individuals to become a mutually understood language.

Similarly Austrian philosopher Ludwig Wittgenstein (1889-1951), explores the philosophy of language. According to Wittgenstein (1953, p. 21), language allows humans to create pictures of the world, which they are then able to apply to speak with one another. If two or more individuals can comprehend one another it is because they visualise the same picture of the world. The theory of embodied development, engraving between mother and child, Merleau-Ponty (1964) mentioned later in this literature review corroborates this idea. Wittgenstein (1953) reasoned that a word can only have importance within the context of human interactions. Language cannot establish itself through a lone individual, however Wittgenstein says it is possible to have a language only one person understands. This gives credence to the mother who notices her disabled non-verbal child communicating in a way that no one recognizes as communication. This is because the child's way of communicating does not adhere to the rules of language as defined by Wittgenstein (1953, p. 53) and Schutz (1932).

It is possible that the mother's search for meaning, and her creation of meaning, ultimately leads her to create a unique language between herself and her child. The creation of language is explored by Merleau-Ponty in consciousness and the acquisition of Language (Merleau-

Ponty, 1973). Everything is a communication, every gesture and every blink building up the tools to speech which can be understood by many. Non-verbal cues such as mothers pointing and gaze direction seem to facilitate comprehension to further develop language ability in infants (Baron-Cohen, Baldwin & Crowson, 1997). Bollas (1987), in *The Shadow of the Object*, stressed the role of the early maternal environment in the make-up of the self. In the early non-verbal months of babyhood, he argued, the infant's communications with the mother are transformational and are stored by the self as self-states which are known in experience but cannot be thought. This suggests that between mother and child a unique languageless communication takes place. With the disabled, permanently non-verbal child, because very few understand the non-verbal communication between the mother and her child, one might extrapolate that the mother becomes a translator that acts as interpreter between the child and the world (Green et al., 2012).

Does the mother look for typical examples of actions that meaning could be ascribed to, and average them in some way, or does the mother, as Weber suggests, look for ideal types of movement and then assigns meaning to it, for example a blink can always mean ‘yes’? By finding some way of typifying and saying these are actions that have meaning, Weber (Weber, 1978) concentrated on rational conduct and traditional conduct. Perhaps the term from Weber that is most useful here is the concept of Vershtain, translated as understanding, which relates to his theory of subjective meaningful conduct. Conduct that is understood subjectively, and the subjective intended meaning, is either grasped or not by the other (Dreher & López, 2015).

While understanding can be empathetic understanding, or it can be rational understanding, for Weber, the emphasis was on rational understanding. Schutz was to realize that many of our forms of understanding are not necessarily rational, with some of it being tacit knowledge (Schutz, 1932). What the mother might look for is what is meaningfully evident. The mother may not be causally certain but will nevertheless attribute a meaning to it (Davis & Andreasen, 1973). Yet, how does the mother search for and interpret those meanings (Merleau-Ponty, 1973)? Causal laws may be too tough a criterion to deal with, so Weber the sociologist dealt with what the typical chances of meaning are. Schutz was to firm this up with the study of typification, to say it is not just by chance, but these chances and these actions follow a pattern of meaning (Barber, 1989). This is affirmed for many mothers who try to explain their child's communication to strangers and professionals (Kirk, 2001).

For Schutz, this means the individual orientates himself in this live world through the stock of knowledge that person will have at hand, and it is that which is drawn upon. Consequently, typification and the historical knowledge that individuals have are crucially important (Barber, 1989), while Schutz departs from Husserl, in that he suggests it is no longer a description of the world but is an interpretation of the world. Interpretations can, of course, be questioned as they can be reviewed and revisited (Schutz, 1932). Thus, as the mother gains more knowledge of her child the language between them and the interpretations may become more nuanced and more complex, excluding more and more people (Cans et al., 2002). These people, in turn, then question the veracity of the mother's assertions of meaningful communication (Rossiter et al., 2017).

On balance, the literature explores the how of how the creation of a language can be created between mother and child. There is an absence of looking at the experience as it is felt. The literature seems to have no explanation for when the co-creation of language does not happen between a mother and her child, or if a mother blocks the communication because what her child is trying to communicate is just too painful to hear.

Mediated Communication

Studies show that mothers possibly start to mediate for their children from pregnancy through the placenta (Haig, 1996). It is not unusual for a mother to touch her bump and say, oh the baby is restless Pisoni et al. (2014). For some mothers, it is suggested that the interface between herself and her bump allows doctors and midwives to know what her baby needs to remain safe (López, 2009). According to many studies, it would seem that the foetus recognizes their mother's voice from within the womb and a communication link is already established that predates the birth (Voegtline, Costigan, Pater, & DiPietro, 2013). These studies omit to explore and fully study the mothers who do not communicate with their bumps, perhaps because to do so is the norm. However, there is a lot that can be learned when the norm does not occur.

Children with cerebral palsy who are severely unintelligible experience the greatest social limitations (Hustad, Allison, Mcfadd, & Riehle, 2013), (Imms, Reilly, Carlin & Dodd, 2008). These children and their parents share a need for alternative methods of communication.

Communication devices, systems, strategies and tools that replace or support natural speech are known as augmentative and alternative communication (AAC). These devices assist a person who has troubles communicating using speech. Augmentative Communication can be explained as when one augments something, one has added to it or supplemented it. Augmentative communication is when something is added to speech (eg. sign language, pictures, a letter board). This can make the message clearer to the listener. Alternative Communication, this is when a person is are not able to speak. It is also when a person's speech is not understood by others. In this case, the person needs a different way to communicate.

Augmentative and alternative communication (AAC) creates a highly effective and positive paradigm shift for many children with cerebral palsy who would otherwise have no way to be understood due to speech or language impairments, or both. While the literature on AAC interventions specifically for children with cerebral palsy who are non-verbal is small, parent-mediated interventions have shown promise, such as eye pointing for 'yes' and 'no' (Ortloff, 2010), (Pennington & Thomson, 2007). Many have challenged the accuracy of mediated communication, often believing that parents are putting words into their children's mouths (Avery, 1998). On the other hand, research using EEG with cerebral palsy participants who had no other way to communicate, established an unbiased brain pattern for yes and no (Neuper et al., 2003). However, the limitation of the EEG study was that it only had 1 participant.

While technology such as Eye-gaze devices have offered a voice to many quadriplegic children with cerebral palsy, often these children cannot use their devices consistently. Looking to the future of alternative communication for profoundly disabled children borders on science fiction. Technological companies are researching brain computer interfaces (BCI) to read thoughts through blue-tooth EEG helmets (Moran, 2017). This would be an accurate undisputed and consistent form of communication should it become a widely available device (Papanastasiou, Drigas, Skianis, & Lytras, 2020).

Green et al. (2012) studied co-mediation, finding that it leaves the mother in the role of human mediator for communication, i.e., the mother is the communication aid (Mont, 2011). The mother will work hard to establish a shared experience of communication (Power et al., 2009), often with great accuracy. In this context, communicating can be defined as to partake and have in common (Mercieca & Mercieca, 2014a), while mediation takes the meaning to be the link between two people (Wyn, 2007). Being an accurate mediator can be highly challenging when the content is emotional and a heavy responsibility if it relates to medical needs (Green et al., 2012). It can also become exhausting being the only interpreter of the child, often causing an existential fear within the mother when she worries about who will take on this role if she was to die (Brown, 2009). Green et al. (2012), used an autoethnographic method for their research which is methodologically close to a Heuristic Inquiry. Their research is limited in that it only focused on the present experience of augmentative communication for both mother and child. It did not explore the entire experience of communication for the mother as the child developed over time, that made a communication aid even possible. The researchers also don't limit themselves to just Cerebral Palsy, so a more intimate look at experiences of cerebral palsy isn't the sole focus.

Mothers of children with complex cerebral palsy are called to enter their child's world. The assumption is that society knows something of the world of children with disability and their mothers, as suggested in the literature (Wyn, 2007). The child with disability seemingly gives the mother a desire to mediate, a desire to connect with the children with disability that he or she is close to (Brown, 2009). This creates a symbiotic relationship, where there is never a moment that the mother is not 'plugged' into the child's world. The mother, it would seem, is constantly in the process of moving towards an understanding and acceptance of the child with severe cerebral palsy (Griffin, 2020). The child attracts the mother into its world, creating space for her to enter, and this helps her to make sense of the child (Green et al., 2012) Wyn (2007) writes that the mother then becomes so enmeshed that she no longer distinguishes herself, and merges with her child. Through the process of living with such a vulnerable child the essential characteristics of a mother of a child with severe cerebral palsy are not intrinsic. i.e. they are not a given but rather they are created out of necessity. They are therefore outside of the mother, (Fisher & Goodley, 2007), challenging the concept of hardship in motherhood acting as a deterrent to mothering, as love and desire to connect take over for the mother (Mercieca, & Mercieca, 2014b). The Mercieca and Mercieca 2014b, research focuses on a biography of Wyn, a talented writer by profession, who conveys her experience in a deeply moving way. Being only one mother, it is difficult to see if the symbiosis described in her writing feels true of other mothers' experiences. Wyn's child was born in 1998, which was before it was possible for Hypoxic Ischemic encephalopathy children to be saved through cooling, (Rutherford, 2005). Brain cooling, or therapeutic hypothermia, is a process in which the subject's body temperature is reduced to a value lower than the norm. In clinical trials in the U.K., the process was used on new-borns who suffered from hypoxic ischemic brain injuries following oxygen deprivation at birth. It is thought to reduce further brain damage and increase survival. Although the diagnosis for this child was the worst possible, this child regained many functions including speech through therapy, possibly because the injury was sustained sometime after birth. Another possibility may be that the medical professionals presented the worst outcome to manage parental expectations for the child's future (Rosenbaum, 2003).

Transpersonal Non-verbal Communication

The transpersonal relationship refers to the unexplainable, the spiritual dimensions of the psychotherapeutic relationship (Clarkson, 2002). It is the point at which psychotherapeutic communication becomes so intense that it makes causality and duality redundant. The highly empathetic therapist will sense a way of feeling and resonance as is described in the therapeutic literature. Resonance must not dismiss Yalom's caution of it in the work, Every Day Gets a Little Bit Closer, (Gondor, 1976). As part of their work together, both Yalom and Ginny agreed to write separate journals on the outcome of each of their sessions. What Yalom suggests was that what one might think is the meaning of something significant to the client can be totally different to what the client sees as meaningful or even significant within the therapy hour.

Another way to think about how the mother and child in the context of profound disability might be communicating is to explore the transpersonal experience of mothering such a child. It is not by chance or by mother's intuition but rather by the mother claiming to be experiencing what her child is experiencing because of an over identification that has developed between the mother and her child (Mercieca & Mercieca, 2014b). This level of mind-to-mind communication cannot be scientifically proven or measured, leaving it open to much debate and scepticism (Stadlen, 2011). There is a need for this vulnerable brain damaged baby to communicate for survival. There is a need for the new mother to be a mother after giving birth (Stadlen, 2011). These two needs meet and therefore the mother and child transcend to communicate (Clarkson, 1997). Again, there is a parallel with therapy work here and the analytic concept of 'countertransference'.

Today, with the science in place to observe the brain, this phenomenon has an explanation rooted in neurobiology. Piazza, Hasenfratz, Hasson, and Lew-Williams (2019) (2019), found that at the non-verbal stage healthy babies and adult brains coupled to the dynamics of natural communication, explaining, that while communicating, the adult and child seemed to form a neurological feedback loop, where the adult brain seemed to predict when the infant would frown or smile. The infant's brain anticipated when more baby talk would be used. Both brains were influencing each other in a dynamic way when there was face to face interaction. This two-brain approach is now opening the door into how care givers are communicating with atypical children who never go on to develop verbal language. Science alone may never be able to flesh out how this phenomenon is felt and lived.

Existential Non-verbal Communication

Here is the point whereby the human ability to survive and adapt is most apparent. There is no way to know what a client is really thinking during a therapeutic session. The world we perceive is limited because it cannot escape the structure of the language we inhabit (Polanyi, 1966). The mother that perceives cognitive ability within her profoundly disabled child found a way to assess these abilities outside the limits of standardized tests used by clinicians (Gumley, Price, & Griffith, 2011). This is possibly done by the mother's acute observation of the child and her noticing even minor changes to an eyelid or a fingertip in response to the stimuli. However, it is known that if one can establish a clear and objective yes or no response from the child then this is a turning point for the mother and child as it opens the world of choices and autonomy (Spitz, 1957).

I-Thou Communication

I and Thou was a theory presented by a German theologian, Martin Buber in his work 'Ich und Du' (1964), loosely translated as I and Thou (You). Buber explores a novel way at looking at communication between people by contextualizing his theory not on the individual or others but instead on the relationships and the relational approaches between two minds. His believed that humans looked at the world with an 'either or' attitude and therefore this theory is particularly about the two kinds of talking and relating, which he defined using two primal word pairs: *I –Thou and I –It.*

Buber (1964) considers that these two fundamental word pairs are crucial to comprehending how one answers or conveys to another. he attitude of the "I" towards an "It", with regard to an object that is isolated in itself, which one either uses or experiences. The stance of the "I" in relation to "Thou", in a relationship in which the other is not divided by distinct boundaries. Both the two basic ways of communication are needed and the act of selecting one or another when replying to someone adds to creating a meaning. *I* does not exist by itself. It takes on a shape established on its relation with factors beyond itself (the other). The other is seen as the completely '*Thou*' or the objectified '*It*.'

Without a clear yes and no it is also possible to consider the metaphysical connection (Wilber, 1993; and Jung, 1960), commonly experienced and described as a spiritual connection. Within the literature there is little to corroborate this, at this juncture it is a potential hypothesis. Perhaps this phenomenon does not occur for every mother, and it would be interesting to explore what that might mean within the experience of mothering the disabled non-verbal child. Moving into existential thought would be the perpetual experience for the mother of living with uncertainty, as possibly, there is no testable way in which one can prove or disprove what the child is communicating.

Child development

Child development is one of the most significant areas of research that explores paradigm for childhood studies and has focused on the role of developmental psychology in explaining young children's lives. Developmental psychology has moved beyond, the set of ideas about the child and the childhood that standardised and endorsed by child psychology' (Stainton

Rogers & Stainton Rogers, 1992, p. 37). In the early 20th century, developmental psychology was recognized as the dominant paradigm for studying young children, shaping professional practice in care and education (Woodhead, 2003). Debates about ages and stages became linked to developmental norms, which led onto fixed milestones and then the idea of developmental delay. Within this framework, childhood is seen as an preparation for adulthood that can be monitored through stages related to age, physical development and cognitive ability: groups of children were clustered according to their birth dates sent to school in age-graded classrooms with their development followed according to expectations of development at the key stages (Woodhead, 2008).

This developmental approach was based on the ideas around evolutionary model that looked at growth as a natural and biological process. Morss (1990), critiques the evolutionary developmental model stating that development is universally constructed as a sequence of progressive states. Pivotal to his theory is a linear progression, where each stage is travelled through completely in-order to go onto the next stage.

Piaget a Theory of Development

Piaget (1954), was one of the most prominent child development psychologists in the 20th century. According to Piaget's theory of development children's rational development is likened to an evolutionary process, one in which the next stages of development come after previous ones because they are more suitable to reality. Development is seen as a self-regulating function between the child and the physical and social environment, which generates to new types of understanding. As children progress through the phases of consecutively linked stages, children slowly discover the cognitive skills involved with reasoning, logic, causality and morality until they achieve adulthood. The focus of developmental psychology is on the immature child moving through childhood to become a mature logical and cognitively able adult. Young children therefore according to developmental frameworks are believed to be in a condition of perpetual transition, either inside or in the middle of stages of development.

Piaget’s approach appears to balance nature and nurture, development occurs both in natural stages and as a reaction to events balancing accommodation and assimilation, ergo a sheltered child unexposed to stimuli will develop differently, or less than a child that is forced to adapt to stimuli (Piaget, 1964). Circumstances etc. Nevertheless, there are still natural capabilities and stages which Piaget says are inherent and set the tone for the reactionary development that occur. Piaget brings the example of a child learning that a kick will cause a toy to rattle so the child then kicks with intent.

Piaget is often criticised for overlooking the relationship between the young child and the adult. Bettelheim (1991), contributes that the down side of much child psychology is that although the findings are important they do not always benefit the child. Much of what is understood by adults of child development is from the outside of childhood (Bettelheim, 1991, p. 120). Piaget held that cognitive development happens through the rich interplay of biological processes of maturations an neural development, as well as language formation via the interaction of social learning.

Piaget's framework of development does not seem to benefit children who are not developing in a neuro-typical way. Simplistically it would seem that no development of cognition or language comprehension can be possible for the child with complex cerebral palsy who never goes through these stages of development. Yet many non-verbal children with cerebral palsy do go on to achieve academic qualifications and have meaningful relationships (Gomm, 2007). Perhaps there are other developmental models that account for this better.

Piaget's theory of development lacks the social dimension which Vygostsky (1978), explores in his theory of social constructivism. Vygostsky emphasised the importance of social-cultural factors, being work and development in relation to others. What is inter-mental between people becomes an intra-mental part of the child's way of thinking. Vygostsky's zone of proximal development refers to what a child is unable to achieve alone but can achieve with the facilitation of others. When adults or more able peers provide support, this enables the child to develop to expand their abilities. Although Vygostsky's constructivism is more in line with Merleau-Ponty's intersubjectivity, it is still limited to a set process which Merleau-Ponty theories of child development move away from.

I would seem that in the case of severe cerebral palsy where no outward signs of development is taking place it might be easy to assume that no development is taking place. So the framework of child development moving from stage to stage does not seem like a good fit for cerebral palsy. In his later work Piaget does take into consideration that external stimuli can encourage development (Piaget, 1964).

It is also worth bearing in mind at this juncture that many of the early 19th century child development theorists have been presented to the world from the point of view of white middle class men. This obviously leaves a void where the female voice on these theories should be and yet these theories have stuck as the underpinnings of child development. If one were to google child development theories by woman nothing comes up at all. Yet historically it was women who stayed at home and watched their children develop and men went out to work (Stadlen, 2005). Perhaps this is the biggest criticism of the child development theories and therefore all the more imperative that mother's are heard when they challenge old theories based on their lived experiences or their child's development (Fisher & Goodley, 2007).

Merleau- Ponty Embodied Development

Merleau-Ponty (1964), perhaps offers an alternative to child linear development. He viewed childhood as an embodied and relational experience. This approach offers a different way of understanding the sociability of children, their, desire to communicate and to interact to others as embodied, sensuous, interconnected human beings. Rather than portraying childhood and adulthood as separate stages, Merleau-Ponty (1964), observes an essential uniformity. The child does not primarily self-consciously think about his or her body and then confront objects; rather, he or she feels both the body and the world as a basic oneness, with each sense working collectively in his or her behaviours. This embodied focus towards the world maintains itself into adulthood. Merleau-Ponty (1968), describes how the human infant is not primarily a human mind that is finds itself in a body and a world. Babies according to Merleau-Ponty (1973), do not first have a self-reflective understanding of their body, they explore other human faces and then proceed to imitate the gestures they perceive.

For Merleau-Ponty (1964), exploring the experience of embodiment takes his ideas away from the traditional Western dichotomy between subject and object, observer and observed. Through embodiment, we are instantly and innately connected in a mutual awareness; no one can come into contact with the other without *being* touched. Totton (2014), describes pattern as an ‘engrams’, an established neurological word for the physical unit of memory, otherwise described as holographic memory. The word ‘engram’ plainly means something *etched inside*. Embodied relational engrams are developed in our most primitive relationships; and we use them, as patterns in each new encounter we experience. There are two interlinked facets to this: the baby *reacts* to the adult in the act of *receiving* the adult's feelings. What this theory suggests is that the mother engraves her cognitive knowledge onto her child, like a printing press imprints a picture onto a copper surface. In this way complex non-verbal communication can take place between the mother and child.

Perhaps, a theory of embodied development it is easier to comprehend therefore, that the mother perceives the reciprocity in a subjective way and therefore she is the one that determines her own reality of the attachment between herself and her profoundly disabled child. A step further is possibly the mother’s ability to embody what her child is physically feeling and therefore shout for help when no one else sees danger (Sevón, 2005). The freedom that Merleau-Ponty gives development allows for different ways of being. While Merleau-Ponty still maintains that there is a course of development his attitude towards it is more flexible than the

Delayed Development

Bearing in mind that Piaget agrees that external stimulation can increase child development. Many parents do recognize social emotional delays when observing their child with complex cerebral palsy (Rosenbaum, 2003). These delays are not linear, it makes sense that a child who spends a lot of time in hospital, is too unstable to attend school and struggles to go out and experience the world will not acquire social, emotional development (Luijkx, van der Putten, & Vlaskamp, 2019). However when placed in front of a communication device it many of these children have vocabularies cognitive and comprehension skills that are far more advanced than their other areas of development (Gomm, 2007).

The developmental stage of puberty might indeed change the way the communication takes place between healthy children and their mothers, but the children in the complex cerebral palsy category are often experienced by the mother as younger than their bodies are because the emotional development is often delayed (Luijkx et al., 2019). Additionally, there are fewer peer social experiences for these children, which further delays their emotional maturity and age-appropriate communication (Stevens et al., 1996).

Conclusion

In summary, within the literature there is much information and knowledge relating to the relationship between a mother and her child (Mayo & Moutsou, 2017). This relationship is built on both the mother and child being instinctively sociable and the child instinctively responding to social situations which leads to the child being cared for (Stadlen, 2011). What is not in the literature is how communication, and therefore attachments, are experienced when infant development does not follow a predicted path, specifically with complex cerebral palsy.

As is evident in the academic literature there are plenty of medical professionals who have scrutinized cerebral palsy in great depth (Bax, 1968). What is not evident is the impact and implications this catastrophic condition has on the life of the parents. By putting this condition into tidy clinical paragraphs focus can be drawn away from the fact that this condition has no cure (Elder et al., 2003).

Most of the research looking at the health of mothers and fathers who have a child with cerebral palsy is quantitative. The focus of past studies was to establish what factors cause parents to cope better and what factors cause stress (Carnevale, 1990). The agenda of this kind of research might be used to inform policy makers on how to create more productive parents and reduce costs to the state (Matravers, 2000). This is often counter-productive as it dehumanises the parents at the point of support.

Past research seems to intimate that many mothers suffer from anxiety and depression post a child's diagnosis of any condition (Davis, 2014). Well documented is the experience of mothers who describe everything they want for their child as a fight. Often these mothers are somehow punished for being difficult and excluded from decisions of care for their children as the professionals know better, leading to an institutionalisation and medicalisation of motherhood (Barbosa et al., 2008).

The assumption that a child is not understanding because they are not communicating normally, or that it lacks capacity because they do not communicate normally, creates maternal anxiety, and it may be depriving the child of future autonomy and dignity simply because they are not understood, like a foreigner who can't speak the language and so can't be understood, but they certainly still have cognition (Green et al., 2012). There is not much research from the mother's perspective of her experience, trying to give her child a voice.

The literature review acted as a scaffolding upon which this research could be built. The social constructs of motherhood, societies approach to illness was key information that later explains some of the existential issues that mothers of disabled children face. The literature highlights the magnitude of the child's disabilities by focusing on the absence of all the normal attachment communications that take place between a mother and a baby.

The research looks at how the phenomenon of non-verbal communication is alluded to in psychotherapy between the therapist and the client, knowing what someone is wanting to convey without words has a basis with in psychotherapy. Exploring different theories of child development further shapes the social constraints that many mothers face when dealing with professionals. Often professionals do not understand a more embodied approach to development that allows for the development of cognition which then leads to offering disabled children augmentative communication more widely.

Finally the literature dispels the myth that mothers are imposing communication onto their disabled non-verbal child. The part of the literature that showed neurobiological processes that account for maternal anticipation of their child needs gave me the confidence to explore this phenomenon knowing that there was more to the communication that just telepathy or magical thinking. The current up to date neuroscience research seems to indicate that non-verbal communication is a more complex and more prevalent part of everyday communications.

The literature had a huge impact on me as the researcher, it began to excite me that the phenomenon I was about to explore was being described in many of the theories I was reading about. The most up to date neuroscience research seemed to fully back up the phenomenon that mother and child do have some kind of implicit communication that does not need language. The deep delving into the past and current research gave me the momentum to keep going and follow my instinct that there was something to be observed from a perspective that had not been done before.

Chapter 3 Methodology and Method

‘We all have many more abilities and internal resources than we know. My advice is that you don’t need to break your neck to find out about them’ Christopher Reeve 2002, p. 7)

Overview of Chapter

This first part of this chapter focuses on the theoretical basis of research methodology before to going onto the design of the study, which is covered in the second half of the chapter.

This first section covers the following areas, Heuristic Inquiry and my personal connection to experience being explored. The philosophical basis of phenomenology in research. The heuristic method and its qualities relevant to this research.

The second section covers, how I conducted my research ethical considerations recruiting participants, consent, and confidentiality. . Interview procedures and data analysis followed by how I analysed the data under the headings of the 6 stages of the heuristic research process. Finally I reflect on the way the stages were carried out and research validity.

Section 1: Methodology

Qualitative Research

My research method is a heuristic inquiry and is therefore situated within the qualitative research methods. Qualitative methodologies have been described as those in which the research informs the theory rather than the theory informing the research (Barnes, 2017). Qualitative research can be used as a general term used to illustrate ways of researching experiences, insights or behaviours through interviews or physical expressions, emotional responses or writings (Bricki & Geen, 2007). To put quantitative research into practice, researchers use methodologies to create and shape the study, and methods to conduct it (Sultan, 2017). Unlike quantitative research, qualitative research moves away from post-positivism, which is the framework that supports deductive, objective approaches in research with a focus on a single reality. Rather qualitative research uses a framework of social-constructivism, (Burr, 2018), which can be explained as a philosophy of life and research paradigm that specifies that reality is equally internally and socially constructed. That there is no one truths or realities a different term that can be applied for this is interpretivism Greene, 2014).

A qualitative approach is one in which the researcher explores experiences predominantly from constructivist perspectives (i.e. the multiple meanings of individual experiences, meanings socially and historically constructed), (Giorgi, 1994). This is done with an intent of developing a theory or pattern) or advocacy/participatory perspectives (i.e. political, issue-oriented, collaborative or change oriented) or both (Creswell, 2003). Qualitative research is not looking for cause and effect. Instead it looks at meaning, human perceptions and behaviours. It is looking for the why or what of human experience.

Qualitative research seeks to produce new knowledge of the meaning human beings give to their lives and their worlds. Qualitative researchers therefore, are characteristically centred on the participants' own experiences of being in the social and physical world, their lived experiences and narratives of their lives, opinions and understandings. Qualitative researchers work from the principle that humans construct their own realities and translate the world to themselves in their own unique ways (Denzin, 2018).

Qualitative research in general does not lead to in generalizable findings, rather, qualitative explorations describe deep narratives of personal lives. The qualitative methods are constructed to produce participants' own descriptions. Therefore the researcher might look to art, literature, media and plays for more insight and data towards explaining the phenomenon (Sultan, 2017).

Phenomenology

Phenomenology is a philosophical movement much written about by Husserl (1969), it also applies to a range of research approaches as it is an approach of investigation in which the researcher finds the essence of human experiences about a phenomenon as depicted by participants. Understanding the lived experiences is an underpinning of phenomenology as a philosophy as well as a method. The procedure entails researching a small group of subjects through long and in-depth engagement to build patterns and connections of meaning (Moustakas, 1994b). In essence, phenomenology is a way of noticing how events seem to us through experience. More than a method, phenomenology needs an open way of being—one that explores sometimes very ordinary human situations as they are lived in everyday life. It encourages researchers and lay people alike to study those facets of experience which often go unquestioned (Sela-Smith 2002).

Heuristic Inquiry is very much aligned with a phenomenological research approach. This is because phenomenology and Heuristic Inquiry both synthesis science and art, and perception as its core source of knowledge and truth (Moustakas, 1994a).

The Heuristic Method

Positioning heuristic inquiry in terms of phenomenology and qualitative research psychology, I can now consider the heuristic research method. Heuristic inquiry was established by Clark Moustakas when he chose to analyse his personal experience of loneliness (Moustakas, 1972). Rooted in the Greek word ‘heuriskein’, it means to uncover or discover or working to find out. It is a method of internal seeking which puts to the fore 'the total person as a research method' (Moustakas & Douglass, 1985, p. 210). The heuristic method is ‘a qualitative, social constructivist. and phenomenologically aligned research methodology inspired by the primary researcher’s autobiographical experience’ (Sultan, 2019 p. 262). It requires a knowledge of a phenomenon centred not on a shallow intellectual understanding rather it is on a deeper, less deliberate exploration that the researcher forms with the subject. It emphasises the understanding and way of learning that is only possible when the researcher becomes completely immersed in the process of discovering a phenomenon on a conscious and unconscious level. Heuristics does not only openly recognize the participation of the researcher, but in fact views the researcher as the research.

Although heuristic inquiry has its roots in phenomenology it is different from phenomenology in the following ways. Heuristic inquiry focuses on the researcher relationship to the material where as phenomenology asks for a degree of detachment (Sela-Smith, 2003). Heuristic inquiry invites a collaborative approach where art and creativity can be expressed with it the research (Sultan, 2018). Heuristic inquiry embrace individual meaning whereas phenomenology leans towards a more structured experience. Heuristic inquiry focuses on the wholeness of the experience and includes the participants as co-researchers. Whereas phenomenology may lose something of the essence of the participants at the analysis stage (Moustakas & Douglass, 1985).

Therefore this research is a heuristic investigation, due to me, the researcher, being enmeshed in the experience being researched. After much self-reflection, using only a heuristic inquiry was decided upon in order to be able to focus fully on the process. Heuristic Inquiry allows for the interpretation to be a collaboration between the participants and researcher. The participants here are effectively co-researchers alongside the researcher’s own process of deep immersion in the material, to see what emerges whilst maintaining the rigor and evidence-based work that is required.

This heuristic way of working, when done correctly, is an exploratory process that is genuine and intersubjective and produces something unique, authentic, and useful about the lived experience being examined. To impose any other qualitative methodology on top of the heuristic method, would be to lose something of the spontaneity of the findings. The whole exploration steers away from predefined themes or predefined established dimensions of the experience.

Rationale for Heuristic Method.

When my son was born, I was a cognitive psychologist, and I loved the precision of the statistical research. After my son was born, when I showed my tutors my son’s diagnosis and asked them how to help him, I was met with a deafening silence. I could not understand this, as these were people who claimed to understand the brain better than anyone else. I realised that human experience gets lost in statistical research, where participants become like rats in a laboratory isolated from the natural world they inhabit.

By using a qualitative methodology, I stayed true to how I now think about purely quantitative research, whereby the objective voice of the academic scientific researcher often unintentionally squeezes out the human aspect of the lives they are aiming to study. As researcher, it is possible to explore the participants lives and experiences for public scrutiny, while at the same time hiding one’s own experiences at a professional distance (Denzin, 2018).

I reflected that separating myself from my research would not achieve the transparency, reflexivity, and therefore depth that would only be possible if I merged myself with my work. I further narrowed my methodology to undertake A Heuristic Inquiry. This method allowed me to choose to travel with my participants through the research, becoming both a participant and observer (Moustakas, 1990), fully disclosing to the reader my stake in the topic, communication of mothers with non-verbal profoundly disabled children. The reader can judge for themselves the degree to which my own experiences may have influenced the findings within this research.

The use of Heuristic Inquiry worked on the premise that I did not know what would be found. Rather, it allowed me to understand the participants' subjective experiences of communication in the context of being a mother of a child with complex Cerebral Palsy and how it has shaped the mother's relationships with her child (Daly, Kellehear, & Gliksman, 1997). It worked to explore if there were common experiences between participants, and the meanings they have made of these experiences. There is a supposition that individuals are always trying to comprehend and make meaning of the world around them (Smith, 2004). This work also looked at individual differences within similar experiences to see how unique and individual each human experience really is. It allowed me to understand and find the psychological constructs and beliefs that support participants' accounts of their experiences (Braun & Clarke, 2006). I did not want to hypothesis an outcome, but rather, I asked questions and allowed each woman to bring her experience to the research.

Using the Heuristic methodology, I was able to co-create the findings with deep understanding of the participants (Moustakas & Douglass, 1985), engaging with the material with my own documented internal process. Not only did this research investigate the people's experiences, but it included my own experiences as I came from within the participant group I am researching (Sela-Smith, 2003). Furthermore I was interviewed and my transcript was included in the findings. I had empathy which was evident from the careful questions posed to the participants.

I chose to self-disclose that I had a son with complex cerebral palsy that was non-verbal after my first participant asked me directly if I had a child in this category. This disclosure helped to build up trust, allowing the participants to really be open and share their experience more authentically (West, 2005). I was aware that it might have altered the responses of the participants and changed the way they responded to me. It may have detracted from the richness of the description because the participants assumed I understood what they are talking about. This may deprive the lay person from fully grasping the phenomenological experience as the participant and researcher engage in the jargon only mothers of disabled children understand. I accommodated this by asking the mothers for more descriptions and explanations and told them to assume I know nothing about their experiences. Upon reflection disclosing that I was a mother in the group being transparent and congruent with the methods of Heuristic inquiry far outweighed the possible negatives of changing the way the mothers responded.

Linked to phenomenology, in Heuristics, emphasis is placed on the human experience subjectively (Birks & Mills, 2015). This method focuses on the participants' perceptions, feelings, and experiences as the most important part of the study. Phenomenology endeavours to bring the authentic voice of the participant as the main source of qualitative research (Charmaz, 2014). This allowed the participants talk about their experience in their own words, free of restrictions from closed questions found in quantitative studies (Dick, 2005).

I used the Heuristic Inquiry as a methodology ahead of other qualitative methods such as thematic analysis (Conroy, 2017), because of the consideration it takes of how the researcher's own explanations affect the end results and it incorporates researcher subjectivity (McKemmish, Burstein, Manaszewicz, Fisher, & Evans, 2012). This method recognised and successfully used the unavoidable dynamic influence my own experiences have had upon the data and the interview process. A Heuristic Inquiry considers the researchers own beliefs as the researcher analyses and works with the data.

Although this Heuristic Inquiry started narrowly within the confines of me the researcher's initial experience, when trying to comprehend women's experiences of mothering in the context of child disability. It was then broadened to incorporate the situation in which the narrative takes place. Which then drew on the broader social, theoretical, and political framework so that it better appreciated the participant's experience (Bricki & Geen, 2007).

Consideration of Alternative Approaches:

Pringle, Hendry and McLafferty, (2011), states that it is imperative for a research methodology to have a robust philosophical foundation. There are some qualitative methodologies that meet this initial prerequisite of phenomenological exploration. I will reflect on why I will not be using them in relation to my research.

Descriptive Phenomenology

Langdridge, (2008), commented that descriptive phenomenology was one of the cornerstone methods that initially endeavoured to apply phenomenology to research in the human sciences. This methodology, created by Giorgi, tries to describe, rather than interpret phenomena, and focuses on finding the unchanging, original structure of an experience (Giorgi, 1992). This method leans on Husserl's basic premise of epoché where one's own biases can be set aside. This did not seem to be cohesive with my research mindset as I wanted to fully disclose my place and personal experiences in the meaning-making process. Therefore, I did not think it was possible to fully bracket myself off. I explored alternative phenomenological methodologies to see if my only option was indeed Heuristic Inquiry.

Autoethnography

Autoethnography seemed similar to a heuristic inquiry, so I asked myself what differentiates Heuristic Inquiry from Autoethnography? Autoethnography is the search for comprehending the heart of a subject of inquiry through self-reflection—that of the primary researcher. In a heuristic study, self-research is but one measurement of the study (Denzin, 2018). Autoethnography's focus on individual experience is through an egocentric lens on research and may not address advancement or movement from the personal to the universal. The Heuristic research takes the work beyond the realm of self into the world (Sultan, 2017).

Grounded Theory

Grounded theory is a method with a few versions which looks to advance a theoretical account of a specific phenomenon (Smith, Flowers, & Larkin, 2009). It was created for sociological research, rather than psychological research, to intensify the comprehension of an explanation of different social narratives (Willig, 2013). Investigating social processes appears to accentuate understanding at the collective level rather than the individual level. Primarily, the attractions of Heuristic Inquiry are the idiographic perspective it brings (Moustakas, 1990). Grounded theory sets out to understand the theoretical premise for the phenomenon through a group of themes that work around a core theme, whereas a Heuristic study aims to find non-hierarchical themes that help in understanding of the nature of the phenomenon (Sultan, 2017). As I had already decided not to have a fixed hypothesis grounded theory was not a suitable choice for my research.

Ontology

Ontologically, my research looked at my own subjective being and reality in the context of my experience as the mother of a non-verbal disabled child for 9 years. Existentially, this sits within the philosophical ideas of Heidegger (1962), who described how one is always being in time in the world as an activity of existing. Heuristic research assumes that reality is subjective, built on each person's context and meaning making of experiences both personal and shared (Sultan, 2017). This creates the orientation of the person - their worldview, suggesting that there is no single reality, but rather, multiple realities. The purpose of this heuristic inquiry was to discover the reality of the phenomenon of non-verbal communication between the mother and her complex cerebral palsy child through deep introspection, self-talk and indwelling (Moustakas & Douglass, 1985). From both the perspective of myself the researcher, and the co-researchers (participants) the material was synthesised and it produced the essential nature of the experience, in a sense, co-created through dialogue and relational interaction a new reality and meaning was given to the phenomenon (Merleau-Ponty, 1962). Each participant's contribution, as well as that of the researcher, was valued and was valid. This was done by looking deeply at participants' experiences that are unique to them and those experience that seem to overlap, constantly being cognisant of both mine and my participants' individual differences. Unlike other quantitative methodologies there are no outliers, those individual findings that fall outside of the pattern. All the findings, however diverse, were accepted as normal and as reality, paralleled with the nature of brain injuries that are as unique as thumbprints. There was emphasis on using the original voices of the participants to keep the experience as close to their original meaning as possible. Once more, the Heuristic method seems to mimic the experiences of many mothers who co-mediate for their non-verbal children.

Epistemological

Epistemology concerns itself with knowledge and how we know what we know (Sutton & Austin, 2015). Husserl, (1980), used phenomenology to access knowledge of experiences as experienced from the first-person point of view. My concern therefore was to know what I know about my own experience as a mother to a non- verbal child, but also to learn and know what my co-researchers know about their own experience of non-verbal communication between themselves and their complex cerebral palsy children. As researcher I am the knower and would be knower (Moustakas, 2001), as are my participants, in this quest to co-create knowledge and understanding of the experience of non-verbal communications between mothers and their children who have Cerebral Palsy . This process is eased through the intersubjective relationship that is created between me and the participants. Each lived experience contributed adds to the knowledge and understanding being looked for. The knowledge was co-constructed with my knowing that the understanding cannot be separated from the contribution of experiences of the other mothers. Moustakas urges this exploratory rather than explanatory approach, though it may lead to uncertainty, for what cannot be explained thus allowing something all-together different to make itself known (Sultan, 2017). This protected me from producing an inquiry to fit an epistemology. What I hoped to achieve was an exploration of the whole experience by immersing myself in each of the individual experiences. This did not preclude the understanding of the limitation that there is an absence of many mothers' contributions who were not interviewed for this research.

The philosophy underpinning Moustakas' methodology (Moustakas, 1990) brought another dimension to my research. For not only did I look to psychology in practice to see how non-verbal communication takes place in therapy, but Heuristic Inquiry also itself seemed to be a method that required deep tuning in, and immersion with the material so that I could find meaning. This process sounded like the literature that describes what mothers do during the non-verbal stage of a child's development (Ainsworth & Bowlby, 1954), once again displaying the circular nature of this research as I undertook it as a process and a journey of discovery.

Limitations of a Heuristic Inquiry

The Heuristic Inquiry has limitations as it does not try to explicate why humans experience a particular phenomenon in a particular way. Alternatively, it describes, explores, and tries to understand the individual perceptions (Willig, 2013). This can be a possible disadvantage as the absence of a description could limit the comprehension of phenomena. With the researcher having such a dynamic role in the analysis process, the explanations may possibly be limited by the researcher's own capability to understand, reflect, and find meaning in the transcripts (Bricki & Geen, 2007). This is a concern of any researcher, especially student researchers. It is for this reason that good research supervision, the researchers own reflective journaling, self-reflexivity and personal therapy play a large role in preventing this, ensuring the calibre of the work is maintained (Berkwits & Inui, 1998).

One of Heuristic Inquiry's biggest criticisms is its lack of objectivity. If done properly, Heuristic Inquiry offers intimacy and detachment, distance, and nearness, and it is a fine balance of the interaction of the polarities of the experience (Aronson, 1995).

Whilst doing a Heuristic Inquiry, because of the very nature of the reflectiveness within the work, the research may hit researcher blocks. This is a natural part of the process brought on by the intense level of engagement with the material being researched. Realizing that one may be subject to self-doubt, social pressures to conform and one's own fears of failure should be accepted as a part of the process. Self-belief that one knows exactly what one wants to be researching should keep the work moving forwards.

Sometimes, the findings at the end of the process are not definitive. However, that statement itself leads one to question what is meant by definitive. While it is true that others may have asked the same or similar questions, each interaction with the findings expands it and develops it further. This sums up Heuristic Inquiry as the living process of an experience that it is.

A Heuristic Inquiry may show up more differences in experiences than similarities, highlighting the truth that no two experiences are the same. Individuals will experience it uniquely, influenced and shaped by their own life stories and circumstances.

Sometimes, the research will effect no apparent social change, even when this is hoped for. However, real change happens slowly over time whereby a lot of small studies accumulate into a body of persuasive work. Each individual research effectively contributes to setting the wheels of change in motion.

Section 2: Method

Research Process

The Research process transcribes how I carried out this research, it started with my request for ethical approval to being the process. Followed by how I designed my inclusion/exclusion criteria, highlighting the idea that my participants are my co-researchers as this is in line with the Heuristic method. I then outline how I recruited my participants, and the measures I took to make consent and confidentiality clear to the participants. I then explain the details of my interview procedure, how I collected my raw data and the reasons why I had interview questions. The research process then ended with the data analysis that moves in and out of the six stages of the Heuristic process to produce the themes that are documented in chapter 5.

Ethics

I applied for and gained ethical approval prior to any data collection. Ethical approval was applied for and granted by the New School of Psychotherapy and Counselling panel in June 2020. This ensured that the research was carried out in a way that no damage could result from the collaboration with the participants, as far as it was possible to ensure. In exploring how to work with vulnerable participants and work sensitively with them, I came across Swanson's middle range theory of caring (Swanson, 2012). This is a five-step process which is as follows:

Step 1: Maintaining belief; refers to believing in the participants capacity to work through and find personal meaning in his or her experience, even though they have faced significant challenges (Swanson, 1993). As the researcher, it is important that I take a positive stance approaching the interviews with strength to convey hope.

Step 2: Knowing; striving to understand what the experience means from the perspective of the participant who is living the experience. Making no interpretations, judgments, assumptions at all, conveying in the research the participants perspective (Swanson, 1993).

Step 3: Being with; the act of being authentically present with the participant to convey to them that their experience is important to me (Swanson, 1993). Being with in a non-burdening way, conveying availability, enduring with, and being caring.

Step 4: Doing for; preserving dignity and protecting participants from undue harm by not coercing any of the participants and upkeeping and maintaining confidentiality.

Step 5: Enabling; this refers to validating, informing, and supporting participants, giving them feedback by creating a dynamic that is non-hierarchical. Enabling can also mean reducing any stresses by ensuring that participants know they can cancel the interview if their child is unwell, doing the interview in a safe place and being sensitive to and reliable when providing resources.

Using Swanson's theory reminded me to be mindful of how possibly very emotional situations must be dealt with sensitively (Rosenblatt, 1995). This exploration believes in the participants capacity to work through and find personal meaning in their experience even though participants have faced difficult challenges (Swanson, 1993). Mothers who choose autonomously to participate might even appreciate the opportunity to tell their story and give it meaning.

The key ethical issues in this study were the safeguarding of the mother from emotional harm following a potentially upsetting interview. To mitigate any harm, the following will be in place:

1) Emotional suitability was gauged in the initial contact with the participant, by asking the mother if she has any current diagnosed mental health issues or is clinically depressed during the screening process, or whether there is a support system around the mother. To protect the mothers who must be excluded from feeling rejected I started the screening process by explaining that there is a possibility I would not be interviewing every mother and I ended the screening process by saying that I really appreciated the participants offer to participate. I also informed the mothers that they could withdraw at any point and that I may have to interrupt the interview and suggest alternative support. I did not exclude mothers who got upset during the interview as it was expected that a certain amount of emotion would be felt during the process as the content is autobiographical and very personally felt by the mothers (Thomas, 2005). I always clarified with any distressed mother whether she feels strong and able enough to continue trusting in the individual's autonomy to decide that they were happy to continue (Swanson, 1993).

2) I gave the reassurance that the mother could stop the interview at any stage. All data produced would then be destroyed.

3) An introduction was given regarding the possible emotional nature of the research prior to the interview. In the case that a mother wanted to discontinue during the interview she would be given the option of doing so. All the data she produced will be deleted and destroyed.

4) Direction and guidance were given on how to access support via the GP if a participant became distressed. I suggested a list of psychotherapists names and contact details in the local area, as well as MIND. The charities Contact a Family, Scope and Cerebra offer emotional support, so a leaflet with this information was left with the participant (See Appendix 6b for full information sheet).

5) To ensure against being interrupted by the phone or anyone entering the room I asked that all mobile phones be switched off.

6) Mothers were debriefed at the end of the interview to allow time for the mother to say how she felt before ending the interview (See Appendix 7d for debriefing form).

7) Each mother was offered to the opportunity to see the transcript of her interview, and any reflections that I had made about her interview, to ensure she felt accurately represented (Swanson, 1993). All identifying details of the mother were removed before submission.

8) Understanding the impact that this work would have on myself, as both the researcher and the participant, I took measures for own self-care and my own emotional wellbeing. I used personal therapy and supervision to process anything triggering that came up in the interviews. I reinforced my support system that included my family who were behind this project and me.

Inclusion Exclusion Criteria

I interviewed eight mothers who have a child with complex cerebral palsy . To increase the likelihood of a homogeneous group, I made quite a narrow set of criteria to pinpoint exactly which mothers I was targeting. From the start, I knew that the mothers would need to have a child that cannot communicate using their voice, hands, or feet. The child will also have to have been diagnosed at or around birth with cerebral palsy , or given some indication that cerebral palsy was a possibility from the start. The child would have had to be unresponsive and unable to feed. Participant mothers will have a child who did not reciprocate any maternal queues from birth, in order that I can explore their lived experience of how communication and the subsequent relationship with that child developed. Since I know how traumatic the start of this kind of mothering is, I looked for mothers of children who were above the age of three, at which point a lot of these children have external nursery provision or a care package of support. On the other hand, I did not want the child to be so much older that the mother has forgotten much of the detail, so this excludes adult children over the age of 16.

Looking at the mental health of the mother will be an important part of the inclusion criteria. Only mothers who say they feel mentally well and do not have any mental health diagnosis will be included in this research. They must have access to therapeutic support, and I came prepared with how information on how to access more support through charities or NHS provisions. If at some point a mother disclosed feeling emotionally unable to continue, then the interview was stopped. I asked the participant if there was any support in place and who she might want to call that helps her family because they have a disabled child.

Ultimately, the mother's emotional wellbeing while being interviewed was my main concern. It was paramount that the mother always felt emotionally safe throughout the interview (Kavanaugh & Ayres, 1998). Of course there is no real way of knowing how a mother is feeling so I had to observe the mothers body language, levels of distress and I had to verbally ask the mother how she was feeling when it seemed appropriate. This was done by observing the participant mothers emotional state and checking in with the participant mothers if they were feeling ok and happy to move on with the interview. I took time to allow the participant mothers to process and deal with the emotions that came up for them using my psychotherapy training to nurture a non-judgmental and grounding space.

I had in my exclusion criteria a current or recent mental health diagnosis, and if a significant concern about the mother's mental health arose during the interview, I referred her to support services and asked her if she would like to interrupt the interview. I also could contact my supervisor and be advised how to proceed, should there have been any further concerns for a participant's wellbeing. I informed participants that they have the right to withdraw their interview at any point before completion of my dissertation.

Participants - Co-researchers

Heuristic inquiries work on finding the unique factors specific to each participant, and the ways in which these are similar or different from the others interviewed. Therefore, it is significant that the sample is small and that the mothers used for the research have a similar situation (Smith et al., 2009) to each other. There is no ideal sample size for a heuristic study in the literature (Smith, 2007), rather, that sample size is reliant on idiographic factors and tries to create an equilibrium between being small enough to find possibly refined nuances of meaning (Collins & Nicolson, 2002) whilst being great enough to have sufficient data to work with. Griffiths, Camic, and Hutton (2009), propose that having eight participants is in accord with other Heuristic Inquiry sample sizes and should be enough to reach saturation point. Because my participants are my co-researchers (and after the pilot study) it was important to honour the methodology and be transparent that I too was a mother with a non-verbal complex cerebral palsy child.

Recruiting Participants

I recruited my participants through the large special needs network. I advertised my recruitment poster (See Appendix 6a of recruitment poster), via emails to private specialist therapists and charities I knew who do not work for the NHS, asking if they knew of anyone who would like to participate in this study. To maintain anonymity for the clients of the professionals, and equally myself, care was taken to maintain a degree of separation. The way in which a participant can put themselves forward to participate will be via email. I also emailed friends and university peers asking them if they know anyone suitable who could be a potential participant. This created a snowball effect that should result in enough of the right participants for this research study.

The potential possibility that I might meet a participant in another context outside of the research interview such as a hospital appointment was addressed in my confidentially considerations below. On my advert to recruit participants, I let the participant know that they would be asked to produce some artwork I specified that no artistic skills were needed and that it was optional.

Informed Consent

Informed consent was addressed through mothers being provided with an information sheet and clarification provided during the initial telephone call, and again at the start of the interview. All mothers were asked to sign a consent form. Mothers were told that they were free to not answer any question. They were also be told that they could stop participating at any time during the study.

Confidentiality

I ensured the confidentially of all my participants, in the event of meeting a participant in another context. I established an agreement with each participant like that of a client-therapist agreement, and it was decided that I would not acknowledge a participant unless they acknowledged me. If my participants connect to me via social media or choose to follow me online, again I will not make any mention that they have participated in my research. This way the confidentially will be maintained for my participants in the future.

To protect the identity of the participants, pseudonym were used throughout the research for both the mothers and the children. The pseudonym ensured that the real names of any participants were never revealed. I recorded the interview on a Dictaphone, and all electronic and paper copies of data and personal information were safely stored on a password protected computer and will be disposed of one month after the research is in the public domain. Anything recorded on the Dictaphone was uploaded onto the secure password protected computer and was then deleted off the external device. Everything was done to ensure that no participants would recognize other participants within the research once it is published. The way that this was done was by changing and omitting any features that could make a mother easily identifiable such as names of places they have been to the name of their child etc. The transcripts were edited in this way to maintain anonymity (Bosk, 2002). With complete transparency, I informed mothers that they might be recognisable by other mothers of complex cerebral palsy children once the work is published, and I asked each participant mother to consider whether she was ok with this before signing a consent form (see Appendix 6c for consent form) .

The disabled world is small. By recruiting through anonymous advertisements, I kept a distance between myself and my participants outside the research context. Through reading about ethics of recruiting in small communities the advice was to geographically widen the recruitment to reduce the possibility of meeting a participant in a different context.

Feasibility and Pilot Study

The research had eight participants who were mothers of children with complex cerebral palsy that were interviewed exploring the phenomenon in a way that it can be objectively studied. For my pilot study, my personal therapist interviewed me. As part of the clinical training and course requirements I was in personal therapy. My therapist had not carried out a research of her own so the experience of being interviewed I experienced was as similar as possible to my own participants. I faced my semi-structured interview questions to see for myself how I experienced them. I then interviewed my pilot participant over zoom. This made me both a participant and a researcher in this research. The pilot study was a test drive to see how the interview would be from start to finish. The pilot study also highlighted that perhaps there was scope to increase the upper age limit of the child. This was to put to the ethic panel, was addressed by the ethics panel and subsequently the upper age was increased to age 16.

Through my pilot participant I established that to remain congruent to the Heuristic method I would have to be transparent and reveal that I too had a child with complex cerebral palsy. The pilot participant asked me during the interview if I had a child in this category and when I replied yes, she immediately opened up and a much richer narrative emerged.

The pilot study allowed me to sit and think through any triggering material or blind spots that I took to personal therapy. I anticipated that emotional content would come up for me and this was reflected upon in personal therapy and which I then used as information to further reflect on what it might mean for my participants.

Interview Questions

For this Heuristic Inquiry I used a semi-structured interview so that the participant and I, as researcher, were able to create a shared interpretation of the participants' account of their experience in relation to the research.

It was created using methods described by (Kvale, 2011) and focused upon several interrelated topics that were based upon a list of mental enquiry questions (Kvale & Brinkmann, 2009). These mental enquiry questions were a guide towards the development of the most suitable questions to be asked during the interview (Barriball & While, 1994). The interview was planned in a way that was flexible and allowed the mother to discuss other issues that are important to her about communication with her child (See interview questions). The interview questions also insured that where a mother may have gone off topic she could be gently brought back to the phenomenon through the questions. The questions also supported the mothers interviewed who were quieter and had less to say in order to insure that enough material was generated.

The questions were developed to be open ended, and they were as neutral as possible. The sequence of the questions went from broad to more narrow as I carefully asked about feelings. I was sensitive to not ask leading questions but at the same time I did want my questions to generate relevant material around communication. Not all the questions were used if a mother gave an answer that covered more than one question. The interview questions mainly allowed me to facilitate conversation about communication in a meaningful way (Eder & Fingerson 2001). I used the words, describe and tell me so that I could learn more about the experience. I asked for the participants opinions and values by asking what in way of support would have been helpful within this experience. I asked about the mothers own knowledge and understanding that she has gained or not gained through the experience. I asked questions that generated material from the participants past, present and future (Patterson, 2002). Finally I structured a question that would stimulate a conversation around meaning and what meaning each mother was making of her life with her child that was non-verbal, with complex disabilities and living with a life limiting condition.

Interview Questions

1) Can you tell me about how communication took place between you and your child in the past?

2) Can you tell me about how communication takes place between you and your child at present?

3) Has communication with your child always been easy/natural?

4) Describe what occurs between you and your child when your communicating…

5) In what way do you know you have understood what your child is wanting or asking?

6) Do you feel that there is a difference between your ability to communicate with your child and the ability of other people to communicate with your child?

7) What understanding do you give to the experience of communicating in this way?

8) Is there a feeling of uncertainty that you might not fully understand your child?

9) How do your child’s difficulties with communication make you feel?

10) What kind of support psychological or otherwise would be helpful to you in terms of supporting your non-verbal communication with your child?

Interview Procedure

The interview with the participant mothers was one hour long via a Zoom link that was sent out in advance. At the end of the interview, I requested whether the participant would like to contribute a drawing towards the artefacts data being collected, and these were sent to me via secure email. (Artefacts are images produced as part of the illuminations in the Heuristic process and they add another dimension to the findings that is more experiential than the transcript verbatims (Sultan, 2017).

The Zoom interview’s allowed me to document and read the body language of the participant to build a more cohesive interpretation. Braun and Clarke, (2013), explain the embodied experience of interview allows the researcher to generate findings beyond what is said during the interview. Zoom was used by necessity for this research because of the pandemic and it did allow for many aspects of non-verbal communication to pass between myself the researcher and my participants. I did see expression, and body language however, I had a keen awareness that it is not exactly the same as being in the room with my participant. The research now coming out of pandemic on remote working for psychotherapists seems to indicate that some interpersonal cues are missing and a reduced physical view of the participant where only the top half is visible. There was also findings that indicated an unsettled feeling from just working with technology (McBeath, du Plock, & Bager-Charleson, 2020). On balance when everything was considered the Zoom interview experience is near enough to a face to face interview experience for it to be allowed as a credible research tool. The zoom interview took place in private quiet room with the door closed so nothing was overheard, in the participants home or my own.

The interview using my clinical psychotherapy skills, such as curiosity and active listening allowed each participant mothers to produce their narrative of their relational experiences as the communication evolved with their child. There were moments where silence was used to allow the participant mothers to truly think back or organise their own thoughts and feelings. Great care was taken to insure that the emotions generated by these recollections where acknowledged and that the interview space was an emotionally holding space for the participant. I was able to create a holding space by drawing on my experience of working as a counselling psychotherapist.

I checked in with the participant mothers asking if they were ok and comfortable. I paid attention to when my participant mothers might redirect a question and reflected with the participant why they might have redirected the topic. I asked for clarification to ensure that the participant mothers to ensure I fully understood the responses when necessary. I tried to gage if a mother was holding back in some way and gently probed to see if the participant mother was able to open up more, however I consciously did not push for more if the mother if the mother responded that something was too private, or said it felt too difficult to articulate.

My interview was aimed at facilitated the participant's free speech. I worked hard to consciously not ask any leading questions. I facilitated the natural flow of the participant mothers so that she could talk about what was important to her even if this went off topic. I schooled my own reactions to remain in neutral as I would when working with clients in clinic, so that the participants would not be lead in a particular direction based on my reactions. I encouraged the mothers to talk as openly as possible about their experiences so that the findings would be a true co-creation of the phenomenon based on what the participant mothers authentically brought to the research.

Being the parent of a disabled child is stressful, and their time is limited, so I wanted to ensure each mother felt that I valued her contribution (Pousada et al., 2013). Therefore, I aimed to make the interview a self-reflective experience for the mother, in some way leave each mother feeling her experience has been actively listened too. I took great care to debrief the participant, checking in with the participant that the ending was comfortable.

Myself as the Researcher

Being an Insider:

As a Heuristic Inquiry, the researcher is the mechanism or implement that compiles and explains the data through their own perspective of reality (Etherington, 2004). There are two terms commonly used, which are emic and etic perceptions. The emic perspective gives the insiders‘ perceptions, and enables the researcher to uncover knowledge of why people behave in the way they do. Equally, the etic is the other perspective and this is when the researcher tries to explain what has been studied without the participant group‘s contribution or perspective (Moustakas, 1990). A Heuristic inquiry by definition is an emic perspective whereby as the researcher I have endeavoured to stay as close to the participants explanations of the phenomenon as possible (Sultan, 2017).

Heuristic research acknowledges that the study is executed by a truly involved researcher (Sultan, 2017), significant research permits the researcher‘s beliefs and ideals to enter inherently and intertwined into the methods, interpretations and epistemology (Throne, Bourke, Bowlin, & Yedgarian, 2018). For this research I endeavoured to implement both emic and etic perspectives. I was an insider and part of the group of mothers because I had child with complex cerebral palsy that was non-verbal. At the same time I was an outsider because I had a lot of theoretical knowledge from the literature and professional knowledge as a psychotherapist. However, after conducting the interviews, I sat with my data, my own sensations, psychotherapeutic reflections and the theory to find a harmonious blend of both emic (The emic perspective is being from within the participant group), and etic (The etic perspective is being outside of the participant group).

Being a mother of a child with non-verbal cerebral palsy, I was aware of the challenges confronting women of children with cerebral palsy who cannot communicate independently, which helped me in this research. This insight was highlighted by Moustakas (1990) who observed that descriptions of being familiar and part of the participant group improved gaining acceptance by participants. Dennis (2014), reflects on this idea, implying that the more intrenched one is with a participant group, the more challenges one might have exploring it Heuristically. Sultan (2017) advised using reflexivity to highlight the researchers own participation, raising the issue that it is that the less aware one is as the researcher, the more likely one is to see inherent cultural characteristics but other more nuanced knowledge might be missed. Alternatively, Green (2014), prefers to think of the inside/outsider dichotomy as a continuum than the either or approach.

As a psychotherapist and researcher, I also have a deep desire to give mothers of children with complex cp a voice through the understanding of these mothers in relation to the historical and social context. I was ready to critically appraise and challenge the status quo of the social system and its limitations (Miller, 1978). Acknowledging that because I was born in the UK and I have lived experience of the social, educational system I am well positioned to understand the inequalities faced by this group of mothers in society. The context of who I am impacts on the research I will obviously influence how I approach the research the values I carry innately and unconsciously. My understanding of the landscape and how it shaped me might help mothers and understand their own place in society, they then have the opportunity to question and reflect on this position with the potential to change it.

I developed as the researcher an understanding of the emic perception or the insider view of the participant mothers views in order that I could articulate descriptions of their emotions thoughts and lived experiences, this stance was vital for the study. This way of executing research was new to me as a researcher as I originally had only researched using quantitative methods My past method used statistics and the medical model which gave me a positivistic (positivistic in this context is the belief that everything can be reduced to statistical data), way of thinking and working with participants. Over the course of carrying out the research in order to understand the mothers‘ perspectives, a medical model was insufficient and inappropriate and I therefore adapted my way of being a researcher to deeply connect with the phenomenon I was researching.

Etherington (2004), reflects that being within the participant group will also influence how my participants mothers respond to me a woman who as a child with non-verbal cerebral palsy. The participant mothers might feel judged and hold back. Equally they might feel affinity and be more open. There is no exact way of knowing how me the researcher has influenced the outcomes only that it inevitably will impact on the end result. Phenomenological research is difficult to duplicate because so much of the researcher is within the research (Etherington, 2004). What is important is that I offer the reader my own awareness of my position within the research (Sultan, 2017).

Data Collection

Using a semi-structured phenomenological interview, I collected data from 8 mothers of children with severe and complex cerebral palsy. The interviews were on zoom carried out with one respondent at a time. The method was conversational and invited opportunities to get in depth detail from the participant. The advantage of this method is that it provided the opportunity to gather precise data about what the participant mothers experienced. I asked open-ended questions to enable me to collect meaningful data. When I needed more information, I asked semi-directed follow up questions that helped the participant give me a richer narrative.

I collected demographic data for each participant. I asked them directly for the information which I then input into a table to be used during the analysis (See demographic table in findings chapter).

To decrease the possibility of the participants knowing myself or other participants I looked further afield for participants. All interviews were on zoom which allowed me to pick up on non-verbal cues and body language, my observations were noted and then checked for accuracy by the participant.

Drawings as Artefacts

Part of the data collection is the non-verbal data that were produced by myself and my co-researchers. Badenhorst and Fitzpatrick (2017, p. 3), describe this kind of data as the scholarly gaze on their intimate memories which can occur in data collection whether it be creative writing, self-questioning or reflections on artefacts. Heuristic Inquires encourage the researcher to explore as many data sources as possible. Hughes, Pennington, and Makris (2012), noted the credibility of bring new sources of data moving awa from surveys and tests to allow for a more experiential data collection that could possibly generate more unique findings. Heuristic Inquiry moves away from research norms and explores data collection in a more innovative way (Livesey & Runeson, 2018). Finally having multiple data sources adds to the transparency necessary to carry out a Heuristic Inquiry especially as the focus of the data is on personal narratives and memories (Ngunjiri & Hernandez, 2017).

I explained the purpose of artefacts to my participants that it was to add another dimension to the final findings. I asked each mother to allow the image of tree to freely surface in her mind (Norum, 2008). These trees were produced after the interview as a reflective product of the interview. The participant mothers then had the choice to say a few words to describe what the tree image was illuminating for them. Many of the mothers linked the tree image to the meaning they find as the mothers of their non-verbal complex cerebral palsy child. Photographs were taken of the artwork and the participants' descriptions were recorded and transcribed to form a part of the illumination's. The participants were under no obligation to produce an artefact as it was an organic part of the process that had to feel authentic to the participant.

The importance of artefacts as data in psychotherapy was highlighted in Bachelard's, (1987) work that explores psychoanalysis, and the imagination. The artwork was a visual record interview which captured a feeling of a moment in time. Yin (2018), highlights the importance for producing the same type of physical artefact for each participant. This allows for a comparison of the data collected allowing the researcher to see the similarities and differences. The idea of a tree being the mother can be found across many cultures and mythological stories (Neumann, 2015) as well as in Jung's work on symbolism (Jung, 1960), (Jones, 1986). Finally, it is a nod to Julia Hollanders book on her experience of her daughter's cerebral palsy – *When the bough breaks* (Hollander, 2009).

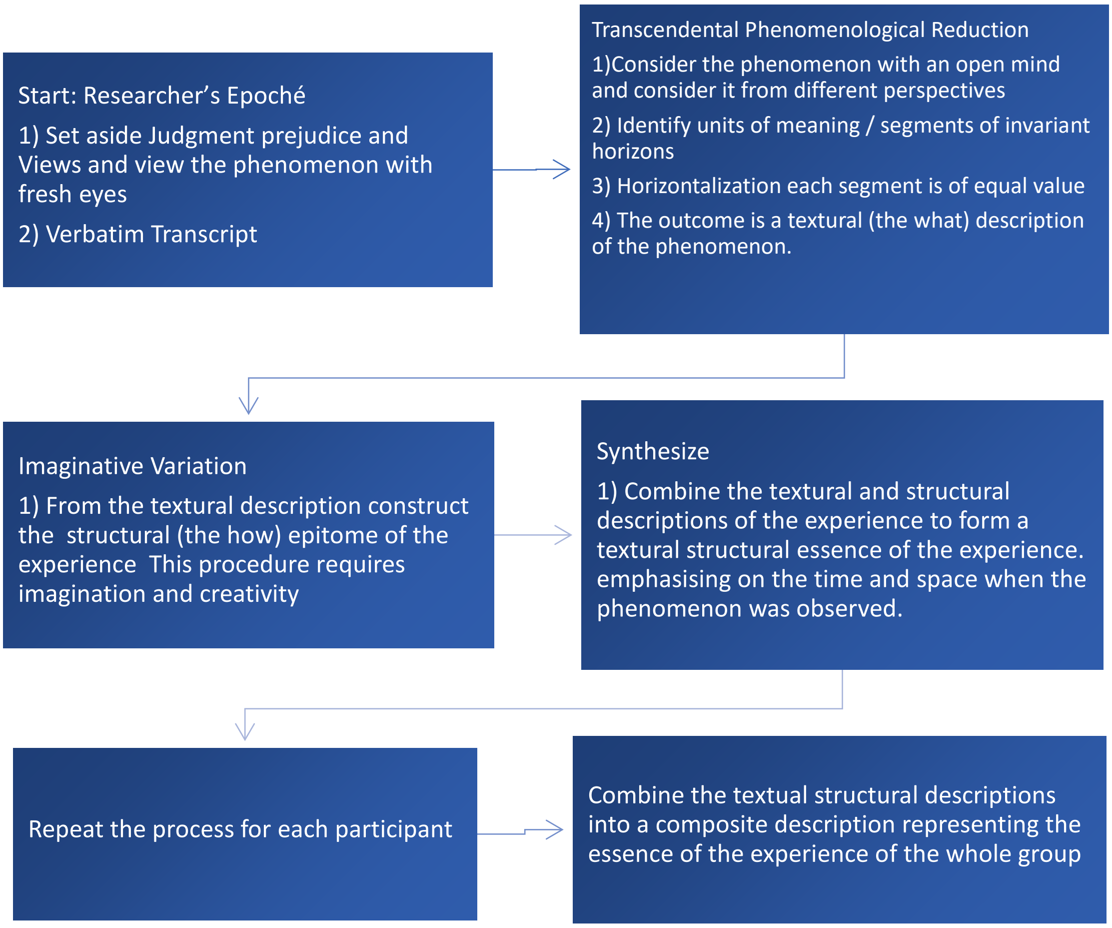
Theme Explication and Data Analysis

Process of Analysis

There are six phases to heuristic research: initial engagement, immersion, incubation, illumination, explication, and creative synthesis (Moustakas, 1990). The first thing I realized during the process of analysis was that there is no one way to conduct a heuristic inquiry within the 6 stages. Unlike other forms of analysis there is little structure of how the internal process goes from inside one's own thoughts on the paper. There had to be an element of surrendering to the process and seeing what emerged. This can only be done through deep self-reflection, self-searching, and a dedication to the work (Sela-Smith, 2002). The heuristic process cannot be rushed or forced in any way, as this letting go allows the emergence of new knowledge of things that were not know before. I usually like structure as it gives me secure boundaries to work in, so this way of working was alien to me. The uncertainty I live with because of my disabled child was paralleled in the uncertainty of this method. There were two other parallel processes going on that began to open the way forwards for me: I sensed the themes with my felt senses - my gut told me what was significant, and I listened to this inner feeling. I also let the transcript speak to me, by reading and re-reading it I began to see things I had not seen before. I would read the transcript each day and then walk away from it. I came back to it the next day - doing this for three weeks before even considering writing up any emergent themes.

I came across Moustakas' framework for analysis, which was a modification of the Stevick-Colaizzi-Keen method of analysis (Moustakas, 1994a), which gives the six-stage process more structure.

Figure 2: Implementing the Modification of Stevick-Colaizzi-Keen (SCK) Method:



Start: Researcher's Epoché

1) Set aside Judgment prejudice and Views and view the phenomenon with fresh eyes

2) Verbatim Transcript

Transcendental Phenomenological Reduction

1)Consider the phenomenon with an open mind and consider it from different perspectives

2) Identify units of meaning / segments of invariant horizons

3) Horizontalization each segment is of equal value

4) The outcome is a textural (the what) description of the phenomenon.

Imaginative Variation

1) From the textural description construct the structural (the how) epitome of the experience This procedure requires imagination and creativity

Synthesize

1) Combine the textural and structural descriptions of the experience to form a textural structural essence of the experience. emphasising on the time and space when the phenomenon was observed.

Repeat the process for each participant

Combine the textual structural descriptions into a composite description representing the essence of the experience of the whole group

(Source: Adapted from Phenomenological Research Methods, by: Moustakas, 1994a, p. 121-122.)

This framework allowed me to work through the verbatims and really think about how I would arrive at the themes. Sela-Smith 2002 comments that Moustakas is a little unclear as to how the researcher travels through the six stages to fully arrive at the synthesis which is the point where the knowledge is transformed. I have worked with the transcripts to clearly show how I arrived at my themes. Rather than include this in the main body of my research I have included it as Appendix 5. This allows the reader to follow with examples the evolution of the themes.

Experiencing the 6 Stages

Stage 1 : Initial Engagement

This is the researcher's first interaction with the topic and inquiry. Moustakas (1990) understood that it is the autobiographical root of the inquiry that creates the energy and passion within the research as the researcher and the enquiry look for clarity, comprehension, and amalgamation. Moustakas directs the would-be researcher to look for a research question ingrained in the researcher's life (Kenny, 2012). Moustakas elaborates on this point, stating that motivation stems from a strong quest to know the phenomenon because of its personal significance and the significance of the personal experience of the researcher. *‘The awakening of such a question comes through an inward clearing and an intentional readiness and determination to discover a fundamental truth regarding the meaning and essence of one's own experience and that of others’* (Moustakas, 2001, p. 265). This personal outlook is crucial to maintaining the researcher's attention during the whole process of inquiry. With the personal significance there is a depth of interest that is unique to Heuristic Inquiry (Moustakas & Douglass, 1985).

At the time of my initial engagement the only other thing occupying my mind was my son’s needs as a disabled child. I thought about how I felt a desire to use what strengths I had to grow my knowledge and the knowledge of people around me. Moustakas’ (1972) discussion of the experience of loneliness really spoke to me because in my world, of being the mother of a child with complex cerebral palsy, I was lonely. I struggled to make people see my world as I was experiencing it so just stopped talking about it at all. As the research question began to formulate in my mind so did my own fear of looking inwards. The very nature of how personal all this was seemed to contradict all the silence I had created around me. It was not a coincidence therefore that I chose to explore the topic of communication. I also thought about my self-care and as I weighted up what I would and would not be happy sharing with the world at large.

Stage 2: Immersion

The experience or question to the researcher to stay fully with the experience of the phenomenon, in whatever form it takes. Moustakas (1990) described the immersion process of stage 2 as it allows the researcher to fully embrace the question – ‘to live it and grow in knowledge and understanding of it’ (Moustakas, 1990, p. 28). This level of intimacy is fundamental to really getting inside the experience. One way immersion transpires is through self-dialog, speaking to the phenomenon, scrutinizing one's own knowledge of the experience and the understanding of the experience as a whole ‘recognizing the place and unity of intellect, emotion, and spirit’ (Moustakas, 1990, p. 16).

For me, this was possibly the easiest part of the stages because I already ate, slept and breathed my communication with my son, and I was already immersed in my son’s world. I realised that I could not research this phenomenon in any other way because it would cause a split within me.

In this stage of immersion, I questioned myself a lot. I did not know why I was delving into an experience that has been painful to live through without making myself live through it again by speaking of it. There was a voice inside me that pushed me forwards: how did I expect my clients to talk about their own pain and fears if I myself was not able to engage with my own pain and fear in an open way?

It was at this stage that I began to see parallels between the way I communicated with my son and the felt sense of my work as a psychologist. I sensed what my clients were not saying about their worlds, and I felt vibrations and resonances between them and myself. I could see that there was some tacit knowledge of what it means to experience something as a human being it is a knowing that lies beyond what is readily observed. My reading went down a path that explored everything from Webbers social constructs of language (Schutz, 1932) to Spiritual dimensions in communication (Clarkson, 2002) to seek out the knowledge that lies beyond my original knowing.

I began to meet other professionals who, little by little added to my thinking, and I would store all these encounters up to go towards my thesis. The books I read for relaxation seemed to bring me back to motherhood and self-discovery. I read biographies of mothers who had children that were non-verbal, and this opened my mind to the experience from another’s perspective, helping me find the language I needed to understand myself. I was struck by the similarities of the experience but also the differences. I wrote things down as I thought them so as not to lose the experience, and sometimes, I drew pencil drawings of things that I just could not put into words. I looked at family videos of how I had interacted with my son over the last nine years. I also read old diary ramblings I had written down about my thoughts and feelings at that time.

Finally, after my PAP-viva, I opened myself up to talking in therapy about my day-to-day life. Through personal therapy I learnt to listen to my body in a Gestalt way - hearing my body telling me it was tired and that I needed to stop working. I tend to fire on all cylinders, but it is an exhausting way of being in the world.

I was also cognisant of the role my son played in all of this, and I found myself squeezing his hand and saying, *We are doing a PhD*. I danced with his chair around the room when I passed my Pap Viva. To think that I laughed at Piaget when I first encountered him because he used his own children as his research (Piaget, 1964). Maybe Piaget knew that studying what is closest to us makes for the best research.

I embraced the philosophy of Victor Frankl:' In some ways suffering ceases to be suffering at the moment it finds a meaning, such as the meaning of a sacrifice', Frankl (1984, p. 117). Frankl found meaning in his suffering, and once I began to find meaning in what I was going through, then I noticed I was no longer suffering (Frankl, 1984). I know that as I pushed my son in his wheelchair wherever he needed to go, he too was pushing me to become a better version of myself. My son gave me hope and encouragement his ability to never give up taught me important lessons I needed to learn.

During this time, I noticed that I was very self-reflective, and I spent time in silent contemplation thinking and processing all. I sometimes felt like I was not tethered to anything and that I was immersed so deeply I might never surface again. The immersion felt like a fully embodied experience with me feeling truly engaged, mind body and soul at one with the research material tuned into it mimicking the dance I had as a mother in my son's early months of life (Merleau-Ponty, 1962). Research supervision became an integral part of grounding me back into reality and not allowing myself to become overwhelmed.

My supervisor also noticed my need to rush things and when reflecting on this point it emerged that I feared running out of time. With sensitive guidance my supervisor encouraged me to slow down and allow the heuristic process to unfold around me, ensuring that my work was not forced, but emerged naturally in a flow that would shape itself rather than me trying to clumsily force the shape.

Supervision was a way to help me see things that I was not noticing, as there was a thrill to seeing what another person was seeing. Many ideas came up that were not previously thought of. There were so many directions to go in and it was hard to know if something was congruent with my felt sense at times. Sitting with the thoughts let them settle, and how to use the emergent findings in a coherent way began to take shape in my mind. One of my favourite pastimes is rummaging at car boot sales searching for a bargain. This immersion stage is not dissimilar, as I rummaged through all my different encounters working out what will be needed to bring all these ideas together. I felt a bit like Bilbo Baggins about to start off with his 13 dwarfs to see what is under the mountain (Tolkien, 2019).

Stage 3 : Incubation

This is understanding the need for the researcher to step away from concentrated and intensive attention on the research to get involved in pursuits that are not related to research. Moustakas and Douglass (1985), imply that tacit knowledge and intuition must be acknowledged - if it is not then the possibility for innovation and understanding is diminished. Put differently, through the incubation stage, the researcher provisionally walks away from the study to prevent compromising the value of the understanding (Sultan, 2017). By waxing (immersion) and waning (incubation) the researcher can start to see what they did not know about the phenomenon (Moustakas, 2001).

For me, this pulling away was necessary because life got in the way of my studies. Because of Covid-19 I was forced to come out of the immersion and concentrate on getting my family through the pandemic. This incubation allowed my brain to process all that it had taken in and let things settle in my mind. It allowed me to work on the implicit level where I could sense the way forwards with my work. I found imagery and ideas would surface in unbidden moments of clarity (Sultan, 2017).

I can’t say that there was a time frame for this stage or that it was consciously planned, rather it happened as a natural cause of events and situational circumstances (Moustakas, 2001), but it was after I had received ethical approval and my pilot interview had been carried out. The result of this moving away allowed for more growth in the work and a deeper understanding. It was also at this point that I fully began to trust in the process and allow it to carry me down the current towards more enlightenment (Polanyi, 1966).

Stage 4 : Illumination

The mental space given to the work by the incubation period often brings about new discoveries and ideas. Reducing the intensity of the investigation by being involved in other activities allows for breakthroughs in the research. These instances of illumination show that the experience conveys a change in insight of the focus of inquiry. The inner frame of reference that had beforehand been in place is often utterly changed. Illumination opens the door to a new awareness, a modification of an old understanding, a synthesis of fragmented knowledge, or an altogether new discovery of something that has been present for some time yet beyond immediate awareness (Moustakas, 1990, p. 30). After stepping away for quite a while bursts of themes would come into my conscious thoughts, nagging at my mind so that I would sit down and type them up. There were two types of illumination: firstly, the kind that came as a slow process of thinking whilst doing the housework or in personal therapy sessions, and secondly, there emerged eureka moments that were exhilarating, with an Ah ha… feeling. One such example of an Ah ha moment was when I thought about the constant need for repetition of laying down the neural pathways by repeatedly doing the same modelling of communication again and again. The image that burst into my psyche was of Sisyphus rolling his stone up the hill day after day after day. The incubation ended when illumination took place, and new ideas found their way into my consciousness again, with the understanding that this process was not and could not be bound by time.

My own creative illuminations also took place during this stage of the process. I too was getting images based on the transcript material and theories I had read. Many images came to my mind during this stage sometimes in the night I began sleeping with a sketchbook by my bed. All these images were included in the findings. One morning with no thoughts or idea about the end result I stared at a blank canvas, I began to splash colour across the canvas and within a few hours I had produced a seascape. I understood in that moment that this seascape was my creative synthesis it had emerged from deep inside me as an explosion of colour and feelings.

Stage 4 was like a deep-sea dive, where I would go into to the data and totally submerge myself in the transcripts. I would then come up for air in the incubation stage and once again dive back in. This part of the process was very time consuming and required periods of deep meditation and silent reflection.

Stage 5: Explication

Explication comprises probing what has come up in the process and coming to an understanding of what meaning it might convey. The process of explication, according to Moustakas, is when bit by bit, through focusing, indwelling, self-searching, and self-disclosure the distinctiveness of each experience becomes apparent (Moustakas & Douglass, 1985). Throughout this process of explication, I began to attend to my awareness's, feelings, thoughts, beliefs, and judgments (Moustakas, 1990) as a preparation to the insight that I would gain from my interviews with the other participants. Analyses for a Heuristic Inquiry can only happen if the start is from one's own experience, the nuances, and elements of the phenomenon can only evolve into the explication if the main source of knowledge comes from the researcher (Moustakas, 1990) (See Appendix 5 for the tables of theme explication). This personal inquiry directs the findings within the experience, exploring the main factors of the phenomenon. Moustakas further explains that the research is not a passive process and it should stimulate self-growth and an inward attention that allows a deep knowledge of something; it incorporates opening the inner mind for critical feelings and thoughts that enable openness to vibrations and observations that direct the way to a clearer notion of what is important. Indwelling is another crucial part that asks the researcher to turn attention inward, to gain understanding in a conscious and deliberate way but not necessarily a logical or linear way.

Through studying my experience of communicating with my son, explication occurred while I deepened my understanding about this type of parenting in my own consciousness. This was brought together by all my previous encounters, experiences with professionals, my daily experiences, and everything I had lived through, seen, and read until now that relates to my research. I created individual depictions for myself and of my pilot participant, containing my understanding of each experience as individual parts. This would all go towards a composite depiction of the experience of communication between a mother and her child with complex cerebral palsy so that a rich and whole picture incorporating all the diversity of the experience might be created. This allowed me to make sense of the sheer volume of the data so that it could be presented in a way that was both true to the experience and valid in its findings.

Stage 6: Creative Synthesis

The many parts of experience and understanding that have come to the fore in the research are connected to create a whole narrative. In this final stage everything that was a part of the other 5 stages come together. I look at the production of this dissertation as the culmination of all the work that has gone into the Heuristic Inquiry. The completed thesis is, and will be, the creative synthesis. I produced a large piece of artwork that acts as another dimension to the creative synthesis alongside my written work.

Although the six stages of Heuristic Inquiry take place, they do not necessarily take place in a chronological order (West, 2005). There is a movement between the stages that is required as ideas and themes emerge. I soon realized that each stage must be fully experienced for it to serve its function there are no short cuts for this method. Within the 6 stages some structure began to emerge as I engaged with each of the stages. For the first time in my life, I had to ignore deadlines and go with the flow of the work as authentically and as uncompromisingly as possible. The contradiction of feeling like I was freefalling, versus the reliability of the heuristic cycle I needed to go through to find what I was searching for.

Theme explication the process:

This is an expansion of stage 5 explaining in detail how the themes came into being. Once the interview was carried out (for each participant), I listened to the interview again the next day. This allowed me to keep in mind the participant's experience. The narrative of the participant was unique to her, and I felt her experience in the words she used and facial expressions she had made to go with those words. I then transcribed the interview within twenty-four hours of having interviewed the participant whilst I still had all the details fresh in my mind. The transcript became so much more than just the text, and I noted my own personal experience and how I processed all the material (Braun & Clarke, 2013).

Whilst transcribing, I thought of the transcript and interview in the following ways. Kinaesthetically - was the participant sweating, was I sweating, was my heartrate increased? Cognitively - why was that word used or oh, I recognize that sentence from another interview? Emotionally - how is my participant feeling, do they look happy or sad, how am I feeling, do I feel happy or sad? Socially - relationally, how was I experiencing my participant, how might my participant experience me? In the pilot study I knew the moment that my participant realized I was the mother of a disabled child myself. Perceptually - thinking about my own subjective and objective knowledge of the phenomenon and then thinking about the participants experience. Spiritually - thinking about that which cannot be put into words so easily and honouring the possibility of things I cannot examine under a microscope. Accepting the unexplainable.

I began the cycle of immersion and incubation from the point of interview with no clear cut off date for this part of the process. I would withdraw from the data, let my mind process the transcript and then I would return to the data a few days later. This return to the work produced new insights and with each repetition of this cycle the depth of my knowledge of the experience deepened.

My own participation took place with me being interviewed by a friend. It was a conscious choice to select someone who had never interviewed before. This allowed me to experience the interview as closely as possible to my pilot participant. I was nervous and a bit guarded at first. As the pilot interview unfolded, I was struck at how similar yet different the two experiences of the same phenomenon were. I noticed that I could access my feelings more easily because I had been building up and preparing myself from the conception of this dissertation until this point. My participant was more closed off and did not have the same effusiveness, possibly as a protection for herself against feeling the trauma of having a disabled child that can’t communicate verbally. I had the advantage of having processed more of the experience because of my extensive reading on the subject and personal therapy.

Walking across to the side of researcher was a huge step out into the world for me. For until now, I had resided solely with my own experience of having a complex care child who had nearly no physical functions. I was eager to meet with other mothers and see what life was like for them. There was a fear that I might not find enough participants because of the stress that the covid-19 pandemic was putting on people’s care packages of support. I also thought about how difficult it is to speak about this journey I had struggled for years to really talk, but at this stage I had a pilot participant and that was currently enough.

At this juncture, I began to document my own reflections and reactions to the participants I was interviewing. I wanted to look out for my own biases, influences and judgments that I experienced as I interviewed, and I would fully disclose this in the findings. The realization that I was learning new things about this phenomenon kept my mind open to all possibilities.

I openly showed my reaction to my pilot participant disclosing her disabled child was one of triplets. I had not thought of multiple births, and this was an interesting difference to bring to my knowledge of the phenomenon, making me question my own experience and delve deeper into my own personal exploration.

Showing The 6 Stages Using Examples from the Transcripts:

Below I show worked examples of how I approached the transcripts to arrive at my themes using the Heuristic stages that are difficult to conceptualise from reading Moustakas account of how this method is implemented. By making the theme explication tangible and showing the process I hoped to add to the validity credibility and trustworthiness of the findings.

Stage 1 : Initial Engagement

Provide a comprehensive description of your experience of the phenomenon.

During this stage, I read through the transcripts and sat with the text and questioned whether the interview statement related to the phenomenon. I highlighted any statements of significance and made amendments if I changed my mind about whether a statement truly described the phenomenon. For example, this is an extract from Transcript 1, showing the statements that were considered significant in red:

Transcript 1: Step A

So it's a very difficult one because I don't fully comprehend how	1.
Y and I communicate. It feels like there is some telepathic	2.
Channel that is open between us and something that goes on in	3.
Our minds together that isn't easy to explain for instance a	4.
Nurse will be caring for Y and she will turn to me as I walk in the	5.
Room and say oh good someone called you, Y isn't doing well	6.
No, no one called me Y called me I could just feel he needed me	7.
And I walk into the room in the moment that a seizure starts or	8.
A temperature is spiking. I just know I have a sixth sense, when	9.
Y needs me and that is very very strong and I cannot explain it	10.

Some statements were quite easy to highlight as significant or not, others less so. At this point in the process, I erred on the side of caution and marked statements as relevant when in doubt. Once again, I went back to the recordings several times to sense and reflect on non-verbal aspects of the interview, especially where a transcript was unclear.

Sage 2: Immersion

From the interview data provide a list of significant statements of interviewees' experiences.

Stage 2 was a natural transition from stage 1 and required listing statements in the transcript with codes for line and transcript numbers. This stage needed an evaluation of when and where to split statements, since statements were often linked to each other and direct context. For this reason, I kept chunks of transcript together for the individual depictions of each mother's experience so that I could keep the context and meaning clear.

Transcript 1: Stage 2

1) **I talked to her, but it felt very strange and difficult because obviously we just didn't know what was going on (JINTY 2-5).**

2) **That's how it was for quite while she started to respond a little (JINTY 9-10).**

Relevant Statements 1 and 2 in the above example from the transcript were taken too much out of context and I had to return to the original transcript to reconnect them with their context and meaning. I revised this to a) include surrounding statements, and b) not break down meaning statements into basic parts until a later stage of the analysis.

The following extract provides an example of this.

'On day the day Emma was born she collapsed and was sent to be cooled, I talked to her, but it felt very strange and difficult because obviously we just didn't know what was going on' (JINTY, 2-5). Jinty describes her confusion but is almost blissfully unaware of the implications of what has happened. '**The neo-natal team were brilliant, they encouraged us to talk to Emma, to gently touch her and stroke her so that she could know she was loved. That's how it was for quite while she started to respond a little' (JINTY, 9-10).**

Text not in bold is my voice as researcher, and my reflective thoughts are in italics where I explore feelings or emotions; the pseudonym in brackets followed by beginning of the line with a number of the transcript, with the numbers following that being the line numbers. These were kept throughout the analysis to allow a transparent reference process back to the original document.

Stage 3 Incubation:

Group the significant statements into larger units of information (i.e. themes or meanings).

This part of the analysis followed on from Stage 2 where each statement was looked at in conjunction with related statements in order to consider whether there was repetition. An example from MANDY of this process is shown below.

Happen. But the first time we knew she understood instructions really		1.
They she started going to hydrotherapy very early on so like baby		2.

A few lines later this statement seems to be repeated.

Water em and that's when we kind of the first time we sort of realized	Judy more relaxed now	1.
She was you know actively understanding what was going on around		2.

Stage 4 Illumination:

Generate textural depictions or descriptions of what research participants experienced.

To start this process, I printed out all the transcripts and highlighted the emergent themes in different colours. I then stuck post-it notes next to each theme on every transcript and I began to tentatively see if a theme was emerging or not. At this stage, a crude clustering took shape where I had key words grouped together. This stage felt a bit disjointed, and a bit disconnected from the phenomenon. It was important therefore to go back into the immersion stage and remember why statements were significant from a more somatic experience of the text. Sometimes, one statement connected into more than one theme and was therefore put into more than one cluster.

An example is provided here that shows how the statements from Transcript 7 linked to two themes, 'Trauma' and ' Communicating for your Child '.

Transcript 7:

Trauma - Trauma is an underlying theme throughout the transcript, although it didn’t relate to the direct communication between mother and child as a theme on its own.

> **Tracy: ‘That trauma is constantly building trauma upon trauma it just stays and it never leaves.’ (TRACY, 564)**

Communicating for your Child – ultimately, if the mother cannot communicate her child’s medical needs, then the child might die. This communication on behalf of the child became the theme that emerged and where this statement was ultimately best used to describe the phenomenon.

> **Tracy: ‘That trauma is constantly building trauma upon trauma it just stays and it never leaves.’ (TRACY, 564)**

Stage 5 Explication:

Generate structural descriptions or depictions of how the experience happened.

This stage was a contemplative process rather than the deep immersion of stage 4. At this step it was necessary to go back to the original transcripts to check the context to make sure that the description was accurate.

The example detailed above becomes:

Transcript 7: Stage 5

Communicating for your Child.

Sometimes, Tracy had to communicate for her child, especially for medical support. Tracy describes the trauma of her child being unable to communicate what exactly is wrong with him. It seems that when the child with cerebral palsy most needs to communicate because he or she is ill the ability to communicate shuts down.

> **Tracy: ‘That trauma is constantly building trauma upon trauma it just stays and it never leaves.’ (TRACY. 564)**

This helplessness around the communication created its own trauma.

Stage 6:

Generate a composite of the phenomenon integrating structural and textural descriptions.

Part 1) Composite phenomenon.

At this stage pulled together all the pieces of emerging knowledge to create one whole composite finding to be encapsulated within the emerging main theme. It was interesting to reflect on how the transcripts sometimes expressed my reflections and where the participant being interviewed was then able to communicate more description. This part of the process drew together many aspects of the previous stages and required a huge amount of introspection, where new knowledge and tacit knowing merged into a more consolidated depiction of the lived experience. Tacit knowledge (also known as implicit knowledge) was the knowledge I had gained through personal experiences of myself parenting a child with complex cerebral palsy who is non-verbal . My knowledge of the phenomenon is subjective to me and although I have the wisdom of 11 years' experience I only know my own experience I also have gained knowledge through reading extensively on the topic of cerebral palsy. Through the interviews I was able to learn more about other mother's experience of mothering a non-verbal child with complex cerebral palsy and their wisdom and knowledge of the phenomenon. It is not always easy to convey tacit knowledge or put it into words, my tacit knowledge became useful and valuable to others because I have shared it through my reflections. By documenting my knowledge of my experience of non-verbal communication both experiential and theoretical, concretely, within this research I allowed my participant mothers to share their tacit knowledge with ease.

It was in this phase that smaller findings were grouped together to form a larger finding. This is shown in the example below:

Time to communicate.

Time spent develops communication.

Time wasted waiting for help with communication.

Not enough time for everything.

Becomes simply, Time to Communicate, and incorporates all the other aspects related to time taken up by this type of communication.

Part 2) Integrating structural and textural descriptions.

This final integration of the transcript into findings was the was the product of all the previous stages. During this process I went back and forth between my analysis and the verbatim transcripts to guarantee as much as I could that I was not imposing something onto the narrative that was not depicted by the research participant. For this reason, I stayed with the verbatim quotes where possible. This step was also done in three parts, the first was to integrate the reflection in italics into the individual descriptions as shown here, the second was to draw any imagery that manifested in my mind and the third was to reflect on the whole experience and present the themes together.

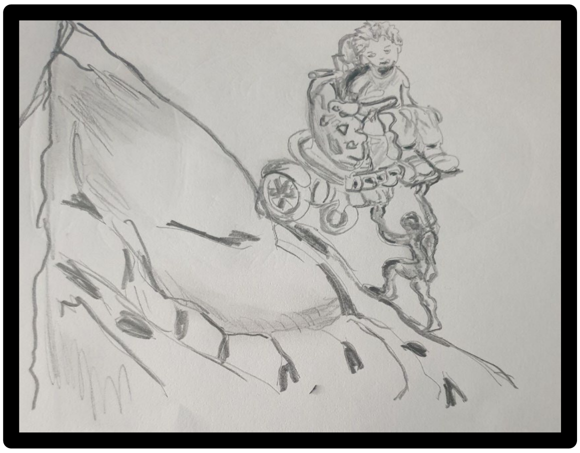
The Relentlessness of this Communication

The work towards establishing communication is never-ending and each day the same thing is repeated as the day before. Jackie describes the daily grind and the challenges of all the skills she must acquire.

Jackie: 'It's not just the using of the Eye-gaze its learning how to edit it how to program it and then you have the board-maker, It's very complicated I learn how to use it and then I don't recall what I learnt the next day. I can learn but I can't retain it I have to keep practicing it.' (JACKIE, 317-320)

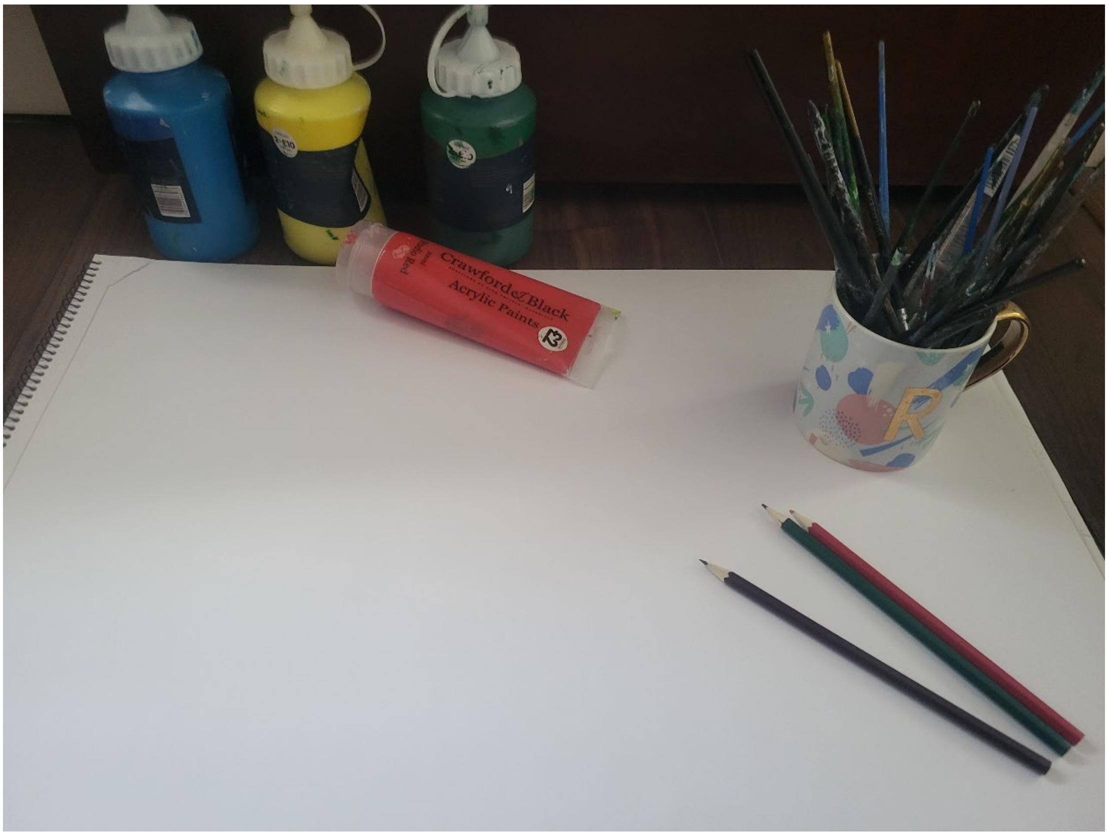
I am struck by the procedure to communicate; it is an endless ritual that seems to need so much effort. The mother is investing so much time and energy in a bid to offer her child some freedom from inside the child's own mind. Suddenly, a strong image of the cursed Sisyphus in Greek mythology, doomed to forever roll a huge boulder up the hill only for it to roll straight back down again. It is not the first time in my reflections that I see this image:

Image 13



Stage 6 Creative Synthesis

The process of painting drawing and transforming the knowledge of the narrative:



Honouring the Context and Content

For the first step towards analysing the data I had to establish what I was looking for. I know I am looking for meanings, and my focus for the analysis of the data was to see what emerged within the dialogue and transcripts. I was not necessarily looking for how frequently certain phrases were used amongst the transcripts, however, if a particular phrase or theme kept re-emerging then, of course, this would be noted as significant. I focused on trying to understand, with the vision of co-creating new knowledge going from the individual to the collective, keeping myself focused on the content and context. I reflected on the following:

My own responses produced by my research questions and my reactions generated through theoretical material; my feelings from day-to-day encounters related to my research and how they might influence the research; the connection between literature I was reading or things I had seen in passing that might become symbolic of something I was trying to express in the research; phrases I heard in passing conversations or in university lectures; imagery I was exposed to through artwork online or in books; dreams I might be having and drawings I was doing in this time; I reflected on my participants' reactions, as well, as I interviewed them, and noticed changes in their demeanour and posture as they spoke during the interview.

I also noted how I was intra-personally, with myself to myself and interpersonally with myself and others. I noted how my participants described themselves, and themselves with others. I noted how I was situated in the sociocultural context and my being in the world. I noted how my participants were being in the world.

Deciphering Potential Themes

I started by looking at the transcripts holistically. I did not look at exact words or phrases, and I deliberately did not go fishing for patterns. To do so would have run the risk of seeing patterns where none existed. Staying away from the details for the first step of analysis allowed the overarching themes to emerge within the content and context as well as at the point where content meets context.

It is at this point that maintaining my self-discipline took on great importance. Within the cycle of the six stages I remained in incubation for too long, then I noticed I would lose my illuminations. Illuminations do not happen automatically as they are part of the active engagement with the material. However, if I felt I was too immersed and was not seeing the wood for the trees I knew it was time to go back into incubation (Moustakas & Douglass, 1985). I was aware that I did not want to lose the momentum of my work with this switch between immersion and incubation, and at times it was hard and my brain got tired. I used guided meditation to clear my mind and totally be at one with nothingness so that I could come at the data again with a fresh perspective.

I found at this stage the use of a table helped me structure my preliminary findings, where some of the more prominent ideas jumped out at me.

Table 4. of Preliminary Theme Identification

Words	**Phrases**	**Feelings words**	**Symbols**	**Non-verbal**	**Implicit/Tacit Meaning Themes**	**Unanticipated Themes.**
Intuition	Mothers just know	Scared		Tearful	Medical words	Multiple births
Loneliness	Getting out	Frustrated		Silence	Disability	
Responsibility	Many appointments	Tired	Break down	Crying	Eye contact	Mothers as researchers
Helplessness	Doing it indefinitely without help	Anger	Work of 10 people	Raised voice	Speech therapy	Grief cycle of loss
Struggle	Everything is a fight	Stuck Difficult Hard	book is a voice	Agitation	Normal milestones	Sense of fulfilment
Lost	Many parents feel lost	Anxiety	Burnout	Chin tilted upwards		
Happiness	She is happy	Good enough		Laughter smiles		Hope for the future.

I felt I needed a bit more structure to really pin down my thoughts and intuitions. I caught myself thinking about my statistical analysis days and realizing that for many this process would not be considered scientific enough. I held onto Moustakas' belief that the lived experience through tacit knowledge and intuition can offer far deeper insights (Moustakas, 2001). The six stages of heuristic process carried on throughout the data analysis provided me with an internal method of analysis.

Horizontalization: the analysis started when I, as researcher, became the participant and participated in an interview to share my own experience of the phenomenon of communication between myself and my non-verbal son. Each participant was subjected to the same procedure as me. The analysis continued by horizontalizing the data. Horizontalizing is the method of documenting each phrase, sentence and statement in a transcript which illustrates an individual idea relating to the phenomenon. Each assertion was at first given as having the same value, and all phrases were documented. Any overlapping or repeated statements and non-word utterances were deleted, leaving only the statements that have an aspect of the experience that is essential for deciphering it. The imaginative variances were then clustered and named as the central themes of the experience. The imaginative variation is the process of seeking to find meaning using varying frames of reference, approaching the phenomenon from different angles and different ways of seeing it (Moustakas, 1994b). The imaginative variants and associated themes were verified against the full transcript of my pilot participant. This process ensured that the imaginative variants and themes were clearly spoken in the transcripts, or that they were consistent with the data if not clearly articulated. If they were not clear or congruent, they were removed.

Textural Description: The leftover imaginative variants and themes were used to build a textural description of the experience of communication between each mother and her non-verbal disabled child for each participant. These narratives recounted each participant's sensory experience and portrayed clear understanding of what occurred throughout the events being conveyed. The participant's explanations are documented using their own words and way(s) of speaking. Moustakas (1994b) describes the essence of the textural description as follows:

‘Throughout there is an interweaving of person, conscious experience, and phenomenon. In this process of explicating the phenomenon, qualities are recognized and described; every perception is granted equal value, nonrepetitive constituents of the experience are linked thematically, and a full description is described (p. 96)’.

This part of the phenomenological reduction helped me create a unique and clear image of each participant’s self-reflection, self-awareness, and self-knowledge of the experience.

Structural Description: Through my use of reflexivity, a structural description for each participant was formulated. Utilizing the textural description as the base, the explanation offered about the core of the experience. The structural description tried to account for how the feelings and thoughts of the experience of non-verbal communication between mother and child connected to the experience. The interpretation depended on my capability as researcher to move away from science, reasoning, and rationality, to take on a reflective view where anything is feasible (Moustakas, 1994b).

Illustrating the essence of a phenomenon is the biggest task of synthesizing the data. Moustakas clarifies:

‘The aim is to reach the structural descriptions of an experience, the causal and leading to factors that give reasons for what is being experienced; the how that speaks to circumstances that explain the what of experience. How did the experience of the phenomenon come to be what it is’ (Moustakas, 1994b, p. 15).

Through reflexivity, I established an increased and greater version of the textural description, looking for all possible implications and opposite viewpoints. This process consisted of immersion into the transcripts, shifting forwards and back from a position of creativity to verification. A reflective space was also needed to let the ideas settle the fit with the structures within the participant data. This space for reflection was a core part of the process for me and the point at which a lot of drawing was generated.

Textural-Structural Description: A textural-structural description of the meanings and essence of the experience was constructed for each participant. This stage in the analysis needed an amalgamation of the Textural and Imaginative variations, which presented a merge of the understanding and core of the experience (Moustakas, 1994a). This synthesis included the

Imaginative Variation that emerged as main themes. The aim was to combine the conscious experiences and insights of the pilot participant with my main explanations to create a synthesized picture of the experience. Throughout this process I continued to maintain both my immersion and self-reflection to bring out the deeper meaning and spirit of the phenomenon for my pilot participant.

Composite Textural-Structural Description: The last stage in this process was to create one composite structural description that incorporated all the participants from the textural-structural descriptions of each participant's experience of her communication between herself and her non-verbal child with cerebral palsy. This composite departed from the specific elements of the experience described by the participants and focused on those parts of the experience that were trans-situational i.e. beyond the personal individual differences demonstrating the core or essence of the experience. Showing the aspects of the phenomenon that were universal to all the participant mothers or an explanation of the experience overall (Schwartz, 1994). The explanations of the experience were taken from the participants' interviews and the psychological significance was applied by me to form overarching theme for the experience (Moustakas, 1994b). This integration of experiences was formed into a thematic structure recounting the essence of the phenomenon. It was created as the product of my immersion into the many readings of the transcribed interview, conceptualizing and reflecting on the participant's experiences, and checking up on my ideas against the transcripts.

Researcher Reflexivity

One of the key components of a Heuristic Inquiry is the reflexivity of the researcher. This process requires a huge amount of introspection and authenticity. To do this part of the process and fully engage myself I worked in a structured way journaling or drawing after I interviewed to document everything I was experiencing. Sultan (2017), advises the researcher to think about the following:

My initial reactions to the Interviews

I spent a few minutes after each interview writing up my first thoughts and feelings. This became a compass for me to deeply reflect on and process the material.

I thought about the following - my feelings of yes! I get that or no, this isn't me at all, which helped me separate myself and connect myself to my participants' experiences. An example of this was my reaction to my pilot participant getting divorced, and for me the shared experience of raising my son had brought us closer as a couple so it was interesting to note the participant's experience of there just being no time for the relationship.

I reflected on what emotions the interview had brought up for me. I felt intense emotions and I documented them as they told me something about the significance of the interview. I sat and worked through whether the emotional reaction was mine alone or was it my participant trying to convey her own feelings to me without words (Clarkson, 2002).

Did the interview give me clarity on any of my own experiences? I felt there were moments during the interview that the participant would say something and suddenly an image would be conjured up for me and I would know something more about myself and my experience than I had done before. An example was when my participant said emphatically, *'I was doing the work of ten people'*, and suddenly I understood better the chronic tiredness that dogged my every waking moment of those early years.

Finally, I sat with my creative brain, and I visualised imagery of what my mind was seeing based on the narrative of the interviews. I could almost see the world through the eyes of my participant, the limitations the participant described as they attempt to get three babies out of the house.

In this way I was able to produce a lot of reflective material as I worked through each transcript and interview. I ensured that I was bringing enough of my own subjectivity to the work in the way that Moustakas (1990), envisioned so that this inquiry retained my authentic voice.

Credibility, Trustworthiness, Reliability and Validity

Using a heuristic method, by its very nature, makes an identical replication of this study impossible. The trustworthiness is the researcher's commitment to conveying the participants interpretation of their own experience. The reliability is the researcher sharing reflexivity without marginalising the participants, and the validity is the researcher surrendering fully to the process of the Heuristic Inquiry (Moustakas, 2001).

The validity of a phenomenological study depends on whether the reader can have trust that the results are well-supported and well-validated (Polkinghorne, 1989). The validity also depends upon the ability of the researcher to satisfy the reader that the results are truthful (Polkinghorne, 1989). The steps, from data collection to data analysis and synthesis, have followed a logical thought process and have to be shown as being carried out authentically, and that can be tracked back through the findings to be legitimate. Polkinghorne (1989) asked five questions that I asked myself to measure the trustworthiness of my research:

1. Did the interviewer influence the contents of the subjects' descriptions in such a way that the descriptions do not truly reflect the subjects' actual experience?

2. Is the transcription accurate, and does it convey the meaning of the oral presentation in the interview?

3. In the analysis of the transcriptions, were there conclusions other than those offered by the researcher that could have been derived? Has the researcher identified these alternatives?

4. Is it possible to go from the general structure description to the Transcriptions and account for the specific contents and connections in the original examples of the experience?

5. Is the structural description situation-specific, or does it hold in general for the experience in other situations?

The validity of the interview process relied on me to be able to epoché from my own experience, to allow the participant to express their own experience uninfluenced by me (Moustakas, 1994b). I made sure to remain aware of my assumptions, to set them aside so they did not bias participants meanings. I regularly checked in with myself to up-hold remaining epochéd, as it affected to the integrity of the research. I went through the process of inner reflection and reflexivity before starting each interview to try notice my prejudices, biases, and assumptions.

To support this, all interview questions were formulated before the interviews and checked by the project proposal panel. This reduced the possibility of any biases at the early stages that might influence the later analysis stages. However, the Heuristic Inquiry is transparent about my own position within this phenomena that must surely come to the surface as it is not possible to utterly epoché (West, 2005). Rather than suppress my inherent reactions and feelings towards the material as it was unfolding, I took the approach to openly include my initial reactions and did not sensor the emotions or thoughts it brought up for me (West, 2005). Part of the methodological process, therefore, was for me to engage in open honest awareness of what I was experiencing in relation to my research (West, 2009).

To further increase the validity of this research I used my supervision time to check and re-check my emergent themes. My supervisor was able to be objective and challenge me to offer concrete data for any interpretations or conclusions.

Because the objective of a qualitative investigation is to produce rich descriptive data from the participant's worldview, thinking about validity is crucial. The cyclical nature of the research process gave me different ways to view the same experience. These measures were implemented to increase validity as a part of my process of answerability in delivering a reliable, transferable, trustworthy, and verifiable dissertation.

Transforming the raw data into phenomenological statements and explanations was also a threat to the trustworthiness of this heuristic exploration. This change from horizontalized statements to significant statements needed to start with a one-sided interpretation on my part. I constructed the textural and composite descriptions, I then verified the interpretations, and I depended on my experiences while immersed in the work, ensured the compilation of enough data, and adequately immersing myself in the data. As well as the maintaining of the standard of thoroughness in the processes, I carried out participant transcript checks and provided detailed descriptions from the transcripts to make sure that the whole experience of each participant was seen in its authentic context.

A realization set in that I cannot separate the mother from the therapist, nor the artist, as these are all things that I am. My inner world and my outer world inform each other. I worry about doing justice to this phenomenon because language is limited yet I owe it to myself and my participants to try and use my researcher identity to at least try.

I therefore choose to centre myself through the work of Victor Frankl, and I reflect on his message Don’t aim at success. The more you aim at it and make it a target, the more you are going to miss it. For success, like happiness, cannot be pursued; it must ensue, and it only does so as the unintended side effect of one’s personal dedication to a cause greater (Frankl, 1984). I would like to see my work published in academic journals; I would also like to advocate more for mothers experiencing the devastation that is complex cerebral palsy. I hope that working through my experience will bring me to a deeper understanding of the phenomenon to give me more compassion as a counselling psychotherapist. Going through this process of research is a valid achievement and if the acknowledgement of the world ensues as an unintended side effect, then I will have found my personal how to the why, (Frankl, 1984).

Conclusion

In conclusion, this research enabled the participants’ authentic experiences to be heard, as this group of mothers who are full time carers, are often hidden from sight, their work unseen, and left behind closed doors. I chose to disclose to my participants that I have a child like theirs (West, 2005), this was in-order to be completely authentic with the participants and truly view them as co-researcher’s alongside of me (Sela-Smith, 2002). Having an external supervisor was so important and enhanced the validity of the findings as the supervisor could explore the material from a different perspective to my own. The benefits of working in this way (as a Heuristic Inquiry) provided entrée to narratives which an outsider would take a lengthier time to arrive at and may never reach or even think to research (Moustakas, 2001).

Chapter 4 Individual Depictions

#A person's ability to communicate is not dependent on their being able to Master certain skills, it is dependent on our ability to listen and communicate responsively.'

(Jo Grace, The Sensory Project)

Introduction to the Individual Depictions

The purpose of this research was to explore the experience of communication between mothers and their non-verbal complex cerebral palsy child. Throughout the analysis I assumed a reflective understanding of the text, and visited the text afresh to obtain a deeper and more meaningful interpretation (Sultan, 2018). Within the individual depictions is my own depiction as well, I have included my transcript into the findings, again allowing myself to be both participant and researcher. The individual depictions clearly bring to the forefront the individual voice of each participant. These depictions show the differences between each mothers personal confrontation of her existence when faced with the existential transition into motherhood (Arnold-Baker, 2021). In addition it maps the mothers mental transition into the world of complex care and living with a child that is not developing the physical milestones as expected.

Participant Artefacts:

Each participant was asked to submit a depiction of a tree this was not part of the interview, not all the participants wanted to contribute. This was a conceptual idea to generate another layer of data beyond words symbolic of non-verbal communication. Therefore there was deliberately no interpretation offered of the images as the images are open to the viewer's own interpretation to reflect the participant mothers work as interpreter for her child. Artefacts were not just produced by the participants for this research but were also produced by myself, the researcher. Although an artefact can be anything from a poem to a photograph, for my research the artefacts were drawings and paintings as this is what the mothers felt comfortable contributing.

Demographic Data

Demographic data was taken from the mothers as part of the debrief, to place the research in a particular context. This data shows that the mothers who participated came from a diverse population, however, the participant mothers were homogenous in that every child had a diagnosis of cerebral palsy acquired through a hypoxic Ischemic Encephalopathy injury at or around birth. The age range of the mothers clearly showed that this too was homogeneous within a 10 year age range. The participant mothers did differ regarding whether they worked or were caring for their child full time. Of if the mothers had a higher education. Over half the children are being home schooled this is an important observation on social provisions for children in this category. Being home schooled or going to school did not change the essence of the experience for the mothers. The children were between age 4 and 14.

Reflecting on the demographics the mother's that were drawn to participate in the study had higher educations, but were from a broad range cultural backgrounds. This felt important to comment on as it was evident in the findings that the essence of the phenomenon was present even with the diversity of social-economic backgrounds. The phenomenon seemed to transcended the individual differences.

Table 5: Relevant Demographics

Mother and Child Pseudonym	**Mother's Age**	**Child's Age**	**Schooling Status**
Judy & Mel	40	9	Home schooling
Bunty& Howard	41	14	Home schooling
Sandie & Jason	45	8	Goes to school
Mandy & Gary	38	9	Home schooling
Jackie & Victoria	41	4	Nursery

Tammy & Robbie	46	14	Part time schooling
Jinty & Emma	42	5	Schooled
Tracy & Mark	47	12	Home schooling

My Ontological Stance

There was a me before my son was born, a person with a strong identity and a determination to survive whatever life threw at me. The day my son was born I lost my identity I lost myself. I became the mother of a complex care child, often referred to as a mum in the hospital. I became an expert carer and a prisoner in more ways than one to my situation, bound by a child that could not tolerate going out, bound by the love I had for this child. Motherhood has its ups and downs whatever child you give birth to, nothing prepares you for the world you are thrust into when your child's brain has sustained an injury that leaves them without all their physical functions. My experience of having a child with complex cerebral palsy has shaped the person I have become. Mothering in this way has altered the way I see life and experience my life it has had a huge impact on me. At the same time I am also an objective outsider approaching the transcripts and individual depictions as an existential counselling psychologist. I have the training that enabled me to listen and hold the transcript material outside of my own experience.

In the participant interviews verbatim text is in bold, and my reactions and reflections of the participants transcripts are in italics. I sometimes shorten Cerebral Palsy to cerebral palsy, and I use the term non-verbal child as an abbreviation to complex cerebral palsy non-verbal child. I include myself in the term participants unless I state otherwise and my transcript is mixed amongst the findings of the other participant mothers.

Individual Depictions

Whilst the transcripts showed similarities within the mothers communication of a non-verbal complex cerebral palsy child experience of participants, each mother came with their own distinctive experience of the process of communication. Each mother had their own awareness of this non-verbal communication that is taking place between herself and her child. The following 'first-person' descriptions of each participant mother aims to give an insight of their phenomenological experience of living with their child from the initial engagement at birth to the present. Focusing on each individual mothers personal meaning of the experience. The individual depictions are therefore ontic in their attempt to capture the 'what it is like' individually for each mother. Following these accounts their processes of the experience which showed that the process of communication started at birth and was worked on throughout the mother child relationship. How the mother finds meaning for the experience evolved and changed as developmental milestones were or were not reached. For each mother, the principle remained the same in each transcript, the desire for mother and child to know and understand each other. Pseudonyms are used throughout for the protection of participants' confidentiality.

Being the Mother of a Non-verbal Child with Complex Cerebral Palsy.

The interviews revealed similarities within the experience of participants *being the mother of a non-verbal complex cerebral palsy*. However, each individual participant came with their own unique experience of the communication between themselves and their child, and their own perception of their experiences with complex cerebral palsy. Writing in the 'first-person', using only phrases from the interview transcript, a description of each participant aimed to give a synopsis of their phenomenological experience of the initial engagement of communication between mother and child, and ultimately how the mother finds meaning within the experience. These synopses are therefore ontic in their effort to portray the 'what it is like' of personal experience. The findings then go into deeper analysis to arrive at a set of themes as part of the findings. As mentioned in the ethics section in chapter 3 pseudonyms have been used to protect the identity of the participants.

Being Mandy

Initial Engagement:

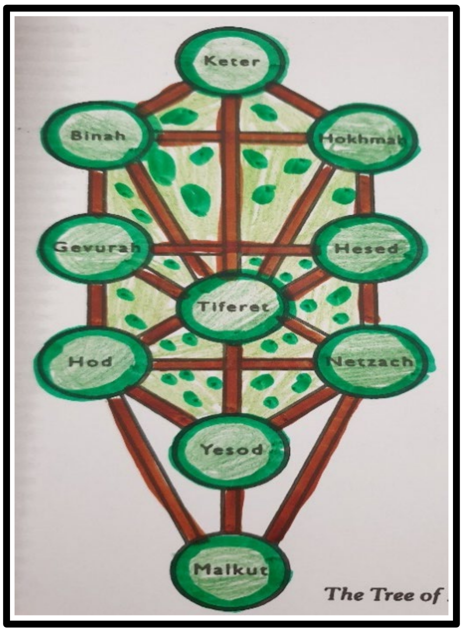
For Mandy, the first time she tried to meet her baby and connect with her new-born it was clear to her that there were many physical barriers impeding the communication. Mandy says that this is because this was not her first baby and she immediately understood that something was wrong. Mandy has had to travel from the hospital she gave birth into the specialist hospital, and did not see her baby in the labour room.

'The very first time I saw Gary he was surrounded by machinery he had a tube in his mouth that was breathing for him he was grey and still lying there. On the way into Kangaroo care there was a sign that said we should try and bond with our babies by putting our hands through two holes in the incubator they said it was good for the baby. I remembered standing there sore from his birth feeling invisible in this hushed room of silent babies I remember wondering whose baby this was and that it just could not be my baby. I had no clue about brain damage or what Gary did or did not having working, I did not know if he could hear me or not. But in that 1st day of his life, I sat by his pod surrounded by beeping machines and I began to sing to him. I stroked him with my hands but as much as I wanted to connect to my 1-day old baby I was terrified that he would die.' (MANDY, 2-17)

Finding Meaning:

Mandy describes the struggle she had to keep finding reasons to carry on trying to communicate meaningfully with her son. To maintain her level of input, she ascribes meaning to her journey. **'I struggled to find words to piece together how life shattering it had been.' (MANDY, 509)** Mandy sees what she has lost in way of normal communication, and the magnitude of it rests heavily on her shoulders.

Image 1



Mandy knows that her son will never truly be safe in the world unless he can communicate with others as well as herself. **'We are shaped by a tragedy that could not be a tragedy because A beautiful boy was at the heart of it'. (MANDY, 512-513)** Mandy has both happy and sad emotions equally and at the same time. This is an odd sensation for her and can at times feel confusing.

'Gary has Taught me that the best things in life are hard fought for and if there is a will there is a way. Attitude towards Gary is everything and the mindset of can do allows for miracles' (MANDY, 556-557). Mandy has embraced radical optimism that Victor Frankl describes, and is not something that was suggested to Mandy, but rather a journey and process that she arrives at**. 'I have actualized not only his potential but my own potential because my choices are different to the ones I would have made if he had not taught me so much about listening to really hear and communicating by observation as well as hearing words.' (MANDY, 565-568)** Mandy is far enough along her journey to have perspective on what she has gained because her son is 9 years old at the time of the interview.

Being Judy

Initial Engagement

Judy's initial thoughts around babies is that they do not communicate, and she observes that babies use eye contact to communicate. Judy does not have any frame of reference as this is her first encounter with motherhood and babies.

'Obviously, babies are babies, so you are not expecting a lot of in way of communication in the first few months Mel is a triplet. Other than eye contact and things there was a big delay getting to normal milestones.' (JUDY, 2-4) However, as time passes it is clear to Judy that her baby isn't making normal progress as the developmental gap grows between the babies.

'I did all the nights I did all the appointments in the first five years and working it was impossible, we share the care now. Looking back having 3 crying babies wasn't any harder than having 3 crying babies I might correct myself on that- I guess it all felt hard and too much. Having 3, maybe it was difficult to tell if one child was crying more than the other 2 or more than a normal child. 3 babies at once isn't normal.' (JUDY, 392-395) Judy's experience of triplets makes separating the time each child took up individually difficult, and for her, it was a blur of crying and care giving so out of the ordinary that the lack of development was just one more thing in the chaos.

Finding Meaning

Image 2

Judy searches for meaning by re-grounding herself because there was a domino effect of things going wrong in the first few years of her daughter's life.

'I went and had some hypnotherapy separately to Mel's communication issues but to deal with all of what happened including my relationship ending with their dad.' (JUDY, 471-472) Judy's experience of hypnotherapy was so positive that it got her thinking about how she might help other mothers going through similar suffering. **'I trained to be a hypnotherapist because I want to do It as a job one day, I saw how much it helped me.' (JUDY, 507-508)** Judy finds meaning for her experience by potentially being able to help others. For Judy, her struggles with the communication have had a profound effect on her, and to her it will have been worth it if she can ease the way for someone else. Judy says that she has acquired a lot of specialist knowledge resources and information regarding communicating with her child and she wants to share it with other parents.

Being Bunty

Initial Engagement

Bunty starts describing her initial communication from when she got home. For her, up until her baby was discharged from hospital it did not seem like the baby belonged to her. Bunty describes herself as having a can-do attitude when the doctors expect her to cry at the diagnosis. Bunty draws strength from religion and God to remain calm about how she will cope. Bunty experiences one way communication for some time post the birth and she described it as a painful experience for her.

'We came home from the hospital he was about 3 months old. He was visually impaired, so he couldn't even see anything I put him in front of my face, and I keep smiling and making movements there was absolutely no reaction. He was very reactive to voice because his hearing is normal. he would cry. I guess crying for him was the only method of communication. I learned that there are different tone or each cry. There are many times where I don't know what it is that he wants I have no idea, so it was really frustrating for me and for him.' (BUNTY, 2-7) Bunty really sits with her baby and puzzles over what her child is trying to tell her, and she starts to really notice different cries, which eventually she begins to understand. For Bunty, the initial feeling of helplessness is not being able to understand her baby.

Finding Meaning

Image 3

Bunty is religious and looks towards religion for meaning to keep herself going forwards with her son's care. **'My faith in that if god took away something from Howard, then He gave (him) something else. So instead of complaining or crying or just continuing to ask why is my son not able to walk why is my son not able to talk or whatever it is…He took away this from him but I believe everybody is equal God did not give somebody more then he gave another person. If I were to take everybody and put what they have on a scale everyone is equal because god is just. So instead of saying he took walking which is a big thing he must have given my son something really big on the scale to make it balanced.' (BUNTY, 392-401)** Bunty finds comfort in her believe that things are balanced in life and feels her son has some hidden strengths that compensate him for his loss of speech and movement. Bunty is experiencing the loss of language and trying to process the pain for herself to keep on going forwards with the limited communication.

Being Jinty

Initial Engagement

Jinty describes a delay in the birth injury where there was a moment before Emma becomes unwell **'On day the day Emma was born she collapsed and was sent to be cooled, I talked to her, but it felt very strange and difficult because obviously we just didn't know what was going on.' (JINTY, 2-5)** Jinty describes her confusion but is almost blissfully unaware of the implications of what has happened. '**The neo-natal team were brilliant, they encouraged us to talk to Emma, to gently touch her and stroke her so that she could know she was loved. That's how it was for quite while she started to respond a little.' (JINTY, 9-10)** Jinty uses touch to communicate love to her baby, and there is a strong need to tell her daughter that she is loved. **'I didn't feel comfortable, I felt strange because it all took place on a ward, with other people and these are not the moments I dreamed of having with a new-born (JINTY, 16-19). I struggled, for a long time… that I didn't feel like I was a mum.' (JINTY 133-135)** Jinty reflects on how bizarre it was to bond in public with her baby and not in private, and she also gives voice to the feeling that she did not feel like a mother because she was unable to see her baby respond to her.

Finding Meaning

Jinty draws inspiration and meaning from her daughter's resilience. Jinty has a change of values because of the struggle her daughter goes through to communicate. Jinty sees her daughter's determination, and this inspires her to keep on working on her communication skills needed for her daughter's independent communication.

'Emma is the toughest little cookie I know, and I think she puts thing in perspective she doesn't know the bad world out there she only knows the lovely stuff she is just living her best life. That's how I give this life with her meaning. I fear if something happened to us parents and we are not here just to make sure she is always alright we fear for her. We are trying to put in enough support that she will always have people to care for her and know her.' (JINTY, 168-175) For Jinty, it is about being a good enough mother and doing her best each day for her child. Jinty feels that if her daughter is content in her life then that is a meaningful existence. Jinty is describing quality of life as an entity rather than living a life of external achievements.

Being Tammy

Initial Engagement

Tammy has experienced the least progress with her son, at new-born, age 1 and now at 15 his capability to respond meaningfully and communicate is not a skill he has acquired consistently. Tammy always knows how to meet his physical needs, but her son does not show promise of cognitive awareness.

'When Robbie was born, obviously for the first 6 to 12 months, very emotional it was all such a shock communication was really about observing him continually, my son was obviously in a lot of discomfort for the first year. Communicating was very much understanding how we could comfort him actually. We found that clearly, as with most babies, but I think even more so with Robbie is that physical affection and verbal affection really did sooth him. He was in continuous pain it was trying to understand how we can reduce the pain and reduce the discomfort on a daily basis.' (TAMMY, 2-14) For Tammy, all communication is about love, comfort and care, and she has no longer has any expectations of more.

Finding Meaning

Tammy comes from a religious family and she herself is religious. Initially, she looked to her spiritual leaders for guidance but was put off by the idea that her son was a reincarnation doing penance for past sins. Therefore, Tammy created her own explanation for her son being locked in his own world, unable to connect with her. **'I am very spiritual about my situation with Robbie, it's been a journey and where I am now, I think yes you have your bad days but over all there is a level of acceptance and actually I understand the journey I have been on.' (TAMMY, 178-183)** At the start, Tammy held on to the hope of a miracle but it never came, and there is a deep sense of loss of an ideal as well as the loss of the perfect child. '**Initially we hoped for a miracle which is a belief in Hindu religion, in reality, things don't change much for Robbie.' (TAMMY, 472)** Tammy holds onto her religious beliefs and looks for a miracle even if it is not the kind of miracle anyone else would understand. '**Having said**

that we have seen miracles not an improvement but a level of non-deterioration that for me is miraculous.' (TAMMY, 480) Tammy finds a way to reconcile her life and her religious beliefs in a way that works for her. Tammy says that her and her husband look at what they do for their son as serving God and this gives them the courage to keep on looking after Robbie.

Being Jackie

Initial Engagement

Jackie describes the horror of knowing that her baby was fighting for her life. There is a fear of loss from the outset, and this, as well as the separation of mother and baby, is a lot for her to process. **'My little girl was in the Neo-natal intensive care unit, so she was in a special unit and she was fighting for her life, um and she was on a lot of medication so there wasn't much communication she was not even recognizing anything. She was sedated heavily and completely unresponsive, the only communication was through touch.' (JACKIE, 2-4)** Jackie resorts to touching her baby though the wires and oxygen to let her baby know that there is a mother there. **'She wasn't a crying baby she was happy; she has always been very loud.' (JACKIE, 16)** Jackie reflects that her baby was very much present on the ward and when she did start to make herself known she was loud. '**If she wants anything, she is very determined It wasn't a cry it was a noise, screaming but it was a sound that I hear as calling me, she will not stop until you came.' (JACKIE, 24-27)** Jackie knows her daughter's personality, and there is a strong bond between them, and the two-way communication has been established between them. **'When she was ill, she would be floppy, and she wouldn't be her energetic self (JACKIE, 34).** For Jackie, this lively personality helps her to recognize when her daughter is ill because her daughter shuts down and becomes withdrawn. **'She is a very happy and smiley child she is using eyes and her facial expressions to communicate she would show it on her face.' (JACKIE, 37-38)** Jackie knows exactly what her daughter wants, as her daughter can really emote in a productive way. This gives Jackie a strong sense of security that her daughter can and will get what she needs.

Finding Meaning

Image 4

Jackie struggled with the initiation into life with a child that has complex needs, but she found solace in reading about coping with struggles. Jackie looks at herself with self-compassion and this helps her to keep on mothering. **'There was this lovely I read it, there is this philosophy of climbing up the hill so you have to go through the mud the really kind of dirty at the bottom of the hill, the trees are very heavily planted and you have to climb over the roots and as you climb the tree to the top there less and less clutter and then you start to have a bit of light coming through the leaves. And eventually you kind of climb up to the top where there is light and you are above the tree canopy and you can see everything and that is how I would describe it so that is kind of my journey, It's not kind of plain kind of walking up hill it's kind of falling down and getting back up, and going sideways and falling back down In some ways when you get to the hill top you see life different, a different way of living, different possibilities. I appreciate things that other people don't realise are important. These special kids they have got something more they have got this little something extra which is quite difficult to describe if you haven't experienced it.' (JACKIE,163-175)** Jackie describes her values shifting and seeing her daughter as not only not disabled but totally unique and special. For Jackie, the overriding love she has for her daughter enables her to fully accept her daughter just the way her daughter is.

Being Tracy

Initial Engagement

Tracy believes in her child's need to communicate his existence to her, and her stance, therefore, is that her son will find a way to reach her even if it is telepathic, as she describes. **'I give the credit to my son because as soon as he was born, he took the initiative of communicating with me. I did not know what happened to him during the delivery he suffered hypoxia I wasn't aware of what was going on during the delivery he was taken to the intensive care unit.' (TRACY, 2 -6)** This is Tracy's first and only child, and she thought that all births go this way, so she was oblivious to the emergency taking place around her. Once she arrives at the intensive care unit, she describes the experience as follows: **'All of a sudden, I felt this, very intuitive feeling and I looked and its almost Mark got my attention to say mum I am here it's me, mum I am here, that was the first communication that I had with him.' (TRACY, 23-26)** Tracy truly feels her son's voice inside of her mind and it is real for her that he is greeting her and calling out to her with his mind.

Finding Meaning

Image 5

Tracy is Buddhist and with that comes a belief system that transcends Western thinking. Tracy finds meaning within the teachings of Buddha. **'I tell every-body and I tell other parents we don't have these special kids these are like old soul monks we are raising, they have done the life. They have lived the body they are living beyond the body experience now so when we are look after such high energy such beautiful spiritual souls.' (TRACY, 465-468)** Tracy glows when she describes the meaning for her son being the way he is. Tracy literally feels privileged to be custodian to her son. **'I always tell Mark thank you for picking me as your mum I truly belief that he picked me as his mother. My soul would have just have been running around the world aimlessly not focused on what important in true living life but in true life energy that will be transferred to the next dimensional world. Wherever we all go, I sense Mark's energy is like coming to this world is to make sure that our souls anybody's life that he comes across touches gets that light to find the path, his life is not just happening he is here for a purpose. And that is one of the reasons I am with Mark I always see that this is all in the bigger picture because special children these beautiful souls they are only here to guide us and teach us patients and teach us what it really means to live.' (TRACY, 483-488)** Tracy, on her journey to find meaning, has not only reached acceptance but a state of gratitude because she understands that if this was given to her then it must be for her own good. This allows Tracy a deep sense of peacefulness which comes through in her narrative.

Being Sandie

Initial Engagement

Sandie’s baby has the most complexity at birth of all the babies described by their mothers. For Sandie nearly the entire first year of life takes place on a ward in a hospital. **‘Jason was in hospital 9 months, ok so the first 6 months he was in Neo-natal intensive care unit, I can remember those days, when, because he was really poorly, he was a miracle that he survived he doesn’t have only one problem he has quite a few. Many times, he was out from Intensive care unit, and then they had to put him he was very poorly.’ (SANDIE, 2-8)**Sandie is overwhelmed by the doctors who keep diagnosing her son with more and more problems. ‘**When he was sort of open eyes.’ (SANDIE, 13)** Sandie hoped to catch her son looking at her because she recalls how her older child used to look at her in the early days after she was born. **‘I can see like those days 4 or 5 months later he wasn’t even looking at me he was looking on top of me, and he never cried. When you are a mum we just look at their face even he doesn’t do anything.’ (SANDIE, 17 -20)** Sandie knows straight away that something is wrong, unlike Judy who was a first-time mother that says **(‘Obviously, babies are babies, so you are not expecting a lot of in way of communication in the first few months’ JUDY, 392).** Sandie says she has something to compare it too and her feelings of anxiety and loss start immediately.

Finding Meaning

Image 6

For Sandie, she was religious back home but once she moved to Scotland her life took on a more secular trajectory. With the birth of her son, she goes back to God to seek meaning and support. **'I have always asked God to give me the love so that I will just love this boy.' (SANDIE, 267-268)** Sandie describes the changes within herself as a person because her son has taught her about the real values in life. **'Before this child I was a totally different person our dream was different we will have money, we will have a house we will go for holidays, but now, these doesn't make any sense to me. I asked help from God.' (SANDIE, 269-271).** Everything is altered, and she and her husband make choices for the benefit of her small family rather than because of what family think of them. **'My husband works as a taxi driver this is not what he went to Uni. to study, but it pays better than his profession.' (SANDIE, 563)** Sandie has experienced self-growth because of adversity. Sandie would not have chosen this experience, but she is determined to make the experience meaningful. **'There are so many things we have changed, we have changed I no longer care because it helps to pay for our child, it helps us to cope because the hours are around our son's needs.' (SANDIE, 569)** Sandie marvels at how her worries before her son's brain damage were around how they would pay the bills, yet now they somehow afford the expensive therapies that her son needs. **'I changed so much, I was the youngest in my family I was spoilt by everyone and I spent my life laughing with friends relaxing with no real worries, and I didn't get married young. Yes, it is very hard, but the good thing is that I stay focused.' (SANDIE, 590-594).** Sandie finds an inner satisfaction at all that she has achieved with her son, and the fulfilment and purpose it has given her life. For Sandie, her whole existence has taken on a new meaning because she cares for her son who depends on her.

Conclusion

The individual depictions were deliberately split into two headings, this was to show the multiple layers to the Heuristic process and the cyclic nature of heuristic discovery. Each mother has an initial engagement with her baby in intensive care, just like I the research has an initial engagement that started with a glimmer of an idea. The mother then explores the landscape of her new baby and as she spends time and gets to know her new role and mother and carer her life with her child begins to take on deep philosophical meaning. Research also becomes philosophical as the researcher reads and delves deep into the phenomenon in order to co-creates meaning from the verbatim and theoretical knowledge of motherhood and non-verbal communication. Finding meaning is an existential concept of survival, it is not clear that every mother will find meaning or find the same level of meaning. Yet each mother will create for herself some kind of meaning so that she can continue to mother her child.

Chapter 5 Findings and Discussion

'Behind every child using a VOCA is a fierce warrior who has battled bravely, the name of this warrior is Mother.' (M. Tasgal)

Introduction to the Findings and Discussion,

The chapter presents the findings based on the transcripts, this includes the transcript that was generated by my own experience of being a mother of a non-verbal complex cerebral palsy child. Each finding has verbatim text in bold followed by my reflections and reactions to the findings. Throughout the findings images kept coming to my mind and rather than ignore these visual depictions of the findings I drew the images and added them as part of the process of developing each theme. Each finding alluded to existential issues that the mother faces as she navigates the world with a non-verbal child. These existential issues are documented at the end of each finding acting as a bridge between the finding and the discussion. The theoretical discussion for each finding is presented at the end of the finding .

In this way the theoretical underpinnings follow on directly from the themes to create a cohesive flow between findings and theories.

Composite Depictions

The composite themes draw on the essence of the experience that each participant mother would recognize as having experienced in some way. The putting together of all the voices of each participant mother acts as a synthesis of the transcripts to showcase how the mother communicates with a non-verbal complex cerebral palsy child and how the phenomenon is felt and lived through. There were many points of correlation between the participant experiences which are highlighted in findings that are presented.

Using the method of analysis described in the methodology (Chapter 3) led to the identification of 29 subordinate themes which were grouped into 7 universal themes. The seven major universal themes were: 1) The Choice to Communicate, 2) Communication Over Time, 3) Impediments to communication, 4) Certainty and Uncertainty, 5) Embodied Communication, 6) Being Towards Communication, and 7) Being in the World with Others. Each main universal theme was made up of between one to eight subordinate themes that had been experienced by at least one of the mothers. Ultimately, the exploration is about a mother's experience of communicating with their non-verbal child, and so it is unsurprising to me that the term Being Towards Communication feels at the core of the experience. The reason this theme is being towards communication is because seven of the children have not yet arrived at independent communication. Only one child was able to communicate independently with an eye-gaze.

Table 6: Main Themes and Subthemes

Main Theme	Sub Themes
The Choice to Communicate,	**1) Desire to communicate 2) Taking responsibility to enable the child to communicate**
Communication Over Time,	**1)The communication of first few days, 2) The communication of the first year 3) Communication Turning point, 4) Accepting the limitations of the communication**

Impediments to communication,	**1) Temporary visual impairment 2) Temporary Hearing loss**
Certainty and Uncertainty	**1) Establishing a yes and no 2) Frustration around communications 3) Uncertainty of understanding 4) Physical aids for communication**
Embodied Communication,	**1) Idiosyncratic bodily communication 2) Involuntary movements 3) Tiredness 4) Medication or Diet that interferes with communication 4) Dualism- mind/body of communication**
Being Towards Communication,	**1) Somatic communication 2) Intuitive communication 3) Mediated communication 4) Enmeshed communication 5) Mother as interpreter 6)Time to communicate 7) Fighting for communication 8) The relentlessness of this communication**
Being in the World with Others	**1) Professional support for independent communication 2) Travelling the world for therapies for communication 3) Communicating for your child 4) Parents supporting parents with communication.**

Table 7: Table of Prevalence

The findings were put into a chart to show the prevalence of each theme across the mothers interviewed.

Findings	Mandy	Judy	Bunty	Jackie	Tracy	Jinty	Sandie	Tammy
The choice to communicate								
Desire to communicate	✓	✓	✓	✓	✓	✓	✓	✓
Taking responsibility to enable child to communicate	✓	✓	✓	✓				
Communication Over Time								
The communication of first few days	✓	✓	✓	✓	✓	✓	✓	✓
The communication of the first year	✓	✓	✓	✓	✓	✓	✓	✓
Communication Turning point	✓	✓	✓	✓	✓	✓	✓	
Accepting the limitations of the communication	✓		✓			✓	✓	✓
Impediments to Communication								

Temporary visual impairment	✓	✓	✓				✓	✓
Temporary Hearing loss	✓						✓	✓
Certainty and Uncertainty								
Establishing a yes and no	✓	✓	✓	✓	✓	✓		
Frustration around communications	✓	✓	✓	✓				
Uncertainty of understanding	✓	✓	✓			✓	✓	✓
Physical aids for communication	✓	✓	✓		✓			
Embodied Communication								
Idiosyncratic bodily communication	✓	✓			✓		✓	✓
Involuntary movements								✓
Tiredness	✓	✓					✓	✓
Medication or Diet that interferes with communication			✓		✓		✓	
Dualism- mind/body of communication					✓			
Being Towards Communication								
Somatic communication	✓		✓		✓		✓	✓
Intuitive communication	✓	✓	✓		✓	✓	✓	✓
Mediated communication					✓			
Enmeshed communication			✓		✓		✓	
Mother as interpreter	✓		✓		✓		✓	
Time to communicate	✓	✓	✓	✓	✓			
Fighting for communication	✓	✓		✓		✓	✓	✓
The relentlessness of this communication	✓	✓	✓	✓				
Being in the World with Others								
Professional support for independent communication	✓	✓	✓	✓	✓	✓	✓	✓
Travelling the world for therapies for communication			✓		✓		✓	
Communicating for your child	✓					✓	✓	
Parents supporting parents with communication.	✓	✓	✓	✓	✓	✓	✓	

The Choice to Communicate

The findings start with when the mother enters the relationship with her child and her choice towards taking responsibility is her initial desire to know her child. The findings then go on to show the intimate and unique journey of the mother who has made the decision to communicate with her child. The findings show many aspects of the phenomenon as the experience of communication lengthens and deepens over time.

With great disability comes great responsibility, and like all superheroes it is a lonely existence. The way to know her child is through two-way communication, however, when a child has so many limitations the mother has to make huge efforts to bond with and connect with her child. The desire to communicate is what allows the communication to unfold. Before the desire to communicate comes a choice to communicate and see the child's potential to communicate.

This theme is divided into 2 sub-themes:

- Desire to communicate - The mothers interviewed start off curious about their child and wanting to know their child.
- Taking responsibility to enable the child to communicate - During the journey with their child the mother realises that it is down to her to get her child communicating by whatever means necessary.

Desire to Communicate.

Mandy wants to connect with her son. Him sitting in a chair in his own world is not satisfying for her. The desire to want to know and hear from the child is what drives each mother forwards in her quest to communicate with her non-verbal child. The mothers interviewed can verbalise this desire, and the child relies on the mother's desire to meet the child's own desire to communicate, since the child has limited capacity to make his or her desires to communicate known.

> **Mandy: 'Communication is a big part of what it means to be human for me. It is an area with Gary that I have invested hours and hours of time. I wanted to reach my son across the abys of his brain injury. (MANDY, 496-498)**

Consequently, Mandy cannot bear to think about the potential passing away of her son. He is under palliative care and medically quite unstable, as are many of the children in this category of cerebral palsy**.**

> **Mandy: 'It is very difficult for me to imagine a time when he is no longer, when we won't be communicating.' (MANDY, 171)**

The end of the potential to communicate with her child is ultimately when her child passes away. This is true for all the mothers who are acutely aware of the limited time they have with their children, thus accelerating their passion and desire to continue communicating.

Taking Responsibility to Enable Child to Communicate.

Judy says, that as the mother, she has taken full responsibility for her child's progress. Her determination comes through in her interview. There comes a time when each of the mothers realise that no one else is going to care as much as they do for the communication goals. This makes the mothers bolder, more determined, and decisive.

> **Judy: 'She was at a special school and the school weren't really pushing the communication device she would only be using it once a week. That was one of the reasons that we decided that she would be home schooled. We got quite a bit of judgement about that.' (JUDY, 316-319)**

Judy is not the only mother taking responsibility for the communication, whether by travelling for therapy, paying for private therapy, or finding out what resources are available, all eight mothers took responsibility. Even Tammy, who realised that her son was not going to progress in communication, takes responsibility for the one-way sensory communication she establishes with her son, when she says**:**

> **Tammy: 'There was a lot of uncertainty about what exactly he was taking in.' (TAMMY, -34-35)**

The mothers worry about their own mortality. Sandie seems to spot that the love she has for her child is unique and special and sets her apart from the carers who come in to care for her son. The ramifications of being the person who most understands the child through love and time is a fear that if the child outlives the mother, then the child will not be able to communicate. So heavy is the mothers' commitment and responsibility, even death seems like a dereliction of duty of care.

> **Sandie: ‘I don’t get depressed the only thing that gets me down is when I think who will love and understand my son if I am not in this world.’ (SANDIE, 594-595)**

I feel a searing pain in my chest for how Sandie is thinking, and I know this pain it is my pain too. Although our lives on the surface are quite different in essence, they are not so different really.

Communication Over Time

Over time, there are major changes to the level of communication that take place between the mother and the child. The normal skills that are intuitive to some or taught to other new mothers become exaggerated when dealing with a child that is vulnerable. The heightened awareness of danger lasts longer than just the first year, with the holding in mind and tuning in to the child can last for the child’s lifetime. Therefore, the communication and bonding between a mother and neurotypical new-born is a well-researched phenomenon of mother-child interactions.

Overview: Four sub-headings emerged from the data regarding the participants’ communication experiences over time. They were:

- Communication of the first few days – The mother seeks to communicate as soon as she meets her baby.
- Communication of the first year - Time was divided into two parts, the early years pre-school and the years beyond that. The most difficult experience of communication was in those formative years of age zero to one, and each mother described things improving to some degree after the first year.
- Communication turning point - The interview data seems to indicate that as the child’s health improved over time the communication between mother and child improved as well.
- Accepting the limitations of the communication - Three of the mothers interviewed have a teenage child and this was the only real point of divergence. The ability to be

> rather than do comes with time, where acceptance and transcendence occurs. It is a journey towards self-compassion and self-forgiveness for the mother's human limitations.

The themes are substantiated with text from the participants' interviews:

The Communication of First Few Days

The starting point of the first few days and even the first few hours of the baby's life indicates that there was no response from the baby towards the mother. Shakespeare's sonnet comes to mind, 'Love is not love, which alters when it alteration finds…' (Shakespeare, 2017 Sonnet 116 of 154) (Original work published 1599), as the mother takes in the situation in front of her. The mother does not feel that there was any communication at all in the first days, yet this is still her baby that she carried inside of her body for nine months. Her feelings for her child are unchanged by the changes the brain injury have inflicted on her baby.

> **Jackie: 'There wasn't much communication she wasn't recognizing anything. She was sedated heavily and completely unresponsive.' (JACKIE, 4-5)**

Jackie describes that there is absolutely nothing, and one might wonder how a mother works with nothing. Nevertheless, these mothers sit a vigil by the incubators hoping and waiting for some communication, as Sandie describes.

> **Sandie: 'I had to tell the nurse can you take a picture if he is awake, I stayed all day, yet I can't see him opening his eyes as he was covered by the oxygen.' (SANDIE, 14)**

The mother experiences a disconnection from her baby as all the intimacy of new motherhood is stripped away from her. There is a hospital, a ward, nurses, doctors, and an incubator all standing between the mother and baby bond, communication, and connection.

Sandie highlights the reality that her child in the hospital does not really belong to her, she is not going to be the first one to see her baby's eyes because at some point she must go to sleep for the night. There is a gulf between mother and child where intimacy and exclusivity should be. Nevertheless, it is clear in that each case, the mother does find, to different degrees, a connection with her child as time goes on.

All eight mothers wanted to show their child that they are there. The way they do this is by stroking and touching their baby**. 'The only way to communicate was through touch.' (MANDY,27 JINTY,12 TAMMY, 36 JACKIE, 6)** Each mother wants her child to know her, even if the mother is aware that she does not seem to know her child yet.

Mandy was told her baby would never be able to cry or smile by the neurologist that read her son's brain scan in his first days of life, so when Mandy heard her son cry at six weeks old it was challenged, until her son's crying was heard by the doctor himself.

> **Mandy: 'The Doctor instantly declared that I had not heard Gary cry because he (The doctor) had not heard this cry himself.' (MANDY, 35)**

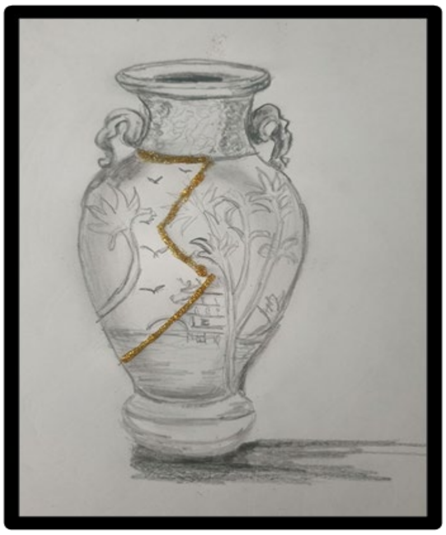
These dire predictions early on only serve to reinforce the anxiety that the mother feels about bonding with her child. Post-birth, Jackie, after hearing that her child will never talk, keeps strong until her family arrives from Europe, and then all her pent-up emotions come to the surface.

> **Jackie: 'I had a massive breakdown when my family – my mother-in-law came. I went from survival mode into almost like just letting go.' (JACKIE, 152-153)**

Rather than the mother gradually discovering for herself her child's limitations and the possible prognosis that involve no speech developing, these vulnerable post-labour mothers, with babies who are only days old, are shocked by too much information too soon.

The Japanese Kinsukuroi way of mending the areas of breakage with lacquer dusted with gold. Making the new item more beautiful and somehow even better than its original version. It makes me think of a line from Leonard Cohens song Anthem, 'forget your perfect offering- there is a crack in everything: that's where the light gets in.' The parallel here is the loss of the perfect verbal child juxtaposed with the mother who goes on to find a way forwards despite feeling broken. This mixture of strength and vulnerability is seen in all the interviews and each mother seems unaware of how incredibly hard she is working.

Image 7



The Communication of The First Year

The mothers interviewed all commented on how difficult the first year was for them. For Mandy, her fear of attaching and communicating stemmed from a fear of losing her child.

> **Mandy 'At around the 1 year mark I began to open myself to attaching to my baby as he no longer looked like he was about to die.' (MANDY, 57-59)**

Mandy's fear did not seem irrational when Tammy seems to corroborate that for the first year her son only communicated pain. The narrative of the first year for each mother was how she dealt with the fall out of the catastrophic brain injury and how her child was communicating the extent of the injury to her.

> **Tammy 'You know the first year was very much it was all one really. He was only ever communicating that he in a lot of pain a lot of discomfort.' (TAMMY, 22-23)**

Many of the mothers described the unrelenting crying **'The constant wailing.' (MANDY, 40).** I could hear that for many of the mothers they had not taken home a baby but a prognosis with little or no support on how to go forwards. Although the baby is in a lot of pain, they are still developing in some way. Jackie describes her daughter's development:

> **Jackie: ‘She was really good at the eye pointing, it’s hard to know when but she was about 1ish when she really got good at doing this looking with her eyes consistently.’ (JACKIE .75-76)**

By age one all seven mothers except for Tammy had seen a smile, this being the first two-way indication that the child is consciously communicating with his or her mother. The smile acts as a motivator to establish more complex communication going forwards, and as Tammy never sees a smile, her journey takes a different path.

> **Jinty: ‘Emma was just over 12 months when we got her first smile, I think early on I struggled because I felt the communication was all very one sided. (JINTY, 28-29)**

It is not just the child that needs positive reinforcement from the mother, the mother needs positive reinforcement from her child. For the communication to be satisfying for both mother and child it must be a two-way process.

Communication Turning Point:

There seems to be a strong indication that life, and communication, turns a corner for each mother and child. Things seem to get easier. For example, for Jinty, it was once they had sorted out some crucial medical issues.

> **Jinty: ‘Emma had surgery for a Tracheostomy when she was just before she was 1 and that is when things changed for us in a good way.’ (JINTY, 60-61)**

Finding the right speech therapist for Bunty and Judy seemed to open the channel of communication between them and their child. Those mothers that pursued private speech therapy thought about children who could not afford to substitute the state care.

> **Judy: ‘We found this new private Speech Therapist who came on board and everything changed after that.’ (JUDY. 69-70)**

Tammy, who did not get a first smile before the age of one, does not describe a turning point, as her child does not progress beyond basic care and remains like a perpetual new-born baby. This highlights the huge range of disability inflicted by lack of oxygen at birth.

> **Tammy: 'For Robbie its honestly down to the basics sometimes it really is. Has eaten got wind, has he done enough stretching today has he slept well.' (TAMMY, 451-452)**

Tammy's sadness in this statement is palpable, with her eyes downcast and her shoulders hunched. Every mother interviewed is invested in her child. The lack of being able to develop complex communication is not a measure of that investment but more a measure of the child's brain damage.

Accepting the Limitations of the Communication

This finding is the only big difference seen between the mothers of younger and older children interviewed. The acceptance described in the interviews seems linked to the time that has passed since the birth of the child. Bunty describes letting care take over from her and look after and communicate as best they can with her son, as she is a single mother and knows that she must accept help.

> **Bunty: 'Time and experience helps with the process of letting go.' (BUNTY, 521-522)**

Tammy describes her acceptance as a journey, and that it took her time to arrive at acceptance.

> **Tammy: 'For me it's a quiet acceptance of Robbie's abilities and progress and now for me it's about keeping Robbie really comfortable.' (TAMMY, 448 - 450)**

Tracy draws from Buddhist teaching that she must transcend her situation because she is the only one able to fully understand her son. There are ramifications of being the most in tune with her son and how she deals with the overwhelming responsibility.

> **Tracy: 'How do I transcend, from this to that, how do I take this and move to the next level.' (TRACY, 566)**

Over time, the mothers are developing coping mechanisms to deal with the reality, and it is clear that there are three stages to the process of communication. The first stage is the initial engagement where the child lies in intensive care and the mother tentatively makes contact. The second stage is a frantic stage of input and early intervention where the mother cannot do enough to try and maximise the communication opportunities. The final stage is a quiet acceptance of the mother doing enough communication to feel that the child has what he or she needs, with the addition of being able to let other people sometimes take over and trusting that the child can communicate enough to remain safe.

Impediments to Communication

The observation that many babies who survive Hypoxic Ischemic Encephalopathy (HIE) births are left with cortical visual impairments and hearing loss magnifies the mammoth task ahead of the mother. The child is locked in its own world, separated by its brain injury, and the mother desperately tries to coax her child into her world.

Overview of this theme: this finding was sub-divided into 2 themes.

- Temporary visual impairment - it seems that with stimulation and time, vision improves for some children, but for others it does not.
- Temporary hearing loss - although it is less common to have hearing loss, this is something that some children will lose as part of their brain injury.

Using the verbatim text from the mothers interviewed, this finding demonstrates the phenomenon of trying to communicate with a baby that is not seeing or hearing.

Temporary Visual Impairment

For some mothers, they felt that the medical teams in Intensive care unit do not predict levels of disability as is it very much an unfolding picture, and the mother is up against a great deal of resistance when trying to communicate the nature of a cortical visual impairment.

> **Sandie: ‘I would say that the proper communication looking eye to eye it happened really late (SANDIE, 125-126) …it got better once he got glasses.’ (SANDIE, 128)**

Judy seemed to try and feel normal even though there was none of a baby's normal reciprocity. This is her first experience of motherhood so there is no real understanding of what her child is supposed to do.

> **Judy: 'I just did a lot of all the normal stuff in the neonatal unit…" (JUDY, 7) she has a visual impairment because of her retinopathy…" (JUDY, 16) so eye contact wasn't there obviously.' (JUDY, 16-17)**

For some of the mothers the children's vision improved over the first year, with stimulation and glasses, but for Bunty, this did not happen, and she took the route of working to communicate with a blind child.

> **Bunty: 'The visual Therapist who worked with us she taught me that when you are talking to him describe everything you do. Because that is what you need to do for a visually impaired person.' (BUNTY, 49 -51)**

This is not just a child with visual impairments, this is a child who cannot move and has visual impairments. This is unlike a blind child who has hand function where the child's hands become the child's eyes. Children with cerebral palsy are trapped in a body that does not move and eyes that do not see.

Temporary Hearing Loss

Not only could Mandy's child not see at the start of his life, but he also could not hear. Like the cortical blindness many mothers experienced, their child did not respond to sound. Hearing is another crucial part of communication missing between the mother and her child with complex cerebral palsy.

> **Mandy: 'I didn't know if he could hear me or not (MANDY, 13) …The doctors said he couldn't hear us.' (MANDY, 24 -25)**

So far, the mother is dealing with a child in pain, who cannot see, who cannot reach with hands, who is not able to root for food and who cannot even hear the voice of its mother. The magnitude of what the mother is dealing with as she tries to communicate meaningfully with her child is overwhelming. As her child gets older Mandy describes her son hearing her in hospital when he was in distress**.**

> **Mandy: ‘The Doctor turned to me and said Mum every time Gary hears your voice his heart rate drops, he recognizes you. (MANDY, 53-54)**

Hearing loss is also temporary for some children, as Mandy describes her son’s hearing returning, and this is corroborated by Sandie saying,

> **‘One day he put the hearing aid in his mouth by accident…’ (SANDIE, 66)** Sandie is saying he did not need the hearing aid anymore**. ‘at 1 year Jason could hear…’ (SANDIE 70)**

The mother keeps working on the communication despite all the odds, and she is effectively doing an ordinary thing in an extraordinary way, with huge limitations. The experience seems fraught with setbacks and more reasons to stop trying then keep trying.

Certainty and Uncertainty

This emergent theme encapsulates the experience, which was laden with uncertainty. It is a relentless journey of what should have been a normal developmental milestone. The real experience of the non-verbal communication between a child that cannot even use a hand switch with accuracy leaves uncertainty in the mind of the mother who so desperately wants to communicate with her child. Equally, some mothers do feel certainty that their child is achieving accurate communication.

Overview: This finding was divided into 4 sub-themes.

- Establishing a yes and no - the building block of human communication is the ability to make a choice.
- The child’s frustration of not being able to communicate - the mistake many outsiders make when seeing a non-verbal child is that the child has nothing to say. Children with cerebral palsy often have a lot to say but have no way to say it. The frustration around communication through assistance is slow and often repetitive. Children get frustrated with the technology because it hard work for an inadequate reward.
- Uncertainty of understanding - when clear speech is not on offer there is always a part of the mother that wonders if she really has understood what her child wants. The

mothers interviewed make it clear that they do not know for sure what is going on in the child's mind. They are always able to understand and meet the child's needs.

- Physical aids for communication - the use of AAC as a part of the communication between mother and child.

Each finding has been linked to the interview texts:

Establishing a Yes and No

Establishing a yes and no is the route into complex communication and choice making. If this is not established, then there can be little hope of the child developing autonomous communication. Tracy says that she always understands her child but yes and no is for other people to help understand him when she is not there. Jackie describes the yes and no coming in stages, because nodding seemed to be easier than shaking of the head.

> **Jackie: 'The yes came first and the no, no shaking her head came later.' (JACKIE, 52-53)**

Paradoxically, Tammy is clear that yes and no could ever be established, and although one or two mothers also say this to start with, it was inconsistent by the time of our interview, and they described their child as making choices for themselves.

Judy: 'The first time we knew she understood instructions, she started going to hydrotherapy very early… And we would do the going under water swimming there is a command that you would use in there ….it was like 1 2 3 then we noticed that she was holding her breath to go under water. That's when we realized she was actively understanding what was going on around her.' (JUDY, 34-38)

I could relate to this moment of realization that cognitively more was going on for the child than first predicted. I felt a shiver go up my back as Judy relates this anecdote to me and the validation that one's child is understanding, and all the hours of therapies is paying off. Many professionals will deny any kind of maternal objectivity and put a lot of what the mother sees and experiences down to wishful thinking.

> **Tammy: 'We have never managed to establish a consistent yes and no with Robbie.' (TAMMY, 175-176)**

Tammy explains that not being able to establish yes and no seems to shut down communication around choice but not communication around health, comfort and physical needs. This signifies that some mothers must live with not knowing their child's inner world and there is a silence where rich communication should be.

Frustration Around Communication

As the child develops, they indicate that they have things to communicate, and not being able to do so causes frustration in the child.

> **Judy: 'I feel a lot of Mel's frustration… she does get frustrated by it all.' (JUDY, 368)** As well as frustration in the mother. **Bunty: 'It was really frustrating for me and for him that there is no way of communication between us.' (BUNTY, 18-19)**

The way that children communicate with cerebral palsy is slow and laborious to start with, pod books and grids requiring endless scanning, either visual or auditory. Most children just open their mouths and words come out. Jackie realises this and describes how it leaves her feeling. The word frustration seems to encapsulate the experience of not understanding, and it brings to mind the biblical story of the tower of Babel (Gen. 11: 1–9), where the inhabitants decided that they would build a tower to heaven so that they could go to battle against God. God punished the people by inflicting them with 70 different languages, and soon the people were fighting each other, destroying the tower out of frustration, with not one person understanding another.

> **Jackie 'I am slightly apprehensive about the frustration Victoria has because that is what happens to clever cerebral palsy kids. because they tend to be clever…' (JACKIE, 246-248)**

Earlier, Jackie has explained that the children get frustrated because of how slow communication is.

> **'Main obstacle not to give up and to find the ways to communicate more effectively and quicker.' (JACKIE, 244)**

There is a two-way commitment to communicate between the mother and child, however long it takes. The mother fears her child giving up and there is an anxiety coming from this that prevails over the whole experience making it more difficult overall.

Uncertainty of Understanding

The checklist comes up in each interview, and whilst the child is distressed it seems that the mother goes through all the possibilities of what might be wrong.

> **Jinty 'For me one of the hardest bits is if she is a bit upset, I don't know really what's going on and obviously I go through my little check list of trying to rule things out.' (JINTY, 117- 118)**

Even Jinty, who has established quite a good mode of communication with her daughter, cannot always be sure that she understands what her child is trying to convey. There is a paradox of both understanding and not understanding, almost as if there seems to be two separate experiences of understanding the child's communication for some of the mothers' The mother becomes extremely good at meeting the child's wellbeing needs but might not pick up on non-emergency needs.

> **Mandy 'communicating with Gary hasn't been easy at all, understanding him has always been natural like, I always understood the next thing he needed.' (MANDY, 123-124)**

Sandie takes this a step further in that she does not know what her son is thinking and whether he is happy or content about things. She measures her limitation as her being a bad mother rather than saying that her child's abilities are limited.

> **Sandie 'If I don't know what's going on in his head then I am a bad mum, and with Jason I don't know that's the thing, that's the thing I feel like I can read him I can read him to know what he wants.' (SANDIE, 292-294)** This sentiment is echoed by Tracy who says: **'And then some you know. So I'm not understanding that is my short coming of not understanding these sounds he is making.' (TRACY, 138-139)**

Physical Aids for Communication

It is worth highlighting the variety of implements available for communication, and it is once again in stark contrast to the neurotypical child who can just speak. The mother is learning new skills in her bid to interact with her child. Not only is it to aid the mother but also to establish independent and objective communication, that anyone, even a stranger might be able to objectively communicate with the child. It is also an opportunity to open the child's world from closed questions to open ended communication.

> **Judy: 'We started using a communication book which has a grid basically and the grid has different symbols on.' (JUDY, 77)** Bunty is using their communication book with auditory scanning as her son has cortical blindness.
> **Bunty: 'There was a part in the communication book that was more academic, alphabet and numbers…' (BUNTY, 140-141)**

Mandy went to great lengths to procure an expensive eye-gaze device for her son and realised that she did not know how to use it as a communication device. The mother is faced with the limitations of her knowledge and skills. It is not as simple as just buying a device, as once equipment is bought a speech therapist trained in teaching communication is needed for it to be of any use.

> **Mandy: 'He has an eye-gaze device that allowed a computer to pick up eye pupil and it then acted as the curser.' (MANDY, 91-92)**

Jackie's daughter showed great potential for communication, and she is the only child of the eight to have gone through all the developmental stages of AAC communication. She is also the only child of the eight children to have received an NHS eye-gaze because she passed the NHS criteria.

> **Jackie: 'She did the big switches she was fine it was difficult at the start, but she got better, and it was eventually too simple for her.' (JACKIE, 272-273)**

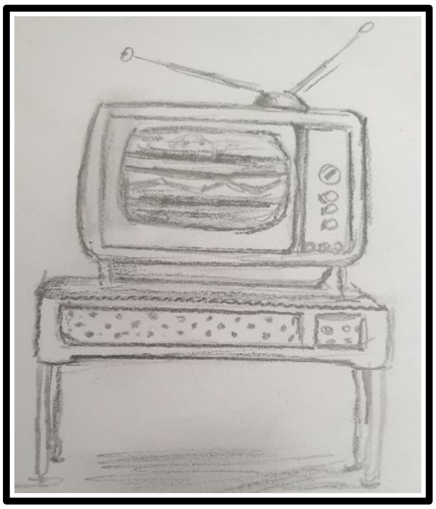
During the interview, Tracy expressed a wish that communication could be more independent of her, and she looks at current research to find new ways for her son to communicate.

> **Tracy: 'We are part of some communication aid research of brains computer interface, BCI, using EEG and brain waves to communicate.' (TRACY, 324-325)**

The amount of specialist knowledge acquired by the mother to communicate with her child seems to go unnoticed by the mother herself. To eradicate the element of uncertainty that the mother might not understand her child fully or something vital is not being said, the mother learns about every kind of communication aid.

I get this image of a vintage television set. If the aerial even moves slightly out of place the whole screen becomes a mess of lines and colour. The mother communicates with her child and knows that many things must align themselves for clear communication to come through.

Image 8



Embodied Communication

The mother reaches a point where she perhaps does not know where her body ends and her child's body starts. The communication is an intimate and all-consuming physical activity. The type of communication typical of a baby between 0-3 months old remains present for longer in the interaction between the mother and her non-verbal child.

There were a variety of ways in which the mother established idiosyncratic ways to communicate with her child. Perhaps these movements did start out as meaningless, but the mother applies meaning to them and with enough repetition the child seems to accept that meaning. There were five sub-themes for embodied communication. Mainly because the physical gestures and ways body parts that were used in communication were so varied, they have been grouped together under the heading Idiosyncratic bodily communication.

- Idiosyncratic bodily communication. Eyes to communicate, looking to communicate, blink to communicate, arms to communicate, scratching, to communicate, legs to communicate.
- Involuntary movements. This way of communicating through bodily movements is often overlooked or ignored by professionals who will not necessarily see this way of communication as such.
- Tiredness. The physical exhaustion of the mother to communicate this way.
- Medication or Diet that interferes with communication. There is a fine balance between keeping a child seizure free and asleep all day. This is an ethical dilemma that many mothers of children with neurological issues must face.
- Dualism - mind-body, of communication. The separation of body and mind seems to get in the way of the child's progress.

Idiosyncratic Communication

It seems that each mother has found unique ways to recognize that her child is conveying something to her, through repeated reinforcements of the exchange between mother and child. Often, this way of communicating is mistaken for seizure activity or involuntary movement. Over time it is seen objectively as a mode of communication between mother and child.

> Jackie's daughter is using eyes to communicate. **Jackie: 'she is using eyes and her facial expressions to communicate.' (JACKIE, 38-39)** With Mandy it's looking to communicate. **Mandy: 'A basic look left for no look right for yes**.' **(MANDY, 82)** Jinty has established blinks to communicate. **Jinty: 'It was a blink to indicate yes.' (JINTY, 91 -92)** Bunty describes the use of arms to communicate. **Bunty: 'He selected the right letters; he would bang his hand.' (BUNTY, 157)** Tracy uses scratching to communicate. **Tracy: 'To communicate he uses his fingers to scratch and the pattern of scratching so he will go**

> **scratch, scratch, scratch, and then wait for me. Sometimes I don't answer him verbally I start scratching with him.' (TRACY, 107-109)** Mandy noticed that her son used his leg to communicate. **Mandy 'When his leg lifts up, I know he has a sore tummy.' (MANDY, 309)**

As soon as this theme emerges from the transcripts then a stark image of a child enclosed in the limbs of the mother is conjured up in my mind. It is also the posture of physiotherapy where the mother works her child's limbs to achieve the sitting position when the child has no postural control. It is a crude and simple image that symbolizes the elemental nature of using one's body to communicate instead of the sophistication and depth that words offer.

Image 9

Involuntary Movements

Tammy, however, cannot establish communication in this way, and she is sceptical of their school who report that her child is using switches with his hand movements. Tammy says it is often fluke and not intentional activity.

> **Tammy: 'it's great what they do at school I truly respect it, I feel that its sometimes a coincidence sometimes uncontrolled movement and not deliberate communication.' (TAMMY, 83-84)**

Within the experience the mother knows when movement is communication and when movement is not communication. There is an innate knowledge that the mother has of her child and her child's abilities.

Tiredness

The mothers are working hard to establish communication with their child. Nothing comes easily and it is an ongoing process. Judy is exhausted and very vocal about how tired she feels.

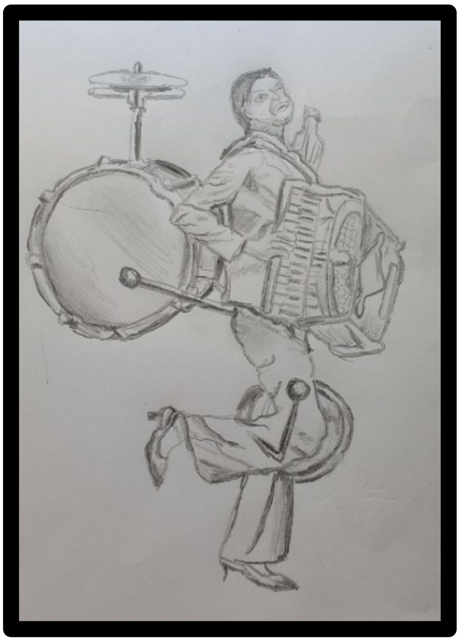
> **Judy: 'Its emotional its exhausting it really is' (JUDY, 419)** Judy further elaborates and says: **'I was doing the work of 10 people!' (JUDY, 490)**

Judy gave birth to triplets, and so not only is she dealing with a child that has Hypoxic Ischemic encephalopathy but also two other babies growing up alongside an intensely needy baby. The tiredness, although not perpetual as in Judy's case, gets to Bunty, as she describes moments of despair and days when things seem hopeless.

> **Bunty: 'I am tired, hopeless, frustrated he will never learn** (to communicate)**.' (BUNTY, 132)**

A memory of Bert from Mary Poppins (Stevenson, 1964) comes into my head, I see the mother as all singing and all dancing. Reaching into her child's world to try and pull the child into her world. It also symbolizes the many hats the mother must now wear, as she learns to be not only a mother, but physiotherapist, occupational therapist, pharmacist, and speech therapist all rolled into one. The mothers of disabled complex cerebral palsy children are literally doing the work of ten people.

Image 10



Medication and Diet that Interferes with Communication.

For Tracy, whilst her son was on 21 different drugs, whose side effects included sleepiness, he would never progress. Once she has weaned her son off all the drugs and switches over to the more controversial Cannabis trial her son does indeed progress.

> **Tracy: 'The turning point for his communication started to come after I had taken him off all the drugs.' (TRACY, 201-202)**

Sandie does not completely stop all medications but notes how lethargic some of them make her son.

> **Sandie: 'A was very lethargic and unresponsive he doesn't have any energy, and he was on baclofen and I hated baclofen for some reason the medicine always bothers me so much…' (SANDIE, 82-83)**

At every turn there seem to be things that hinder the mother-child communication and interaction. Tied into motherhood is the need to feed one's child, and children with this level of cerebral palsy are often tube fed. A child that does not get the right food might become lethargic and not communicate through lack of energy.

> **Tracy: 'Your second brain is your stomach his communication started to come on even more after I put him on ketogenic diet.' (TRACY, 199)**

Sandie explores her son's feeding options and once the medications have been reduced, he seems to gain some ability to swallow.

> **Sandie: 'The communication it suddenly came on very perfectly when we started the blended food, blended food changed my son it was a miracle.' (SANDIE, 118-119)**

Dualism – Mind and Body of Communication

Of all the mothers interviewed, Tracy is the only mother troubled by the separation between the child's mind and body, perhaps because she follows a Buddhist life philosophy. For Tracy, the two are inextricably linked.

> **Tracy: 'Different ideas treatments doing a holistic approach to reach the goal you are not thinking the mind and body are two separate you are seeing them as one, and you find solutions.' (TRACY, 396-397)**

The Western medical model takes the splitting of the body a step further. Each child will be under different specialities and each part of the child will be looked at on its own. For example, a child will see a gastric specialist, neurologist, dysphasia specialist, orthopaedic specialist, cardiologist and optician, to name but a few… nothing is seen holistically by the medical teams involved.

Being Towards Communication

In this section, I have used the participant mother's individual transcript statements and composite accounts to explore their experiences of communication with their complex cerebral palsy child.

Overview: there are eight Sub-themes that explore what it means to be towards communication.

- Somatic Communication - this phenomenon is harder to explain, and it is not scientific in its nature.

- Intuitive communication – intuition, when explored more fully, is the brain absorbing a lot of detail in order to know when something has changed.
- Meditated communication - the mother is a facilitator, and although the child aims for autonomous communication the mother is often relied upon to hold up books or plug in computers.
- Enmeshed communication - the mother is so single-minded in her dedication to her child that there is a merging of mother and child to almost become one.
- Mother as interpreter - although the mothers interviewed did not seem to think they had any special understanding of their child, often they have to act as interpreter.
- Time to communicate - this unusual way of communication impacts on time, and what time is spent on, as well as the child.
- Fighting for communication - state funding means that many gatekeepers must be surpassed before help is offered.
- The relentlessness of this communication - the mothers not only do the daily immediate care tasks expected of a mother such as feeding, bathing, bedtime, etc., but they relentlessly do all the extra tasks as well.

Fighting for Communication

Augmentative Assistive Communication (AAC) requires financing, expertise, and belief in the child. When funding is short and not enough therapy is offered, Jinty says:

> **Jinty: 'It was just a fobbing us off with well maybe that is all that she needs. I knew she definitely needs more.' (JINTY, 255-254)**

Judy also experiences fighting for communication support.

> **Judy: 'There yet, I still have a few things that need to settle first. Everything is a fight and battle everything. If I could change one thing it would be that in order to access help it wouldn't all have to be such a fight.' (JUDY, 499-502)**

This fighting is not just a dispute of words, and can become messy, with many mothers already stretched to the limit find themselves advocating and fighting in court.

> **Mandy: 'Gary didn't meet the criteria for Eye-gaze but when we bought him one, he used it like a duck to water. Everything is such a fight we have more lawyers than friends.' (MANDY, 543-545)**

The communication devices plus adequate speech therapy for the child to make progress is expensive, costing many thousands of pounds, and, therefore, it is often denied to the child by statuary services. A strong image comes to my mind as I recall a demonstration for the rights of disabled children that cannot access adequate provision. There is a fight about social responsibility to protect the weakest in society.

Image 11

Somatic Communication

Mandy is sheepish when she describes the non-verbal communication that takes place away from the communication aides and yes, no answers. There is a felt sense in the mother's body that the child is communicating to the mother.

> **Mandy: 'I walk into the room in the moment that a seizure starts, or a temperature is spiking. I just have a sixth sense, when Gary needs me and that is very strong, and I cannot explain it.' (MANDY, 304-305)**

Tracy is more confident about this phenomenon and says that she hears her son in her mind **'Mum I'm here…' (TRACY, 29).** She feels comfortable with this way of communicating and even expects it to happen.

Intuitive Communication

Judy knows that she understands better than anyone what her daughter wants to say and describes it as intuition. The mothers are observing their child day and night, with all the information being computed by the mother's brain, and so if something exceedingly small changes the mother's brain will recognise it, even if the physical change is not immediately apparent to the mother.

> **Judy: 'There is a difference intuitively of what I pick up compared to what others are able to pick up.' (JUDY, 194-195)**

Tammy offers a reasonable explanation of how intuition comes about. There is nothing unscientific about it as the mother is not just guessing what her child wants.

> **Tammy: 'It was really about observing him continually…' (TAMMY, 2)**

Mediated Communication

Even if a child can use a communication device the mother is needed to aid and facilitate the communication.

> **Judy: 'we started off with a really big book one person has got to hold it and go through it, Mel can choose a topic of conversation.' (JUDY, 180-181)**

Jackie, who has a daughter using eye-gaze independently, realizes that she will always have to switch the computer on for her daughter, and often, if her daughter is not in the mood then Jackie is left to do the work for her daughter.

> **Jackie: 'She will decide if** (using the communication aid) **is worth the effort she would look at mummy and say with her behaviour you do it mummy with your finger.' (JACKIE, 100-102)**

Enmeshed Communication

Mandy spends more and more time with her son, and she becomes very tuned in to him, but this can come at the price of two individuals almost merging into one.

> **Mandy: 'I have tuned into him so utterly that I am feeling everything he might be feeling…'(MANDY, 118-119)**

Sandie also describes her sacrifice of self when she moves out of the marital bedroom because her son does not cry with sound,

> **Sandie: 'I still sleep in his room, so if he wakes up, I wake up.' (SANDIE, 218)**

Bunty gives up sleeping in her own bed to better care for her son,

> **Bunty: 'I also used to sleep with him in my bed.' (BUNTY, 276)**

Bunty can tune herself in to wake up just before he vomits and wakes up just in time to catch her son's vomit to avoid having to clean the bedding in the middle of the night.

In two of the interviews the mother never talked in the singular. This is extremely unusual, and even in the interviews where the mother did use the pro-noun 'I' the pro-noun 'we' was used on many occasions. The 'we' was used in the context of both me and my child, and 'we' as me and the person helping care for my child. Mothers in Judy's position might use the pronoun 'we' rather than 'I', as if the mother is not a separate person to her child and can no longer think of herself as an individual person. Judy is fully immersed in her daughter's communication, and it is as if as a mother she exists purely to fend for her child.

> **Judy 'Mel can choose all the categories in her book and if something is missing in way of vocabulary, <u>'we'</u> can add it.' (JUDY, 182-183) Judy: 'Which takes '<u>us</u>' to the present and to really how '<u>we</u>' communicate with my daughter now.' (JUDY, 72-73)**

This possibly stems from the way the mother is forced to be in the world with her child. These children are surrounded by professionals and carers, so the mother has not had the child to herself from birth, and as the child grows older more physical help is needed.

Mother as Interpreter

Bunty says that however much care is in place there are still times when she is needed to interpret what her son needs or wants. Her extreme example highlights just how on call to translate she has to be:

> **Bunty: 'Sometimes I have to give care remotely…' (BUNTY, 514) I was in Peru …' (BUNTY, 515) from the top of a mountain I was giving the carer instructions.' (BUNTY, 516)**

Tracy, who innately understands her son, teaches her husband how to understand their child.

> **Tracy: 'I did spend a lot of time explaining to my husband how to tell if my son needed anything.' (TRACY, 39-40)**

The mothers interviewed seem very weary of putting words into their child's mouth, choosing words for her child. Judy says of the future,

> **Judy: 'when she uses her device independently then we can really know that this is what she wants, and no one has said that for her she alone is saying it.' (JUDY, 176-177)**

The mother wants the child to choose the words for herself. Judy continues,

> **Judy: 'I want to see her showing us her opinions… her selecting and starting her own conversations about her thoughts on a topic.' (JUDY, 302-303)**

Time to Communicate.

A huge amount of time is needed to practice and support communication once communication aids are in place.

> **Judy: 'communication is time consuming it takes up so much time for her because she has to go through so many options just to be able to communicate.' (JUDY, 106-107)**

Jackie keeps updating the computer to keep the vocabulary current and useable. The ability of the child to communicate is very much linked to the mother's ability to up-keep the communication.

> **Jackie: 'I have to edit like add her weekly books in so she can then use it in the nursery and then updating her news, so it really does take up a lot of time if you really want to be effectively using it.' (JACKIE, 323-324)**

The innate communication without an aid that is idiosyncratic to the child requires spending a lot of time with the child. Tracy describes this very nicely, and it is paraphrased by each mother, as each mother interviewed wonders if she has something special with her child, or if anyone could develop innate communication with her child.

> **Tammy: 'Communicating comes from time, the more experienced carers who have spent some time with Robbie have developed their own strong bonds with Robbie.' (TAMMY, 150-151)**

Judy has a tremendous sense of maternal guilt, with her pathway to communication centred around the early intervention philosophy, so she questions if she could have done more.

> **Judy: 'Really there was lost time in being able to move her communication forwards… if she would have had her book from age 3 or 4 then she would be more advanced in using it then where she is now.'(JUDY, 264-265)**

Motherhood is time consuming when nothing goes wrong, as a single woman transitions into becoming a mother. The experience of not having enough time is amplified when a baby, then child, has so many additional communication needs.

> **Tammy: 'I would love to do a bit more, (TAMMY 440) … it's just finding the time.' (TAMMY, 443)** Judy experienced there not being enough time because of supporting her daughter's communication. **Judy: 'There is never enough time…' (JUDY, 250-251)**

As Judy speaks, I get a sense of her rushed life, an image of Lewis Carrol's rabbit rushing around, always late, always running from time, springs up in my mind. I am not surprised that Alice in Wonderland (Alice in Wonderland, 2010) comes up as the whole experience of having a child with complex care for these mothers might feel as if one is down the rabbit hole hoping to wake up, and all of it has been just a dream.

Image 12

The Relentlessness of This Communication

The work towards establishing communication is never ending and each day the same thing is repeated as the day before. Jackie describes the daily grind and the challenges of all the skills she must acquire.

> **Jackie: 'It's not just the using of the Eye-gaze its learning how to edit it how to program it and then you have the board-maker, It's very complicated I learn how to use it and then I don't recall what I learnt the next day. I can learn but I can't retain it I have to keep practicing it.' (JACKIE, 317-320)**

The journey of communication seemed to produce real highs, joy and happiness as described by Bunty,

> **Bunty: 'After I came back from speech therapy, you can imagine I was ecstatic about his communication.' (BUNTY, 379-381)** And real lows, **Jackie: 'These children tend to shut inwards if they are not heard…'(JACKIE, 232)**

Mandy says that, for her, the daily input to keep up progress is hard but only possible because of the love she feels for her son.

> **Mandy: 'The paradox of the love and hardship was so difficult to put into words.' (MANDY, 513-514)**

I am struck by the procedure to communicate; it is an endless ritual that seems to need so much effort. The mother is investing so much time and energy in a bid to offer her child some freedom from inside the child's own mind. Suddenly, I see a strong image of the cursed Sisyphus in Greek mythology, doomed to forever roll a huge boulder up the hill, only for it to roll straight back down again. It is not the first time in my reflections that I see this image:

Image 13

Being in the World with Others

Disability changes the way the mother is as a parent. It is so all consuming and a complete revamp of the mother's social life. The mother enters the world of non-verbal communication having to suddenly acquire a huge amount of specialist knowledge about their child. This does not always happen for every mother and some mothers struggle to become expert in their child, making the specialist parenting a traumatic experience.

Overview: This theme - Being in the world with others has four sub-themes:

- Professional support for independent communication - The mothers interviewed found that it was not enough to have a willingness to communicate with their child as professional support was needed too.

- Travelling the world for therapies for communication - There is a need to find a cure or fix the child that motivates mothers to literally travel the world for therapies.
- Communicating for your child - Sometimes the mother had to communicate for her child, especially for medical support.
- Parents supporting parents with communication - Three mothers felt the benefit of having other parents guide them in their quest to find out information, and this even galvanized one mother to set up a charity to offer mother to mother support. Except for one mother, all the mothers interviewed used this support.

Professionals that Support Independent Communication

The key to independent communication for a child that is showing promise of cognitive activity is having speech therapy. Bunty describes being written off by her local authority speech therapist who did not seem to have the expertise, so she searches for an alternative.

> **Bunty: 'When he was 7 years old that's when we went to see a speech therapist…who specialised in AAC.' (BUNTY, 113)**

This experience articulated by Judy, Jackie and Tammy, who realise that the therapists might have limits to their skill base.

Jackie feels limited in her ability to use AAC, so although she says earlier that she understands her daughter better than anyone, she experiences a contradiction and says:

> **Jackie: 'I almost think her speech and language therapist…I think she is the one who is the best to understand Victoria and she is the one who can speak with Victoria.' (JACKIE, 120-121)**

School seems to be a contentious issue for cerebral palsy because non-mainstream schools in the UK do not specialise in just cerebral palsy but have a variety of conditions in any one class. Some mothers like Judy are forced, therefore, to home school, and other mothers, like Tammy, experience school as the only way to advance their child. This highlights that cerebral palsy is not a condition where one size fits all regarding communication.

> **Tammy: 'At school they talk a lot about switches and things like that Robbie responding to things cause and effect.' (TAMMY, 79-80)**

This conflicting picture of schooling possibly links to the “postcode lottery” Jackie describes. There are different things available in different parts of the UK.

Travelling the World for Communication Therapy

cerebral palsy is very much about being stuck and not having control over movement. Yet there seems to be at least three mothers who have travelled far and wide to find therapies. Bunty, who loves travelling, used her son’s situation as an opportunity to see the world and explore what it had to offer in way of therapy for her son.

> **Bunty: ‘Then when he was 7 years old that’s when we went to see a speech therapist in New York who specialised in AAC.’ (BUNTY, 111-112) … We were going a lot to chilli.’ (BUNTY, 81)**

Tracy started off as a client travelling with her son for therapy, but soon became a practitioner, and now offers children bio-feedback therapy herself.

> **Tracy: ‘We travelled a lot to Chile for therapy…’ (TRACY, 266)**

Sandie joined many Facebook groups and whatever she heard about she tried to get for her son.

> **Sandie: ‘We went to America for speech and language’ (SANDIE, 556) … We took him to Chilli…we had a 26-hour plane journey.’ (SANDIE, 453)**

With cerebral palsy, if you are not actively doing something for your child at any given moment of the day then potentially your child is deteriorating. Early intervention is pushed, and Bunty describes doing every kind of therapy so that her son would maximise his potential.

> **Bunty: ‘I worked so hard…with lots of therapies you know and treatments.’ (BUNTY, 370)** Later Bunty says, **‘Now when I look back, I don’t know how I did it all.’ (BUNTY, 469)**

Bunty says her motivation came from thinking her son might be the next **‘Steven Hawkins’ (BUNTY, 228),** and she did not want to leave his mind trapped in his body. All the mothers go on a journey of communication with their child, for some it is just metaphorical but for others it is also a literal Journey.

Communicating for Your Child

The mother will always do what is necessary to get her child heard within the journey of her complex need child, and her concern for her child's health seems to push her to break with hospital protocols to get her son what he needs.

> **Mandy: 'The whole communication with Gary was about keeping Gary alive, I would get him medical help…sometimes I would arrive with Gary at the hospital before Gary got seriously ill…' (MANDY, 193-194)**

This is significant because the doctors often challenge mothers because to them it is not obvious that the child is communicating distress. Mandy describes being proved right,

> **Mandy: 'The doctors would see infection in the blood results, but the location of the infection wasn't so clear.' (MANDY, 195)**

Tracy describes the trauma of her child being unable to communicate what exactly is wrong with him. It seems that when the child with cerebral palsy most needs to communicate, because he or she is ill, the ability to communicate shuts down.

> **Tracy: 'That trauma is constantly building trauma upon trauma it just stays and it never leaves.' (TRACY, 564)**

This helplessness around the communication created its own trauma.

Parents Supporting Parents with Communication.

Tracy feels like it is her duty to go up to parents that she sees outside school or in the shops and offer them her wisdom and ideas about how she achieved her communication with her child:

> **Tracy: 'The minute I go up to a parent and I help the mother with something it changes the life of their child.' (TRACY, 552-554)**

Jackie makes it clear in her interview that for her the best source of information about everything came from other mothers.

> **Jackie: 'The parent supporting other parents, if you didn't have the parents' you wouldn't know what else is there isn't it.' (JACKIE, 376-377)**

This way of learning about communication tools via other parents is corroborated by Mandy, Judy, Jinty, Tracy Bunty and Sandie but not by Tammy.

> **Jackie: 'Already therefore I was asking the NHS team about the pod book so I had the knowledge about the different tools or resources that my daughter might explore from other parents.' (JACKIE, 286-288)**

This sharing of knowledge and information both serves to normalise what is an abnormal form of mothering, and it also advances the communication between mother and child.

Discussion

Introduction

As the findings emerged from the verbatims, the existential issues the mothers are facing evolved in parallel these are the felt sense of the lived experiences for the participant mothers. I note these existential confrontations at the end of each discussion for that finding as the feelings that can be denoted from the transcripts. Naming the mother's existential dilemmas adds to the already growing body of existential works on motherhood. In the conclusion chapter I then contrast my participant mother's experiences of the existential with the past work on motherhood to see what having a non-verbal complex cerebral child brings to the fore that is not perhaps seen in mainstream motherhood experiences.

Wittgenstein (1968/1993), questions how it is possible to share a private sensation, as all the mothers interviewed have. His observation is as follows 'He gave a name to his sensation, yet one forgets that a great deal of stage-setting in the language is presupposed if the mere act of naming is to make sense' (Wittgenstein, 1958, p.257). Language is about drawing the individual into a social context and at the start of this research my main aim was to give a voice to the voiceless. I have wanted to lift a curtain on a private world of mother and child that is not often explored in a phenomenological sense. I feel the weight of responsibility to adequately communicate the phenomenon as experienced by the participants. The irony of my position is not lost on me as the mothers in this research possibly feel this same sensation of doing justice to their child's communication, when communicating with their non-verbal complex child.

The purpose of this heuristic inquiry was to discover more about the communication between mothers and their non-verbal child with complex cerebral palsy. Additionally, the unique aspects of this communication that enable discourse between mother and child to flourish were explored. In this discussion I looked at the overview of the phenomenon and the narrative of why the mothers keep on communicating despite the many difficulties they face with the communication. I went onto explore the seven themes that the analysis arrived at referring back to the existential philosophy and theories brought in the literature review.

The Choice to Communicate

One of the existential crises faced by new mother as she transitions into motherhood is the confusion of understanding her new baby in the pre-verbal stage. Initially, there is no real communication between a mother and a new-born (Arnold-Baker, 2020). Obviously, subtle communication is taking place in the form of rooting, reciprocity and synchrony (Brazelton et al., 1975). The mother will learn the pattern of her baby and a mutual understanding will be established between them. In the case of babies who end up in neo-natal intensive care immediately after birth, these patterns of communication are slower to establish (Anderson, 1981). With children who have acquired brain injuries that result in cerebral palsy it is clear that none of the normative and expected patterns of subtle communication are taking place (Rosenbaum, 2003). The mother is now faced with a huge responsibility to learn how to communicate with her child sufficiently enough to be able to go home safely, but there is no real knowledge of what the future for her and her baby holds (Kirk et al., 2005). As with any mother, a curiosity to know her child might have been building during the pregnancy. The mother has a desire to meet and know her baby intimately after nine months of waiting (Stadlen, 2011). Slowly, the mother takes back her baby from the hospital and she assumes responsibility for her child. This is a transition unique to mothers of children who have been in neo-natal care and there comes a point where the mother understands her baby with cerebral palsy better than anyone else (Green, 2003b).

The choice to learn how to communicate with her child is not a moment in time but rather it is a series of unfolding moments. For some mothers as the situation unfolds the pain is so intense, they cannot stay with it, and they seek ways to escape the pain and grief of losing the child they expected (Hollander, 2009). For other mothers, the child slowly takes over every space that exists in the mother’s life and she communicates almost exclusively with her cerebral palsy child, sometimes shutting the world out (Wyn, 2007). It is this slow induction process that is so pivotal to the experience, not an overnight realisation and for the first-time mothers they may only realise, in hindsight, how difficult communication was at the start. The idea is that ‘Life can only be understood backwards; but it must be lived forwards’(Kiegergarrd in Collins, 1953 p. 37). This looking backwards is how the mother’s choice to communicate is made, and she will communicate until such a time that she can no longer find the strength inside to do so or the child passes away.

This finding generated one experience where the mother takes full responsibility for her sons care but does not find a way to communicate. This mother chooses to leave the alternative communication work up to the carer’s and school. This finding differentiates between responsibility and choosing to communicate suggesting that the choice was about taking on the responsibility of motherhood and the mother by doing that is being a ‘good enough mother’ (Winnicott, 1960).

The existential confrontations faced by the mother that arise from the findings:

As the mother starts the journey and relationship with her child who is clearly unwell and not likely to develop normally, she is faced with choices. The choice she has is whether to take the child home and mother it or walk away. In a sense the mother is choosing suffering for herself so that her vulnerable child will suffer less. In making this choice the mother gives up one possible freedom in exchange for the freedom to care for her child. The mother takes responsibility for her child in the moment she makes the choice to engage with her child. The mother feels she has a choice, to engage with her child or not engage with her child. This feeling is followed by a secondary feeling of freedom, through choosing for herself the mother finds her freedom.

Communication Over Time

Marina Thomas (2018), explains that recollections of mothering can alter the mothers temporality. Meaning that her perception of time is altered in the recalling of memories. It is clear from the findings that the linear experience of time was disrupted for the participant mothers in the days and weeks following their babies birth injuries. Thomas (2018, p. 76) brings a Heideggerian concept that might explain this phenomenon, which Heidegger calls ‘moment of vision’ where time takes on a dream, like quality as the mother faces being in the world and her own mortality. Arnold-Baker (2020) describes how mothering feels stretched out in some parts and Stadlen (2005), describes mothering as the days are long but the years are short (2005 p.66), which seems to really fit well with how the participant mothers describe and recall their memories of communication. The time in hospital felt endless but the years of speech therapy and communication practice seem to have gone by in a blur.

In the first stage the mother of a non-verbal complex child experiences her time on the neo-natal ward as having slowed down, with what occurs in eight weeks or a few months feeling like much longer, as the mother is denied the possibility to communicate with her child with any facility other than touch because of all the life supporting equipment and the baby’s sedation (Bytomski et al., 2020). This period ends for the mother when her child indicates that they know the mother. For some mothers, this time never comes to an end as the child does not ever learn to smile or show any form of recognition of the mother as such.

In the second stage of communication between the mother and the child, if the child reaches a turning point, the mother experiences time speed up as she intensifies her desire to conform to society’s mode of communication, through many therapies (Eger, 2018). In this stage, the mother is of her time and her generation, a reference that Heidegger makes about society and normative social behaviour for any given generation in time (Alweiss, 2002).

In the third and final stage, time slows down again because the mother transcends society’s concept of communication and communications aids. The mother establishes her own way of communicating with her child and understands their limitations. The mother can go beyond her time, becoming flexible as she leaves behind society’s expectations. This allows her experience of time to slow down again, as acceptance of self and child affords a more spiritual and meaningful existence. Frankl 1984, says that if man finds himself in a situation that he cannot change then the only option is for the person himself to change. This might explain how the mother adapts her thinking and way of communication with her child because they are not able to communicate in a more conventional way consistently.

In the book Boy in The Moon, As Brown (2009) gradually lets go of his self-blame and hope for a cure, he starts to accept and love his son, just as he is, in a very similar trajectory of the participant mothers experiences. This is both encouraging that acceptance is a natural part of time passing that cannot be rushed and that a father has experienced a similar phenomenon to the mothers showing that a deep connection can be built with either parent if they choose to communicate with their disabled non-verbal child.

The theories of attachment (Bowlby, 1988), do not seem to account for a baby that starts out life unable to move, see or cry or hear for the first few months of life. Although the attachment is seemingly only one way it is clear from the findings that when the child does become responsive he/she knows who their mother is. The child seemingly can single their mother out by looking towards their mother or only calming down when they hear their mothers voice.

The existential confrontation of being in time for the mothers:

Time changes things, and this is a truth of existence. In the findings the mothers describe that things seem to improve over time, it gives pause to the thought that perhaps the mother has simply adapted to the situation in a bid to survive it. The mother goes through three stages, first she feels shock, so time slows then she feels her anxiety so there is a flurry of activity finally time rebalances as the mother finds peace on her own terms as her child is moving towards adulthood. The feelings do not stay the same for the duration of the mothers experience they change over time.

Impediments to communication

The magnitude of lost functions is often missed in this experience because many of the children with oxygen deprivation improve over time (Rosenbaum & Rosenbloom, 2015). The mothers interviewed described their children at the start as being deaf, blind, and mute and sometimes the hearing or vision did not return. None of the children developed any coherent speech or hand function later in childhood. The mother has no way to be seen or heard by her child and she herself does not hear her child cry. Ultimately, to understand the communication that develops between mother and child is through the work of Frankl. 'I grasped the meaning of the greatest secret that human poetry and human thought and belief have to impart: The salvation of man is through love and in love.’ (Frankl, 1984, p. 46). The mother does not give up on communication that is in any way apparent, and even the most basic use of touch to let her child know she is there is a form of communication. There is also a sensing of the child that is communicated to the mother and for this to be understood then one must be open to the more mystical aspects of communication. Wilber (1993), describes a oneness between conscious minds that allows for consciousness to connect in a dimension that is infinite and connected to the entire cosmos. Buber (1970), also describes a force of collective energy, a symbiosis between people through intense emotion that might give alternative possible explanations as to how the mother is able to reach her child beyond her baby’s many limitations (Schaurich, 2011).

Ultimately, each mother in her own way is like Helen Keller, establishing and finding methods to communicate with her child. The idea that it is possible to have an active mind in a body that does not work comes directly from the teaching of Helen Keller (Kirman, 1973). The shift from thinking that a disabled child does not have anything to say, to a disabled child is a fully cognisant person, paved the way for the mother of a child with severe disability to challenge the assumptions that they are lacking in mental capacity (Kavčič & Vodušek, 2005). The mother goes through heroic efforts to establish and maintain communication despite the odds stacked against her child (Green et al., 2012).

Emerging Existential Confrontations of the Mother

The existential realisations that the mother comes to through her experience of communication over time: The self is not determined (Adam, 2018), this concept is one that the mothers interviewed embraced in a very natural way. Each mother believed that her child could improve in the early stages, and, indeed, some of the children did improve. The mother sees that the child’s past does not define the child’s present nor the child’s future. Although in the past visual and hearing impairments seemed fixed and was a part of the child’s facticity that limited the child, the mother sees all the limitations of the child as obstacles to be worked around. In this way the mother continues to work for her child’s autonomy and freedom. The feeling this finding portrayed is that of hope. The mother feels hope for her child in order to continue trying to communicate.

The child cannot see the look of the mother, and this mutual looking one at the other is denied to both. Existentially, the look is limiting because it tends to objectify what it sees (Adams 2018). The child might see in the mother's eyes some of her initial feeling of 'you are damaged'. However, each day the mother recounts that things improve, so perhaps at the point that the child can see the look of its mother the look itself has changed to one of love and not fear. The mother feels a myriad of emotions in the first weeks of her child's life. There is fear, there is worry, shock, anger, even disgust yet these feelings feel socially unacceptable so the mother hides her eyes not allowing anyone to 'see her' she hides her look and the look she gives is hidden.

Certainty and Uncertainty

Existential philosophy has long grappled with uncertainty within the experience of human existence. Simmons (2019) describes the anxieties around new motherhood and the many uncertainties new mothers experience as they have significant moments of motherhood that for a time remained unresolved. This underlying feeling of uncertainty is exacerbated when things do not go on the expected path and the mother is thrown into a world of uncertainty around whether she really understands her child's communication or not (Barbosa et al., 2008). Clearly, the mother's experience has an understanding of the basic care needs that keep the child alive and well. The communication between a mother and her non- verbal, complex child, for basic care, is strong and consistent. It is the finer, more nuanced communications and choice making that often, but not always, eludes the mother. The mother of a disabled child is not doing any worse than a mother of a neuro-typical child, (Stadlen, 2011, p. 46), describes new mothers as often feeling 'un-knowing'. Furthermore, it is often the mother's own expectations that stand in her way of understanding her baby (Stadlen, 2005).

To some extent there is a level of uncertainty experienced as an uneasy existence of not really knowing what one's own child's inner landscape consists of that lasts beyond the new baby stage. At the same time, knowing one's own child's responses and reactions to the world because enough time has passed that the mother has learnt about her child. Existentially, one might propose that one never truly knows any person's inner landscapes outside of one's own inner world (van, Deurzen, 2010). For the mother in this situation, not always having an objective way to verify that she has understood her child creates an uncomfortable uncertainty (Kierkegaard, 1980) the finitude of her existence as a mother and possibly a guilt of not doing enough to free her child from the confines of its own body (Heidegger, 1962).

A certain amount of frustration exists within the communication that does not run as smoothly as it should. There is a tension that exists between the child and parent remaining motivated to keep communication going and not giving up (Thomas et al., 1987). There also exists an uncertainty whether parental input stimulates responses and the evolution of establishing the choice making yes and no. There can be no objective way to scientifically observe this phenomenon because it would not be ethical to withhold communication and stimulation. Therefore, it would be equally wrong to prescribe certainties to mothers as their efforts might not necessarily be rewarded (Cockerill & Carroll-Few, 2001). What works with one child might not be constructive for another so there are no givens for communication between mothers and their non-verbal complex children. This idea of not having any givens comes from the existential premise that one is not fixed, and one can create and re-create the self as needed throughout one lifetime (Sartre, 1956). In relation to the non-verbal communication this might mean that a mother has more than one way of communicating with her child. This might be because a different mode of communication may be necessary on different occasions. For example, on a very bright day, a child's eye-gaze might not work as the sun effects the camera, and the mother might need to resort to another type of communication.

Emerging Existential Confrontations of the Mother

The existential realisation that the mother cannot control her own destiny and that life has a way of being unpredictable the existential term used is thrownness. The mothers interviewed have all been thrown into this situation, not having chosen it. The uncertainty of her life with her child manifests as an anxiety that perhaps justifies her doing for her child rather than being with her child. This anxiety is further pushed onto her by professionals who might sell her the early interventions mindset that stems from the professional's own anxiety of an incurable disease. The feelings that this finding highlights is certainty and uncertainty, and anxiety.

Embodied Communication

Arnold-Baker (2020) describes the embodied experience of the mother when she has a new-born baby. This is because the baby has many physical needs over the first year the focus shifts away from the embodied experience as the child develops his or her own physical independence (Winnicott, 1960). For the mother of a child with complex cerebral palsy this shift does not happen because the child never gains physical independence (Wyn, 2007).

The disability that leads to being non-verbal is a physical one that the mother is very aware of as she wipes drool from around her child's mouth because the muscles needed to co-ordinate speech cannot even co-ordinate a swallow (Hustad et al., 2013). Even if the child could manage to articulate some language, the language areas of the brain are so damaged that the neural pathways that allow language to become verbal no longer work (Chao et al., 2007). These are the physical barriers that exist between the mother and communication with her child. What develops from this barrier is a physical form of communication where both mother and child use their entire beings to create two-way meaning (Merleau-Ponty, 1973). The use of gestures and movement become one method to create a primitive signal for yes and no, although these movements might be seen as involuntary meaningless movements, but the mother experiences them as meaningful (Oliver, 1993).

There are other physical barriers to the communication that the mother observes and researches as she tries to maximise her interactions with her child. The mother sees that medications and synthetic feeds seem to increase lethargy and reduce communication (Kirk, 2001). Mothers who want an active child will then negotiate with medical teams to reduce what goes into the child's body. It is this deep awareness of the child's physical being that the mother develops as she realises the philosophy of dualism. Philosophically, Descartes (Lacewing, 2016) asserts the duality of mental and physical, thereby the mental can exist independently of the physical Taken in the context of a heavily neurologically medicated child, one could easily perceive that the mind is thinking but only the body has been put to sleep. More simply put, the mother sees that what is happening to the body is affecting the communicating mind of her child, but the mind is potentially intact. The mother cannot split the communication of her child from her child's body which the medical model for palliative care unintentionally does through symptom management medication (Malthouse, 2014). This mother's feeling of not splitting the communication from the body is precisely because both mother and child are using the body to communicate.

This physical, embodied form of communication is exhausting for the mother. The mother experiences many levels of fatigue as the communication takes so much out of her (Green et al., 2012). Camus (1955), would describe the mother as living an absurd existence, one where every day that she continues to try and hear her child. Camus would explain the mother's continued exhausting efforts towards communication as having accepted that this absurdity is a part of her life and so she chooses to live with her tiredness.

Emerging Existential Confrontations of the Mother

Emerging from the findings is the existential idea of embodiment, the physicality of the experience for each mother. When mother and child communicate it is an embodied experience, meaning that the whole body is needed to develop a system of communication. Gestures take on a shared meaning, and even seizure activity can become a part of the communication when verbal communication is not possible. The mother and child become so intertwined in this establishment of their unique language that it becomes difficult to see where the voice of the mother ends, and the child's starts.

Being Towards Communication

Over time, the child seems able to physically transmit or communicate pain to the mother where the mother will have a physical ailment mirroring her child's. This somatic experience of the mother seems unexplainable if one were to only account for logical and scientific life experiences. Wilbur (1993), explores this concept of oneness in his theory the great chain of being. Wilbur believes that reality is in the end a nondual unification of emptiness and form, with form naturally evolving over time. Taken in the context of the mother and child communicating, if the child cannot communicate his or her distress then the child will not survive, and nature must find a way to survive even if it seems supernatural. Furthermore, if synchrony can occur on a neurobiological level between mother and baby it does not seem like such a great leap to say it can occur physically in other parts of the body (Feldman, 2007).

Alternatively, some of the mothers explained the communication as intuitive, and when probed further, intuition was described as constant observation. Agatha Christie puts it perfectly ‘Women observe subconsciously a thousand little details, without knowing that they are doing so. Their subconscious mind adds these little things together—and they call the result intuition’ (Stadlen, 2020, p. 76), (Christie, 1926). The mother notices small changes because of her observations and those changes galvanize her into responding to her child.

The experience of facilitating communication for one’s child and often acting as the interpreter and advocate for them acts as a heavy burden of responsibility. This taking responsibility for another is part of the transition into motherhood (Arnold-Baker, 2020), yet, taking responsibility for all the child’s communication takes responsibility to another level. Not only is it a huge responsibility where the mother fears putting words into her child’s mouth (Green et al., 2012), it is also very time consuming. The mother clearly experiences her ability to communicate for her child as a direct correlation to the many hours spent with her child. Therefore, the mother extrapolates that anyone who gives her child enough time could learn her skill set (Royal College of Speech and Language Therapists, 2018). Mercieca and Mercieca (2014a) make this point when exploring the value of short educational assessments that see little of a child’s full potential. A few hours of observation cannot show the complexity of the child’s capacity to communicate, where standardized testing of communication does not do justice to the profoundly disabled individual. Wittgenstein challenges the notion of universal criteria within language, stating, ‘that which no-one else understands but which I appear to understand might be called a private language’ (Wittgenstein, 1953, p. 243), (Kripke, 1982, p. 62). Those assessing children assume that there must be an objective understanding of an individual’s subjective language when possibly each child has his or her own ‘private language’.

Following on from the above it seems that although there are many critiques of Piaget’s 1954, linear model of child development. A model that is primarily based on the premise that a child must go through each stage to enter the next stage. This linear developmental approach is clearly still in use as the participants describe not being able to access communication devices because their children had not gone through each stage of how speech and language hubs assess the necessary communication skills (Green, et al 2012). Yet Ortloff, (2010) clearly delineated between computer communication and non-technological communication. Stating that the computer held different possibilities as it appealed to different parts of the brains reward systems. Therefore the idea that the communication is dependent on communication scaffolding does not seem in line with what the participant mothers have reported. The modelling of alternative communication to the child through scanning and selecting by the mother mimics the engraving and imprinting that Merleau-Ponty (1964), describes in his model of child development. The child learns the language and method of the communication aid through watching his/her mother act out the method first.

In all the skills that the mother acquires there is still a spiritual aspect to the communication that cannot be explained by logic. The findings reveal that some mothers had an almost telepathic quality to the communication and no gestures, language or intuition was used. This can be explained by Bubers' (1970), I–Thou relationships. These relationships are developed in the spirit and mind of an "I" for as long the emotion or thought of relationship is the predominant form of awareness. This means that whilst the mother is so tuned in to the child and thinks only of her child the connection and therefore the communication mind to mind will not be broken. Buber further elaborates that this happens because the mother is drawn into a mental or spiritual relationship with the child through the love that bonds them. It is these positive thoughts that allow for this way of communication to develop. Clarkson (2002), describes a similar spiritual space that can be developed between two people when authentic empathy is channelled towards another's vulnerability and need. The mother knows that her child is vulnerable and she therefore uses her empathy to build a spiritual connection with her child. However within this findings not all the mothers were able to create this spiritual I-thou connection and those mothers mainly used intuition or observation skills.

Finally, within the experience of being towards communication, there is a risk of becoming enmeshed with one's child to the degree that they and the mother merge into one being (Mercieca & Mercieca, 2014b). This enmeshment risks the mother over identifying with her child's narrative and she loses some of herself in her being in relation to her child (Manuel Naughton, Balkrishnan, Smith, & Koman, 2003). The merging of the two voices increases the mother's experience of how relentless achieving communication between herself and her child feels. It is only at the point where the mother can let go of sole responsibility and hand over some of the communication work to others that she can find a way to separate herself from her child's communications (Hollander, 2009).

Emerging Existential Confrontations of the Mother

The mother is subject to social constructs that govern what she will receive from the system, and what she will not. However, there comes a time that the same laws that keep the mother in check can be used to her advantage. The mothers interviewed described going to tribunal to get access to resources, especially speech therapy and assistive technology, where they were told by the council that the child had not met the narrow criteria to receive these resources. The mother then discovers her power as she wins these disputes, because, ultimately, the English law system promotes equality for the disabled. The feeling that emerges from the findings power and powerlessness this emotion is felt most strongly by mothers of non-verbal children with Cerebral Palsy because of how much they have to fight for resources.

The existential confrontations of the mother are around how she will cope and deal with the crisis that the situation has forced upon her: The mother faces her own authenticity - Being towards something denotes never actually arriving at it, similar to the existential idea of living authentically. For the mother of a non-verbal communicating child each milestone arrived at only opens doors to further work ahead. This is seen most clearly by the child who is mostly communicating with assistive communication technology. Her mother can see her child making progress but sees that the computer is too slow, and she looks to the future for faster equipment. There is no substitute for speech in the mind of the mother, but she will work with what there is for the sake of her child. The feeling that the participant mothers express is one of conflict, conflict between authenticity and inauthenticity.

The mother also grapples with the feeling of absurdity of the situation in the existential context brought by Camus (1955). The mother of a non-verbal child resides in the hostile world shaped for people who speak. The mother works relentlessly with her child to achieve objective communication, as she confronts the world with her need to understand her child. Thus, the myth of Sisyphus plays itself out in the absurdity of the mother's endless endeavour of being towards communication.

Being in the World with Others

The experience of mothers who communicate with their non-verbal complex cerebral palsy child seems to come full circle. Within the three phases there is another less noticeable process playing out. The baby starts out in a mitvelt that is full of professionals and the intimacy of that new-born experience is lost. The tiny world consisting of mother and child communicating basic needs of feeding and cleaning is invaded by intensive care. The mother perhaps must re-create this intimacy to truly connect, communicate and keep her child alive, so she shrinks her mitvelt down to herself and her child possibly to the point of the two of them becoming one being (Wyn, 2007). However, as the mother transcends through the experience of the world as full again, she lets others join her in communicating with her child. The mother having spent time with her child can now teach others how to communicate with the bespoke system of communication she has created (Kirk, 2001). The mother now feels confident in her role as interface between her child and professionals because she understands that she does indeed hear her child's communication (Schaurich, 2011). Within the experience the mother can now critically evaluate what other professionals such as speech therapists bring to her child's communication (Pennington & Thomson, 2007). Looking at the social world around her the mother reaches out to other parents, both giving and receiving support. Other mothers who are experiencing similar struggles and emotions around communication link up with each other through support networks and this normalizes some of the absurdity of the experience for each mother.

Within the finding one participant describes the strength she got because the paediatric doctor showed her that her son's heartrate (High heartrate indicates pain and distress) was coming down when she was speaking. The anecdote happened in 2011, and it was gratifying to see that Filippa et al. (2021), showed that maternal voice decreases pain and increases oxytocin levels in infants during painful medical procedures. The paediatric doctor saw something that helped the mother see that her child knew her. Showing the power of the professional mitvelt and its impact on the mother child communication.

Emerging Existential Confrontations of the Mother

The mother is being in the world, her Dasein, she exists in the world, but she cannot exist in the world alone. The world around her influences the thoughts, feelings and moods. Each encounter that the mother has with the outside world throws up the possibility of either being a help to her or a hindrance. The mother feels intruded upon by strangers who are called professionals. The mother has to tolerate these professionals and their protocols so that she can best help her child towards her end goal of communication.

The existential confrontation that the mother faces is her existential isolation. The mothers interviewed described, to varying degrees, struggling to connect with others because of their experiences. The existential isolation each mother experiences stems from the unbridgeable space between the mother and the world outside of her child.

This isolation is a combination of each mother being thrown into the world of disability alone at the point that she gives birth, and the ultimate knowledge that the mother knows that she will leave this world alone. The mother of a complex care non-verbal child gets as close as it is possible to get to another human being and the loss of such a child must feel like losing oneself for many of these mothers. The mother feels contradictory feelings of isolation and connection.

Conclusion

The analysis of the interviews clearly shows that despite the mothers experiencing no reciprocity or synchrony or any mutual eye contact between mother and baby, the mothers interviewed were all to some degree able to establish an attachment with their child. Not only that, but over time each mother was able to tune into her child's body and movements to really understand what they needed from moment to moment. It also emerged that communication using communication aids such as voice output communication aids (VOCA) or augmentative and alternative communication (AAC), required huge perseverance and skills from both mother and child. The children did not lack the cognitive capacity to communicate with devices, rather they were inhibited by their movement disorders. Finally, there was clearly some uncertainty when the mother questioned her ability to understand her child and her ability co-exist with this paradox. Although the children did show a degree of frustration overall, they were content. The mother is affected by the loss of her verbal child and feels this loss of communication acutely as the mother sees the larger safety ramifications for her child because they cannot communicate consistently.

Creative Synthesis

Image 14

The paradox of dusk, the most beautiful time of day, just before the darkness comes. Or is it the dawn just before it gets fully light, offering the hope of another day? I also feel the healing strength of my participants reflecting my own experiences, like the water reflects the colours of the sky. Each mother of a non-verbal complex cerebral palsy child would recognize her reflection somewhere in the transcripts of the mothers interviewed for this research, transcending their superficial differences to feel the solidarity with each other.

Chapter 6 Conclusion:

'It's about listening to each other, not just the words but the gaps in between' (Stephen Grosz 2013 p.11)

Introduction

In this discussion I set out to reflect on the process of the research as well as bring together the findings and explore those findings in the context of the literature review. I will conclude with my thoughts on the ramifications that this research has on working as a counselling psychotherapist, in general, and within the context of being the parent of a complex care needs child.

Moustakas (2001) suggests that to explore the ending is to look back at the beginning. I started by knowing that mothers of non-verbal complex cerebral palsy children are a unique group of mothers about whom there is little research. No previous research has specifically explored the experience of mothers of babies who have acquired their cerebral palsy through a hypoxic ischemic injury at birth, meaning that the baby needed possible resuscitation, a ventilator and intensive care almost immediately after delivery. My position as a mother of a non-verbal child with complex cerebral palsy and as an insider researcher has revealed new insights about the experiences of myself and my participants. I went into the research knowing what I know and learning from what I did not know so that I could understand the lived experience better (Sultan, 2018).

The idea to look at mother-child communication within the context of cerebral palsy took shape because of the many emotions it stirred up in me. I wanted to draw attention to just how much goes into the process of communication between a mother and her non-verbal child when speaking should be effortless. At the same time, I was aware that I was not so much interested in the technicalities of the communication (Speech and Language), but more interested in how communicating in this way is experienced by the mother and child.

Reflecting on Supervision

There were nine terms of five hours of supervision with my primary supervisor, and having a good relationship with my supervisor allowed me to express my fears and doubts about the project. The supervision acted as one way to check the validity of my own work ,and between the meetings with my supervisor I was also able to email questions, work, and ideas back and forth. Ultimately, my supervisor tested my own understanding of the phenomenon that I was researching, gently guiding me back to the research statement (Sultan, 2018).

Reflecting on the Literature

The exploration of the literature was as informative as it was uninformative. I learnt interesting facts about the history of cerebral palsy and Freud's involvement in the original understanding of the condition. As with each stage of this research I emersed myself if the literature and was deeply involved in what I was reading.

The work of Victor Frankl spoke to me throughout the research, his words kept going over in my mind; look at the why, it shows you the how. The mothers have attached meaning and love to their child. That is how the mothers have found meaning in the way they communicate and that is how they can keep on communicating.

Additionally, Reading with Love caught my eye, by Daniela Mercieca and Duncan Mercieca (2014b), their work describing the incredible love between a mother and her child with cerebral palsy and the resulting over identification of the mother with her child. It was through this piece of creative research that I began to understand the possibilities for my own work as a legitimate researcher. Finally, I was inspired by Green (2003b) whose research titled Mothering Amanda captured so much of what it is to be the parent of a child with complex cerebral palsy, a psychologist and a researcher using her own experience within the research.

Contribution to Knowledge

This research gives insight for psychotherapists working with carers of children with complex cerebral palsy. It aims to give healthcare professionals such as paediatricians, nurses, physiotherapists, speech therapists, occupational therapists and social workers a deeper understanding into the lives of mothers who care for and communicate with their children who have complex care needs.

Additionally, exploring literature on phenomenologically working with the non-verbal messages that the client brings to therapy might explain how mothers communicate non-verbally. One can work with all senses, not just one's ears (Crawford, 2009), and perhaps there could be a strong argument for including all senses in all phenomenological work. The therapist feels their way tentatively through the client's narrative (Clarkson, 2002).

This research adds something to the already vast body of knowledge on how humans create the meaning to communicate (Kee, 2018), broadening the perspective from the intense experiences of the participants in my research to the finding's wider ramifications (Moustakas, 1990).

Reflecting on Using Heuristic Inquiry

A certain amount of passion is needed to do a PhD and there was nothing I was more passionate about in my life at the time then my son's communication. It was for this reason that I chose the Heuristic Inquiry as my method, however I struggled to be comfortable with showing the world my own vulnerabilities. I was always someone who hid herself behind strength and stoicism going forwards with a keep calm and carry on attitude. I also acknowledged the irony of using Heuristic Inquiry as my method when I tend to intellectualise my own experiences through theoretical reading rather than deal with the feelings. Perhaps Heuristic Inquiry is the ultimate way to intellectualise through theory and the lived experience, and yet I experienced every part of the research so intensely that at times I wondered if a Heuristic Inquiry was academically rigorous enough and I worried about whether I was producing credible research or not. There is a quote by Polkinghorne that sums up what I set about trying to achieve and it articulates just how complex the Heuristic Inquiry really is:

> *'Human science seeks to know the reality, which is particularly our own, the reality of our experience, actions, and expressions. This realm is closest to us, yet it is most resistant to our attempt to grasp it with understanding. Because*

> *of the success we have had knowing the world around us, the human realm has expanded its power to such an extent that we can act to create wellbeing and physical security and comfort and to inflict untold suffering and destruction. Serious and rigorous re-searching of the human realm is required'* (Polkinghorne, 1984, p. 280-1).

Reflecting on the Data Collection

The pilot study also highlighted areas for improvement and amendment within the execution of my research. The first issue I reflected on was around disclosure - The pilot interview felt blocked, and I could not understand why. I went back into the theory of heuristic inquiries to sit with what is needed for the process. The block was around participants being co-researchers and the process being a parallel experience. The collaboration of participants being co-researchers is only possible because the participants know that the researcher has lived a similar experience to them. My pilot participant guessed that I was the mother of a disabled child - her attitude towards me shifted at the point that she realised; I realised the exact moment when she realised. From that point onwards this participant really talked openly with much more emotion.

I needed to go with my instinct which is in keeping with the heuristic exploration and let the future participant mothers know that I have a disabled child myself by explaining in the interview what a heuristic inquiry is. At the same time, I trusted my clinical skills as a counselling psychotherapist to allow me to be fully present for my participant during the interviews, safely holding the space for the participants and bracketing my own experience of for the duration of the interview.

My second issue was around artefacts during my incubation period, as part of the illumination visual images were surfacing for me, triggered by the interviews. It was the non-verbal communication that was coming up and I had been drawing non-stop during the immersion stage of process. I therefore took the pressure off my participants and requested that they draw something only if they felt comfortable, especially as interviews had gone onto zoom due to covid restrictions. I used my own drawings as a part of my six stages as and when these images are appropriate.

The third realisation I had was around the age of the children. It seemed to me that the parents of slightly older children had more time to participate in research. I had some mothers come forward whose children were 13 to 16 years old. I took my request back to the ethics board and made a case for why mothers of slightly older children could and should be included. I expanded my inclusion criteria, trusting my intuition and ultimately it enriched my understanding of the phenomenon.

From when the seed of this research took root, there was an awareness of what a mammoth task I had set for myself. Firstly, to try and research mothers who were so busy in their role of caregivers. Secondly, I also knew how hard being the researcher was going to be for me, yet I was committed to doing this research, often working in hospital whilst my son was ill, or typing up transcripts late at night as I did the waking night care my son required.

Reflecting on the Research Limitations

From the start I knew that my research would only look at the experience of a particular kind of mother. This might seem like I had foregone conclusions for my outcomes, but this is not the case, rather, I could deduce this reasoning as follows:

The research advert asked for mothers of children with complex cerebral palsy to come forward. There is a percentage of these mothers who place their children in foster care or residential care homes. These mothers, although they are not living with their child full time, are still communicating with their them (Hollander, 2009). These mothers were unlikely to feel able to participate in this type of research and I felt their absence, so I want to acknowledge these brave mothers now.

The other mothers that this research would not reach, for ethical reasons, were the mothers who were unable to find their emotional strength on this journey. These mothers would be too vulnerable to interview and the interviews might cause them additional distress. I want to acknowledge that not having their voices present means that I was only meeting a very niche group of mothers and my findings are in the context of those that are absent. Therefore, I am very clear in my mind that I offer insight into the lived experience of 8 participants and I would therefore not like to generalise my findings as the only way to experience communication with a child that has had a hypoxic brain injury. When I refer to mothers therefore within my research findings I am referring to the participant mothers interviewed for this research.

Through the literature I discovered that there are so many ways that humans use to communicate, and non-verbal communication incorporated a plethora of nuanced methods. Then, unsurprisingly, there was the problem that language is often limited for the description of a phenomenon and does not always do the experience justice. This was something I felt deeply from my own experience of wanting to put my finger on the illusive words that could fully sum up what takes place. The mothers I interviewed also at times struggled to find descriptions for that just out of reach je ne sais quoi that could sum up their entire experience. Jane Austen sums up the inadequacies of languages as *'Sometimes I have kept my feelings to myself because I could find no language to describe them.'* (Austen, 2013, p. 144)

Reflecting on the Data Analysis

I could not have anticipated how affected I would be by the narratives of my participants. I was struck by how individual each mother's life was, each context a world of its own. Nevertheless, each transcript had common threads linking them together. I became very tired after each interview and found transcribing the interview very draining. Through self-reflection I understood that things were coming up for me that I needed to deal with and process. There was no way for me to wriggle out of facing my own vulnerabilities and by doing so I was honouring my participants experiences (Throne, 2019). Through my own self-processing I was better able to showcase my participants' experiences. Where initially I had only my own voice, I could now hear the voices of my participants to give their experience a voice and this came through in my findings. Moustakas (2001) described this as the degree of epoché or not knowing that is needed to create valid research, whose centre point is the researcher, that can then expand to incorporate wider understandings of the phenomenon (Moustakas, 2001).

I clearly knew at the outset of my journey that I was going to immerse my mind, body and soul in the process of exploration of the phenomenon. I knew I would have to tread a fine line between being in the experience myself and the emotional content that it would bring up for me. Alongside the academic rigor and objectivity that a formal research project requires, I was transparent about my own bias throughout the research. At the point of creative synthesis, the work ceased to that of each individual and became one cohesive harmonious depiction (Throne, 2019).

To ensure that I could indeed find this balance, I kept a therapeutic journal throughout the process, starting from when I submitted my proposal. I took a lot of my conflicting thoughts and feelings to personal therapy ,and between personal therapy and the process of research I did not come away from my research unchanged. There was a quieting of my mind and a new perspective on my lived experience that resulted in an unanticipated healing where raw pain had once existed (Kumar, 2017).

The artifacts produced by the participants provided a rich source of data. They were another piece of information not available from interview. The artifacts produced by the participants were not analysed or interpreted in any way, it is for the viewer to derive meaning from each of them. This deliberate ambiguity challenges the reader to feel the frustration of not being sure of the message within the artifact and this effectively is what the mother experiences with her non-verbal child (Norum, 2008).

Reflecting on Validity

As emphasized by Moustakas, validity is closely related to the meanings. I asked myself, does the study describe, in a vibrant, accurate way, the essence and of the studied phenomenon (Hiles, 2002)? The analysis was only completed by the rigorous process of my reflections, explorations, checking, reading, and rereading the interviews, descriptions, and synthesis (Sultan, 2018). Throughout this process I went back and checked my findings against the phenomenon time and time again until everything but the findings relevant to communication was left (Abbott, 2004). For example, this line in the transcript really stood out:

Mandy: 'There was a lot of family who just see Gary has an inanimate object in a chair or they talk to him like he is a baby.' (MANDY, 260-261)

Although it is a powerful statement it does not directly link to the phenomenon of communication between the mother and her child, so it was omitted from the findings.

Similarly questions around communication between siblings especially the triplets or fathers arose in my mind. However, these questions although hugely interesting did not directly relate to the phenomenon being researched (Sultan, 2018). I put them aside in my mind for future explorations.

To my amazement, the six stages of researching organically occurred exactly as Moustakas described it (Moustakas, 1994a). The process itself was a lengthy one and I was aware that I ran the risk of not moving forwards, and stalling if I stayed in anyone one stage of the process for too long. I set myself targets and my supervisor was supportive of me meeting the targets and keeping my self-goals for the work realistic.

Summary of Findings

I came to the exploration with my own knowledge of the phenomenon of how I experienced communicating with my non-verbal complex cerebral palsy child. Like myself, each of the mothers I interviewed started her communication journey with the choice of whether she would communicate with her child or not. That choice in the individual depictions was described as the initial engagement with the child. The choice to communicate stemmed from the mother's desire to know her child and from a sense of responsibility to meet their needs as best she could.

What I learnt was that communication happened in three distinct phases for the mothers I interviewed. Phase one was a tentative one-way mother communicating her presence to her child and this phase went on for as long as the child was unresponsive. Winnicott (1960) explains that this one-way communication is a natural phenomenon seen between mothers and new-borns so that the mother can meet the baby's needs. What is remarkable is that this phase seemingly in the case of the mothers interviewed, lasts for as long as the mother has no other way to communicate.

The first phase was then followed by a phase filled with activity, therapies and over identification with the child to maximize the potential of the communication and establish independent communication. For one mother, the child became an independent communicator, with minimal mediation from the parent. However, for those mothers, including myself, where this did not happen, by expanding my age inclusion criteria I learnt about the third and final phase of letting go. In this phase the mother's interviewed for this research, reaches acceptance of her child's limitations. This allows the mother to become unmeshed from her child and be two independent beings no longer two bodies with one voice.

Within the first phase of initial engagement of mother and child the mother discovers the many impediments to communication such as cortical blindness and temporary deafness (Rosenbaum & Rosenbloom, 2015). These impediments necessitate early intervention through a speech therapist, providing all sorts of gadgets to aid communication. Subtly, the child's problem in communicating is being medicalised, but the mother is still unaware that this is taking place. Malthouse (2014) observes that medical professionals can lose sight of the individual, in this case the mother and child. These professionals then fail to understand that the mother is negotiating on behalf of her child. This negotiation is not based on rigorous criteria for suitability of equipment rather to add quality of life to a child who is categorised as life limiting or palliative. These devices work to some degree and the mother finds herself having to learn complicated technical skills to keep up with her child's needs.

In the second phase the mother discovers that some of her child's movements can be used for communication and through repeated negotiation between mother and child these gestures become language. Merleau-Ponty (1973) describes this occurrence in consciousness and acquisition of language as the apparently direct symbolism of spoken language being replaced by a gestural language, where the meaning cannot be released by the person making the gesture. Importantly for some of the children, this gesturing establishes a yes and no within the communication which allows for the child to make choices (Spitz, 1957). The consistency of being able to use a device accurately and all the time is not possible for every child, and this limits the amount that the child can convey of his or her thoughts and feelings. The mother might really tune in, use her intuition, or even get the feeling that her child is trying to say something and by her child's physical or emotional response lets the mother know she has understood her child.

The mother carries the heavy burden of being the only one who fully understands her child, especially when her child is ill, and she attributes this to how much time she spends with her child (Green et al., 2012). Within the world the mother often advocates or interprets on behalf of her child to negotiate for their quality of life. Within the experience there are mothers who get no response from their child or acknowledgement of being the mother and this is a painful realisation. Even when there is no acknowledgement from the child the mother will still meet all of their emotional and physical needs. The mother then finds something within herself to keep on communicating love when it is all one sided. As time goes on the mother continues to communicate with her child but there is a more settled routine and less frantic nature to the acquisition of independent communication. The mother shows others how to communicate with her child so that both mother and child can function as two independent beings (Mercieca & Mercieca, 2014b). Yet even when this does happen the mother is often called upon when the child is being difficult or upset and those caring for them cannot work out what is wrong.

Implications for Counselling Psychotherapy in Clinical Practice

The findings of this research have shown that becoming a mother (for the mothers who participated in this research) to a baby that has had a hypoxic injury affects mother and child on every level of existence which changes the way they communicate. This increases the pressure on the new mother who might already be struggling to get to grips with caring for a new-born (Arnold-Baker, 2021). Previous research has highlighted how the pressures of disability can have devastating effects on the care giver, usually the mother (Kirk et al., 2005). As the mother contends with the transition to motherhood plus full-time carer, she is tired and possibly traumatised because her child is not behaving like a baby.

The mother is possibly exposed to a judgemental societal view of motherhood and chronic disability, and this adds to the stress that she feels, often leading to depression and anxiety (Green, 2004). Stadlen (2005), explores the idea that no mother really starts off as understanding her child. However, given time and encouragement through intense observations the mother and child form a coherent form of communication. Motherhood is a situation that is already laden with guilt, pressure and myths which leaves mothers of healthy children floundering, so how much more must the mother of a profoundly disabled and vulnerable child flounder (Arnold-Baker, 2020).

Another aspect explored was the mother’s fears of the look of the other, the feeling of being othered by society and the feeling of alienation (Green, 2003a). This often further isolated the mothers who struggled in many ways to find words to communicate their experiences, even in the interview. Many mothers felt unable to go for psychotherapy for fear of being judged and felt that people on the outside of the experience could not understand what was happening to them within their lived experience (Van der Kolk, 2015). This coupled with having no time for anything because care needs are so intense and time consuming meant that this group of mothers often do not come for therapy, but if they do it is often because social services have sent them. This re-enforces the mother's feeling that she cannot cope, and that the look of the other is judgmental and she is in some way faulty ((Clement & Aiello, 2021), (Howe, 2006).

At first I was tentative to put into words implications for clinical practice, because I had read so many papers, in journals and other pieces of research that seemed to prescribe a solution for parent carers. I did not want to become another advisory prescriptive voice. Then I realised that I could offer an existential perspective that would be unlike the other works I had seen and might be extremely valuable to practitioners and mothers of non-verbal cerebral palsy children alike.

My findings show that mothers of children with complex cerebral palsy that are non-verbal are usually the result of a birth injury (1 in 1500 births result in hypoxia). This is a traumatic event for both the mother and her baby. If the baby sustains a grade 3 injury as explained in chapter 2, then the resulting injury most likely will be life limiting and the baby will be categorised as palliative (Rosenbaum & Rosenbloom, 2015). Palliative care for cerebral palsy is symptom management with no hope of a cure. The mother will be told this within 2 weeks of her child's birth

(Rutherford, 2005), the diagnosis in itself is a trauma and the extended hospital stay has lasting effects on the mother's emotional wellbeing and her ability to mother her baby in the usual way.

The findings suggest that the mother understands what is at stake for her here and makes a commitment to her baby to continue mothering for as long as she can. The mother takes responsibility for her child's life time of medical and communication needs, even though this life is filled with trauma upon trauma with little or no hope. The magnitude of the terrible loss for the mother stares her in the face day after day, she has a child in limbo, a baby who defied death but is forever altered. The mother's loss of her perfect child is a pain that is present even if it is never verbalised and more importantly there is no closure for this loss until the child passes away. On this journey the mother watches as other mothers say goodbye to their children as they do not make it through a bad winter and the communication on behalf of their child's health takes on even deeper meaning. The mother in this scenario pushes aside her trauma until there is a gap a space, more physical support with her child and then she begins to digest and process what has happened to her and her child. As her child does not reach the normal developmental communication milestones the reality of the mothers situation begins to sink in. Yet the mothers in this research are clearly attached to their babies and their children as they grow, and the mother is communicating on behalf of the child's needs.

With all these challenges, it seems that both medical and psychological support is lacking as the mothers come up against a world where everything is a fight. The mother's in this research seem to be grappling with making meaning of their lives and their existence against the knowledge that they will probably outlive their child. The mothers have to face this alone and there is a deep feeling of isolation. The mothers in this research are also living with human error as they reported mistakes were made during their labours, so the mother's in this researcher have also developed a deep distrust of professionals. These findings clearly show that counselling support from highly trained therapists could be beneficial to carve out a space for the mother as she tirelessly gives all of herself to her child.

There then becomes a fine balance between checking in that a mother feels ok and checking up and imposing support onto the mother. Professionals such as social workers, doctors, therapists, teachers, working with the mother, should not be risk assessing in that way that might come across as judgmental. Rather they should be able to have compassion for the huge loss and the ongoing trauma's suffered offering the possibility of emotional support not as solution but as a space for the mother to talk freely and to communicate about herself. As these mother's so clearly spend most of their time communicating and interpreting for their children.

This research emphasizes that the life changes these mothers face are fundamentally existential and that it can be valuable to deal with their experiences through existential exploration. Existential psychotherapy's focus on the unavoidable limitations of human existence can support these mothers in creating their own meaning for their lives and allowing each mother to come to her own version of acceptance in a bespoke way (Stolorow, 2015). An existential approach will sit with uncertainty and the thrownness of the situation being comfortable with the discomfort without trying to ease it if that is not appropriate for the mother at that time (van, Deurzen, 2010). The existential approach has a way of bringing out the meaning even in the most horrific situations so the mother of child grappling with trauma and hope might feel a resonance towards this approach to gain a broader perspective again this has to come authentically from the mother herself and cannot be forced (Frankl, 1984).

One of the biggest benefits of existential therapy is that it should provide a non-judgemental environment for these mothers to express and discover their own emotions, of loss and grief, supporting these mothers to be in the world with their contradictory feelings, with the therapist skilfully offering validation and acknowledgement for their suffering, the relentlessness of it and that has no happy ending (Stolorow, 2015). For the mother sitting with all the confusion surrounding the inability to really know if how the mother interprets her child is accurate and the burden and anxiety that having such a role entails. Will generate feelings of loss, loss of their child's words and loss of the possibility of ever hearing their child call them mummy. It is in therapy sessions that despair will manifest itself and the existential therapist will travel with the mother through those moments of despair (van, Deurzen, 1984).

The unusual birth conditions separates these mothers from mothers healthy babies and the mothers find it difficult to be in the social world with other mothers who have healthy babies (Green, 2003b).The lack of communication that unfolds as their child does not develop speech, causes feelings of unease and worry. Existential therapy can also offer insight into the mothers four dimensions of existence to fully explore for each mother the impact having a disabled has on each of these areas of being in existence. The mother can then more clearly articulate which dimensions are impoverished and think about ways to refill her cup of support (Deurzen & Adams, 2015). This approach towards meeting the mother where she is at and sitting with the mother in each of her dimensions might take away some of the loneliness that the mother experiences and it might support the mother to create language for an experience that is somehow diminished by the language that relays it (Stolorow , 2015). This research might be of use to therapists who really want to facilitate bespoke therapy sessions, as it gives a deep awareness of the complexity of the life of these mothers for just communication between the mother and her child. How much more complex must the rest of the care being given be for these mothers.

With survival of birth hypoxia increasing because of new advances of medication there is a parallel increase in the mothers who are left carrying the baby. Therefore, the volume of mothers needing psychotherapeutic support is also rising,. Mothers who survive birth injuries and take home brain injured, palliative children have therefore created a phenomenon that they will bring to psychotherapy which will take a lot of courage on the part of these mothers. It is therefore possible that counsellors, psychotherapists and social workers are going to require more knowledge of this what it is like to live with a child that has such profound disabilities they have no speech, so that the professionals can meet the emotional needs of these mothers. Current social media content from advocates for disability such as Rachel Wright (Born in the Right Time, 2015) and Joanna Grace (The Sensory Project, 2019), seem to indicate that there is a growing awareness for the challenges that this group of mothers experience but that more education for professionals is necessary.

This exploration is consequently valuable to professionals and counselling psychotherapists as it reveals a unique and sadly growing phenomenon that is possibly becoming more commonly faced by therapists in the therapy room. This research is the first existential perspective on non-verbal communication between mothers and their children. Which then connects the niche emotional experiences to existential psychology theory and practice. This research advocates for more awareness of the wellbeing of a growing minority whose live experiences need to be seen and sensitively supported. I hope as the researcher it has provided a glimpse into this unique mothering experience that possible, hopefully will inform future clinical practice.

Implications on Existential Knowledge of Motherhood

As mentioned in the introduction of this research there is a growing body of exploration into existential aspects of motherhood. Arnold-Baker 2021, builds on previous research of the transition into motherhood and the confrontations of the mothers new existence in the light of her new status. Her work aligns with Stadlen, 2005 and 2011, where the mother faces her new responsibilities as a mother. Arnold-Baker describes the existential issues that arise as the mother deals with, her fears of her own mortality, isolation at finding herself a mother and the shock of being unprepared for this life transition. Arnold-Baker goes on to describe how anger is also a feature of motherhood as mothers felt tired from lack of sleep and worn down by the repetitive tasks of mothering each day. All of these existential themes surfaced during this participant interviews for this exploration what was very striking was how much more extreme some of the existential confrontations felt in the light of a mother who was not experiencing the expect path of motherhood.

Shulman 2020, describes the limbo of mothering a child in Neo-natal intensive care unit, in the context of a premature baby. Shulman finds that the mother struggles to form a bond and an attachment but this comes later. Shulman describes how this delays the mothers feelings of identifying as a mother. My findings clearly show that the mother feels at odds with the Neo-natal intensive care unit environment and her relationship with her baby is interrupted by not having privacy. The delay in feeling like a mother the case of complex cerebral palsy seems to last for many months after Neo-natal intensive care unit as the child fails to respond to the mother. Shulman describes guilt, loneliness and fear all existential issues that emerge for the participants of this research.

Shulman describes a loss of blissful naivety of the mother (2020), which comes from the realisation the premature baby might have died. The findings within in the phenomenon of this research and the experiences of the mother whose baby has a hypoxic brain injury. Differs to the Neo-natal intensive care unit experience as the mother spirals into a trauma response that forces the mother into hyper activity. The mother starts early interventions and a myriad of therapeutic appointments in a bid to rehabilitate her child. This acts as a way of not thinking about death because death is a possibility on every day of her child’s life. The mother has to find a way past death, to communicate on behalf of her child so that her child might have a life.

The new elements that this study on non-verbal communication between mother and child brings to the literature is that mothers describe absurdity of doing a task of communication. Using alternative communication aids the mother describes the hours and hours put into trying to establish this objective communication only to have to do it all again the next day as if the skill was never taught the day before.

Additionally this exploration highlights the agony of realising that mothering is not an autonomous process. It becomes clear that motherhood is steeped in laws that most mothers are not conscious of as they start their journey of parenting (Miller, 2000) . Once a child is born with additional needs a power dynamic arises between the mother her wants and desires of what she wants for her child and the state who she challenges to fund these additional needs. This is an aspect of motherhood not seen as clearly with neurotypical babies but is surely there in the many visits to health visitors in the first year checking and insuring a baby has its vaccinations, is gaining weight etc.

Garland (2019), describes the realisation of motherhood being a sense of being something bigger than oneself. For the participant mothers of this research the feeling of motherhood being something bigger is tied to a sense of responsibility, loss of freedom and a clear knowing that communication is key to their child's survival. The loneliness of this responsibility and the embodiment of motherhood is exacerbated by the mother becoming one being with her child and relinquishing her entire physical self to the process of her child's objective communication development.

This exploration looks at how existentialists view being in the world with others and for the mothers who come up against challenges to their child's potential to communicate 'Hell truly is other people' (Sartre, 1972 p.56). Though perhaps this is seen less intensely within the experience motherhood of healthy children, as Stadlen (2005), so accurately highlights in her reflections on motherhood in the chapter 'Who understands?' Hinting, at the social constructs that influence mothers.

The exploration also brings to the fore that motherhood is a choice, and although it is not much talked about there is always a choice whether to keep a child or give it up for adoption. Although these findings look intensely at the choice of the mother to engage her child, there is more scope to broadly explore the existential meanings around mothers who decide not to keep a baby at birth.

It is clear through past research that the transition into motherhood forces the mother to create meaning for her existence as well as motherhood giving her existence meaning (Arnold-Baker, 2021). The meaning derived in past research is not the same meaning that this exploration arrives at. The existential meaning for each participant mother was different and this is because a journey towards process the trauma that has occurred at birth and further trauma that the mother will never hear her child call her mother is different for each mother. Finding meaning for the mothers interviewed is about survival in the marathon that is being a carer for a vulnerable person for much, longer than just the first year of development. Trauma in of itself is an aspect of motherhood that is diluted when the experience follows a predictable path. Though many mothers feel trauma because of a bad birth or a challenge that was unexpected (Shulman, 2020).

In conclusion it is clear that parenting a child that has cerebral palsy and no real way to communicate consistently exacerbates the existential issues becoming a mother brings. As well as a confrontation with existential dilemmas that mothers of healthy children do not have to face in their day to day parenting.

Implications of Non-verbal Communication in Psychotherapy

Within the literature review of this research, I included the many forms that non-verbal communication can play out within the therapeutic alliance (Merleau-Ponty, 1962). I looked at more than one modality where silence and body language can be used as a tool to connect and meet the other person (Buber, 1970).

This research contributes another valuable insight when practising psychotherapy, and this is the element of time. It is possible, rather it is probable, that an instant connection might not form between client and therapist. The findings in my research shed light on the value of spending time to build up communication and learn about the other person (Stolorow, 2015). Through observation of the non-verbal the therapist might learn about why the alliance is not forming (Clarkson, 2002). Similarly, if the therapist attends to the somatic experience of being with a particular client, then that too might provide information about what is taking place between the therapist and client (Clarkson, 1997).

However, this exploration of non-verbal communication between mothers and their non-verbal children with complex cerebral palsy, clearly indicates that non-verbal communication has limitations. There is a very real need for mutually understood language in order to go beyond the client's needs and explore the inner landscape of the world within their minds. Non-verbal communication as one can see from the findings can offer insight into needs, emotional states and distress but it cannot reveal thoughts opinions or deep excavations of internal worlds.

Implications for Social Justice

The above observation leads onto the mother's experience as mediator, interpreter and voice of her child (Green et al., 2012). The mother can communicate and anticipate her child's every need better than anyone else and this is an exhausting 24 hours a day occupation. The onus therefore is on educators and social funders to provide for these children alternative communication equipment and adequate speech and language therapy to train everyone around the child how to communicate with communication aids. Clement, Aiello, 2021, describe how intensely parents are having to fight councils for care and Education, and Health Care Plan (EHCP)S, parents who already have so much to contend with. The mothers interviewed for this research make it really clear that they always know what their child needs, what their child wants but there are parts of their child's inner world that they cannot gain access to unless alternative augmentative communication is made available. Not only that but for the child to ultimately be safe in the world and objective form of communication must be reached so that the mother can be off duty and have some respite.

Implications in the field for Maternal Theories in Psychology

The findings of this research seems to imply that if the child is chronically ill, disabled and highly vulnerable, the mother perhaps remains in a state of preoccupation for the duration of mothering this child (Stern, 998). Leading to an extension of the non-verbal attuning that allows the mother to know what the child needs (Winnicott, 1960). How this emotionally plays out for the mother being in the world is explored further by (Mercieca & Mercieca, 2014b) who delved into the intense tuning in of one mother and her child and the all-encompassing all-consuming relationship (to the exclusion of all else), she develops with her child that has cerebral palsy (Wyn, 2007).

This research clearly shows that the participant mothers do not have magical powers. Nor is the communication a figment of their imagination. What can be seen is that through tuning in, observation and the felt sense the mother has exercised skills of communication (Winnicott, 1960). Similar to a ballet dancer perfecting dancing or a pianist practicing scales the mother develops highly skilled non-verbal communication skills between herself and her child which she could probably use elsewhere (which might be a subject for further exploration).

Finally it is clear that the participant mother's know independence of speech is not possible for their child. So what is the aim of all the communication efforts on the part of the mother especially when using communication aids? The participant mothers understood that it was not about independence it was about autonomy, choices, the freedom to choose and giving her child some autonomy within the confines of the child's disability. Piaget explains that being able to choose is stage of child development necessary for maturity that the participant mothers seem to instinctively recognize (Piaget, 1964) .

Transferability of Findings

The exploration of the experience of non-verbal communication can transfer across other conditions that require palliative care or no hope of recovery. The communication that I have explored is true of all mothers according to the literature (Winnicott, 1960) who find the ability within themselves to mother, just seen more intensely through the lens of such extreme mothering (Stadlen, 2020).

As a counselling psychotherapist whose past professional experience was working to encourage productivity, I have read many research papers that prescribe ways to support mothers of disabled children to continue to provide care for their children (Power et al., 2009). This prescriptive attitude might come through in the alliance and the mother might not feel heard or fully understood (Robertson & McGilly, 2009). As a phenomenological existential counselling psychotherapist, I have realised within my own client work the value of being with and listening to the experiences of the other person opposite me. It is important to explore with curiosity from a place of unknowing, holding in mind that my understanding of another person's use of language is limited to my interpretation. My realisation of the language barriers allows for the client to communicate a richer more personal experience because I constantly confirm that I am understanding my client correctly. It is this mindset that makes it possible for the counselling psychotherapist to be with, hold in the space and connect to experiences that the therapist has no prior knowledge of.

Dissemination

I believe that my work adds to a growing body of literature around motherhood and existential philosophy, and I intend to explore journal publication - by refining my thesis into a paper that I will try and get published in psychology and the speech and language therapy journals. I would like to continue to write for journals on the topic of non-verbal communication within the therapeutic alliance. I would also like to take the research to relevant conferences. I hope to develop this research into a book that might reach the mothers of disabled children who may not want to see a psychotherapist but are grappling with their existence within their lived experience.

Conclusion

Image 15:

AN ORCHARD OF MOTHERS

Dear Participant Mothers

Thank you for entrusting me with your words, and your drawing of trees, I wondered what a collective of mothers would be called in the context of this research and I came up with an orchard because of the fruits of your uterus's is the focus of this research. It was a privileged to sit and listen to each narrative and without participants this exploration could not have happened. I listened to the descriptions of the pain, the suffering, the joy and the achievements. This final picture is a nod to the babies before their birth injuries. Communication as you have all taught me takes on many forms and each mother has a unique way of forging a path through parenting a child with complex care that is non-verbal. I was moved by each mother I met and I hope that by documenting these findings others will be equally moved and perhaps these words put into sentences will start the process of positive social change and more effective professional support. By giving voice to the experiences of communicating with a non-verbal child we have also given a voice to those children and their determination to know their mothers and those people they grow to trust and love.

Humbly yours

Miriam

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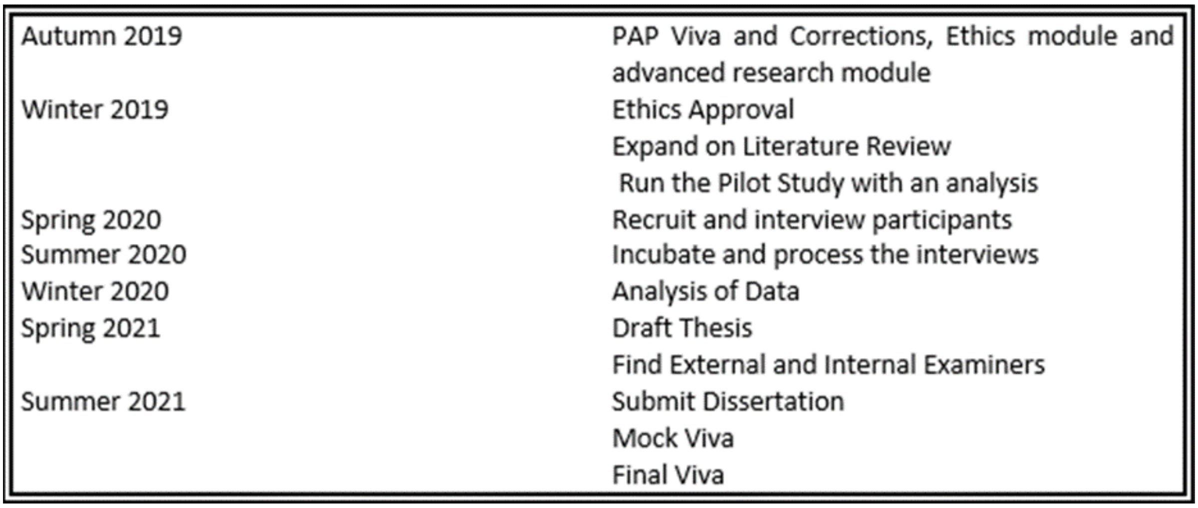
Appendix 1 Systematic Narrative Literature Search Terms Used:

Cerebral Palsy	Attachment
Care givers and Cerebral Palsy	Reciprocity
Communication and Cerebral Palsy	Synchrony
Complex care and motherhood	Maternal Love
Non-verbal communication and Cerebral palsy and mother.	Attachment and Cerebral Palsy
Maternal Grief and Cerebral Palsy	Maternal Competence and Cerebral Palsy

Social Justice and Cerebral Palsy	The experience of Cerebral Palsy
Parental stress and complex care work	Non-verbal communication in psychotherapy
Existential themes and living with Cerebral Palsy	Existential themes of motherhood
Phenomenological mothering Cerebral Palsy	Reciprocity and Cerebral palsy neonates
Mother Mediated Communication	Mother Mediated Communication Cerebral palsy

Appendix 2 Research Timetable

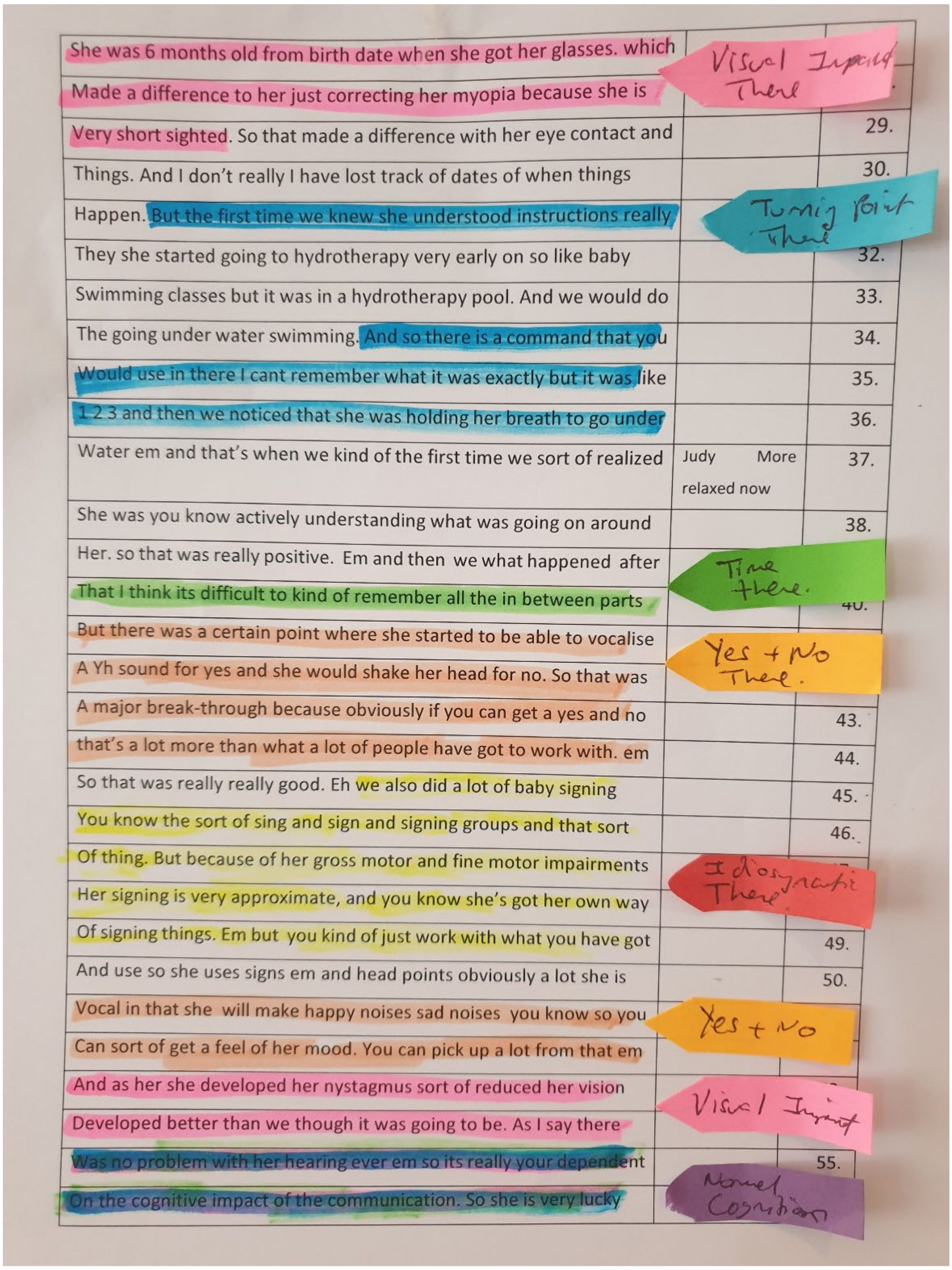
Timetable



Autumn 2019	PAP Viva and Corrections, Ethics module and advanced research module
Winter 2019	Ethics Approval
	Expand on Literature Review
	Run the Pilot Study with an analysis
Spring 2020	Recruit and interview participants
Summer 2020	Incubate and process the interviews
Winter 2020	Analysis of Data
Spring 2021	Draft Thesis
	Find External and Internal Examiners
Summer 2021	Submit Dissertation
	Mock Viva
	Final Viva

Appendix 3 Sample of Theme Explication

Using a highlighter I went through each transcript and colour coded each theme as it emerged.



She was 6 months old from birth date when she got her glasses. which	Visual Impaired There	
Made a difference to her just correcting her myopia because she is		
Very short sighted. So that made a difference with her eye contact and		29.
Things. And I don't really I have lost track of dates of when things		30.
Happen. But the first time we knew she understood instructions really	Turning Point There	
They she started going to hydrotherapy very early on so like baby		32.
Swimming classes but it was in a hydrotherapy pool. And we would do		33.
The going under water swimming. And so there is a command that you		34.
Would use in there I cant remember what it was exactly but it was like		35.
1 2 3 and then we noticed that she was holding her breath to go under		36.
Water em and that's when we kind of the first time we sort of realized	Judy More relaxed now	37.
She was you know actively understanding what was going on around		38.
Her. so that was really positive. Em and then we what happened after	Time there.	
That I think its difficult to kind of remember all the in between parts		40.
But there was a certain point where she started to be able to vocalise	Yes + No There.	
A Yh sound for yes and she would shake her head for no. So that was		
A major break-through because obviously if you can get a yes and no		43.
that's a lot more than what a lot of people have got to work with. em		44.
So that was really really good. Eh we also did a lot of baby signing		45.
You know the sort of sing and sign and signing groups and that sort		46.
Of thing. But because of her gross motor and fine motor impairments	Idiosyncratic There	
Her signing is very approximate, and you know she's got her own way		
Of signing things. Em but you kind of just work with what you have got		49.
And use so she uses signs em and head points obviously a lot she is		50.
Vocal in that she will make happy noises sad noises you know so you	Yes + No	
Can sort of get a feel of her mood. You can pick up a lot from that em		
And as her she developed her nystagmus sort of reduced her vision	Visual Impairment	
Developed better than we though it was going to be. As I say there		
Was no problem with her hearing ever em so its really your dependent		55.
On the cognitive impact of the communication. So she is very lucky	Normal Cognition	

Appendix 4

Full List of Emergent Themes and Prevalence

Findings	Mandy	Judy	Bunty	Jackie	Tracy	Jinty	Sandie	Tammy
	mt	Eh	Oa	Lg	K	Sk	Ash	Sp
1. The communication of first few days	✓	✓	✓	✓	✓	✓	✓	✓
2. Temporary visual impairment	✓	✓	✓				✓	✓
3. Temporary Hearing loss	✓						✓	✓
4. The communication of the first year	✓	✓	✓	✓	✓	✓	✓	✓
5. Desire to communicate	✓	✓	✓	✓	✓	✓	✓	✓
6. Communication Turning point	✓	✓	✓	✓	✓	✓	✓	
7. Establishing a yes and no	✓	✓	✓	✓	✓	✓		
8. Uncertainty of understanding	✓	✓	✓			✓	✓	✓
9. Paradox of both understanding and not understanding	✓	✓	✓			✓	✓	
10. Child's frustration of not being able to communicate	✓	✓	✓	✓				
11. The Frustration around communications	✓	✓	✓	✓				
12. Eyes to communicate	✓	✓			✓		✓	✓
13. Blink to communicate						✓	✓	
14. Arms to communicate		✓	✓	✓			✓	
15. Scratching to communicate					✓			
16. Legs to communicate	✓		✓					
17. Involuntary movements								✓
18. Felt sense communication	✓		✓		✓		✓	✓
19. Intuitive communication	✓	✓	✓		✓	✓		
20. Meditated communication					✓			
21. Enmeshed communication			✓		✓		✓	
22. Embodied communication	✓		✓		✓			
23. Physical aids for communication	✓	✓	✓		✓			
24. Speech Therapy support for communication	✓	✓	✓	✓	✓			
25. School support for communication				✓		✓	✓	✓
26. Fathers ability to communicate	✓	✓		✓	✓	✓		✓
27. The use of pronoun "We" to describe communication		✓				✓		
28. Sibling communication	✓	✓					✓	
29. Mother as interpreter	✓		✓		✓		✓	
30. Speech therapist as expert in communication				✓				
31. Time to communicate	✓	✓	✓	✓	✓			
32. Time spent develops communication	✓	✓	✓	✓	✓	✓	✓	✓
33. Time wasted waiting for help with communication		✓	✓					
34. Not enough time for everything		✓						✓
35. Taking responsibility to enable child to communicate	✓	✓	✓	✓				
36. Medication that interferes with communication					✓		✓	
37. Diet that interferes with communication			✓		✓		✓	
38. Dualism- mind/body of communication					✓			
39. Making religious meaning of this way of communication	✓	✓			✓		✓	✓
40. Making personal meaning of this way of communication			✓			✓		
41. Transcendence and acceptance	✓		✓			✓	✓	✓

42. Becoming a support to others for this kind of communication		✓			✓	✓		
43. Other parents as a support of this kind of communication		✓	✓	✓	✓	✓	✓	
44. Fighting for communication	✓	✓		✓		✓	✓	✓
45. Local resources for communication			✓					
46. Knowing what is available to help communication	✓	✓		✓		✓	✓	✓
47. Changes to social circle	✓					✓	✓	
48. Communicating with extended Family	✓		✓				✓	✓
49. Fathers who stay	✓			✓	✓	✓	✓	✓
50. Fathers who leave		✓	✓					
51. Impact on siblings	✓	✓					✓	
52. Medical professionals that disempower	✓	✓	✓		✓	✓	✓	
53. Medical professionals that empower	✓	✓				✓	✓	
54. Maintaining old social circles								✓
55. Living towards death with a very ill child	✓	✓			✓	✓	✓	
56. Doing versas being towards communication	✓	✓	✓	✓	✓	✓	✓	✓
57. Tiredness	✓	✓					✓	✓
58. The relentlessness of this communication	✓	✓	✓	✓				
59. Travelling the world for therapies for communication			✓		✓		✓	
60. Fear if one outlives the child	✓					✓	✓	✓
61. Paradox of being strong and at the same time vulnerable	✓	✓	✓	✓	✓	✓	✓	✓
62. Paradoxical emotions	✓	✓	✓	✓	✓	✓	✓	✓
63. Post Traumatic Stress	✓	✓	✓	✓		✓	✓	
64. Trauma upon a trauma	✓		✓	✓			✓	
65. Having EMDR for trauma	✓			✓				
66. Communicating in therapy	✓			✓				
67. Mothers struggle to communicate her experience	✓	✓					✓	✓
68. Suppressed Emotions		✓					✓	✓
69. Mother feeling heard					✓			
70. Mother feeling not understood	✓	✓				✓	✓	✓

Theme Explication Grouped and Coded into Themes

Findings	Mandy	Judy	Bunty	Jackie	Tracy	Jinty	Sandie	Tammy
	mt	Eh	Oa	Lg	K	Sk	Ash	Sp
1. The communication of first few days	✓	✓	✓	✓	✓	✓	✓	✓
2. Temporary visual impairment	✓	✓	✓				✓	✓
3. Temporary Hearing loss	✓						✓	✓
4. The communication of the first year	✓	✓	✓	✓	✓	✓	✓	✓
5. Desire to communicate	✓	✓	✓	✓	✓	✓	✓	✓
6. Communication Turning point	✓	✓	✓	✓	✓	✓	✓	
7. Establishing a yes and no	✓	✓	✓	✓	✓	✓		

8. Uncertainty of understanding	✓	✓	✓			✓	✓	✓
9. Paradox of both understanding and not understanding	✓	✓	✓			✓	✓	
10. Child's frustration of not being able to communicate	✓	✓	✓	✓				
11. The Frustration around communications	✓	✓	✓	✓				
12. Eyes to communicate	✓	✓			✓		✓	✓
13. Blink to communicate						✓	✓	
14. Arms to communicate		✓	✓	✓			✓	
15. Scratching to communicate					✓			
16. Legs to communicate	✓		✓					
17. Involuntary movements								✓
18. Felt sense communication	✓		✓		✓		✓	✓
19. Intuitive communication	✓	✓	✓		✓	✓		
20. Meditated communication					✓			
21. Enmeshed communication			✓		✓		✓	
22. Embodied communication	✓		✓		✓			
23. Physical aids for communication	✓	✓	✓		✓			
24. Speech Therapy support for communication	✓	✓	✓	✓	✓			
25. School support for communication				✓		✓	✓	✓
26. Fathers ability to communicate	✓	✓		✓	✓	✓		✓
27. The use of pronoun "We" to describe communication		✓				✓		
28. Sibling communication	✓	✓					✓	
29. Mother as interpreter	✓		✓		✓		✓	
30. Speech therapist as expert in communication				✓				
31. Time to communicate	✓	✓	✓	✓	✓			
32. Time spent develops communication	✓	✓	✓	✓	✓	✓	✓	✓
33. Time wasted waiting for help with communication		✓	✓					
34. Not enough time for everything		✓						✓
35. Taking responsibility to enable child to communicate	✓	✓	✓	✓				
36. Medication that interferes with communication					✓		✓	
37. Diet that interferes with communication			✓		✓		✓	
38. Dualism- mind/body of communication					✓			
39. Making religious meaning of this way of communication	✓	✓			✓		✓	✓
40. Making personal meaning of this way of communication			✓			✓		
41. Transcendence and acceptance	✓		✓			✓	✓	✓
42. Becoming a support to others for this kind of communication		✓			✓	✓		
43. Other parents as a support of this kind of communication		✓	✓	✓	✓	✓	✓	
44. Fighting for communication	✓	✓		✓		✓	✓	✓
45. Local resources for communication			✓					
46. Knowing what is available to help communication	✓	✓		✓		✓	✓	✓
47. Changes to social circle	✓					✓	✓	
48. Communicating with extended Family	✓		✓				✓	✓
49. Fathers who stay	✓			✓	✓	✓	✓	✓
50. Fathers who leave		✓	✓					
51. Impact on siblings?	✓	✓					✓	
52. Medical professionals that disempower	✓	✓	✓		✓	✓	✓	
53. Medical professionals that empower	✓	✓				✓	✓	
54. Maintaining old social circles								✓
55. Living towards death with a very ill child	✓	✓			✓	✓	✓	
56. Doing versas being towards communication	✓	✓	✓	✓	✓	✓	✓	✓
57. Tiredness	✓	✓					✓	✓

58. The relentlessness of this communication	✓	✓	✓	✓				
59. Travelling the world for therapies for communication			✓		✓		✓	
60. Fear if ones child outlives the parent	✓					✓	✓	✓
61. Paradox of being strong and at the same time vulnerable	✓	✓	✓	✓	✓	✓	✓	✓
62. Paradoxical emotions	✓	✓	✓	✓	✓	✓	✓	✓
63. Post Traumatic Stress	✓	✓	✓	✓		✓	✓	
64. Trauma upon a trauma	✓		✓	✓			✓	
65. Having EMDR for trauma	✓			✓				
66. Communicating in therapy	✓			✓				
67. Mothers struggle to communicate her experience	✓	✓					✓	✓
68. Suppressed Emotions		✓					✓	✓
69. Mother feeling heard					✓			
70. Mother feeling not understood	✓	✓				✓	✓	✓

Theme Explication with Major Themes

Findings	Mandy	Judy	Bunty	Jackie	Tracy	Jinty	Sandie	Tammy
Communication Over Time								
The communication of first few days	✓	✓	✓	✓	✓	✓	✓	✓
The communication of the first year	✓	✓	✓	✓	✓	✓	✓	✓
Communication Turning point	✓	✓	✓	✓	✓	✓	✓	
Temporary Sensory Impairment								
Temporary visual impairment	✓	✓	✓				✓	✓
Temporary Hearing loss	✓						✓	✓
Certainty and Uncertainty								
Establishing a yes and no	✓	✓	✓	✓	✓	✓		
Child's frustration of not being able to communicate	✓	✓	✓	✓				
The Frustration around communications	✓	✓	✓	✓				
Uncertainty of understanding	✓	✓	✓			✓	✓	✓
Paradox of both understanding and not understanding	✓	✓	✓			✓	✓	
Embodied Communication								
Eyes to communicate	✓	✓			✓		✓	✓
Looking to communicate	✓			✓				
Blink to communicate						✓	✓	
Arms to communicate		✓	✓	✓			✓	
Scratching to communicate					✓			
Legs to communicate	✓		✓					
Involuntary movements								✓
Tiredness	✓	✓					✓	✓
Medication that interferes with communication					✓		✓	
Diet that interferes with communication			✓		✓		✓	
Dualism- mind/body of communication					✓			

Being Towards Communication								
Physical aids for communication	✓	✓	✓		✓			
Felt sense communication	✓		✓		✓		✓	✓
Intuitive communication	✓	✓	✓		✓	✓	✓	✓
Meditated communication					✓			
Enmeshed communication			✓		✓		✓	
Mother as interpreter	✓		✓		✓		✓	
Time to communicate	✓	✓	✓	✓	✓			
Time spent develops communication	✓	✓	✓	✓	✓	✓	✓	✓
Time wasted waiting for help with communication		✓	✓					
Not enough time for everything		✓						✓
Fighting for communication	✓	✓		✓		✓	✓	✓
Local resources for communication			✓					
Knowing what is available to help communication	✓	✓		✓		✓	✓	✓
Doing versas being towards communication	✓	✓	✓	✓	✓	✓	✓	✓
The relentlessness of this communication	✓	✓	✓	✓				
Travelling the world for therapies for communication			✓		✓		✓	
Being in the World with Others								
Non-Medical Professionals								
The use of pronoun "We" to describe communication		✓				✓		
Speech Therapy support for communication	✓	✓	✓	✓	✓			
School support for communication				✓		✓	✓	✓
Speech therapist as expert in communication				✓				
Changes to social circle	✓					✓	✓	
Power								
Medical professionals that disempower	✓	✓	✓		✓	✓	✓	
Medical professionals that empower	✓	✓				✓	✓	
Immediate Family								
Fathers ability to communicate	✓	✓		✓	✓	✓		✓
Sibling communication	✓	✓					✓	
Paradox of being strong and at the same time vuJUDYerable	✓	✓	✓	✓	✓	✓	✓	✓
Extended Family								
Communicating with extended Family	✓		✓				✓	✓
Becoming a support to others for this kind of communication		✓			✓	✓		
Other parents as a support of this kind of communication	✓	✓	✓	✓	✓	✓	✓	
Maintaining old social circles								✓
Being towards Death								
Living towards death with a child that is ill	✓	✓			✓	✓	✓	
Paradoxical emotions	✓	✓	✓	✓	✓	✓	✓	✓
Fear if the parent outlives the child	✓					✓	✓	✓
Trauma								
Post Traumatic Stress	✓	✓	✓	✓		✓	✓	
Trauma upon a trauma	✓		✓	✓			✓	
Having EMDR for trauma	✓			✓				
Maternal Isolation and Disconnection								
Communicating in therapy	✓			✓				
Mothers struggle to communicate her experience	✓	✓					✓	✓
Suppressed Emotions		✓					✓	✓

Mother feeling heard					✓			
Mother feeling not understood	✓	✓				✓	✓	✓
Responsibility and Relatedness								
Desire to communicate	✓	✓	✓	✓	✓	✓	✓	✓
Taking responsibility to enable child to communicate	✓	✓	✓	✓				
Transcendence and acceptance	✓		✓			✓	✓	✓

Checking Themes Against the Research Phenomenon

The Phenomenological Experience of The Non-Verbal Communication Between Mothers and their Child with Complex Cerebral Palsy.	**Yes**	**No**	
Communication Over Time	**Y**		
The communication of first few days	Y		
The communication of the first year	Y		
Communication Turning point	Y		
Temporary Sensory Impairment	**Y**		
Temporary visual impairment	Y		
Temporary Hearing loss	Y		
Certainty and Uncertainty	**Y**		
Establishing a yes and no	Y		
Child's frustration of not being able to communicate	Y		One theme Fraustration
The Frustration around communications	Y		
Uncertainty of understanding	Y		
Paradox of both understanding and not understanding	Y		
Embodied Communication	**Y**		
Eyes to communicate	Y		One Theme idiosyncratic communication
Looking to communicate	Y		
Blink to communicate	Y		
Arms to communicate	Y		
Scratching to communicate	Y		
Legs to communicate	Y		
Involuntary movements	Y		
Tiredness	Y		
Medication that interferes with communication	Y		One theme Medication and Food
Diet that interferes with communication	Y		
Dualism- mind/body of communication	Y		
Being Towards Communication	**Y**		
Physical aids for communication	Y		Not sure this belongs here
Felt sense communication	Y		Somatic
Intuitive communication	Y		

Meditated communication	Y		
Enmeshed communication	Y		
Mother as interpreter	Y		
Time to communicate	Y		One theme Time
Time spent develops communication	Y		
Time wasted waiting for help with communication	Y		
Not enough time for everything	Y		
Fighting for communication	Y		
Local resources for communication		N	No direct link
Knowing what is available to help communication		N	No direct link
Doing versas being towards communication	Y		
The relentlessness of this communication	Y		
Travelling the world for therapies for communication	Y		Being in the world?
Being in the World with Others	**Y**		
Non-Medical Professionals		N	
The use of pronoun "We" to describe communication	*Y*		*Enmeshed?*
Speech Therapy support for communication	Y		Professionals one theme
School support for communication	Y		
Speech therapist as expert in communication	Y		
Changes to social circle		N	
Power		*N*	
Medical professionals that disempower		N	
Medical professionals that empower		N	
Immediate Family		*N*	
Fathers ability to communicate		N	
Sibling communication		N	
Paradox of being strong and at the same time vuJUDYerable		N	
Extended Family		*N*	
Communicating with extended Family		N	
Becoming a support to others for this kind of communication	Y		One theme parents supporting parents
Other parents as a support of this kind of communication	Y		
Maintaining old social circles		N	
Being towards Death		**N**	
Living towards death with a child that is ill		N	
Paradoxical emotions		N	
Fear if the parent outlives the child		N	
Trauma		**N**	
Post Traumatic Stress		N	

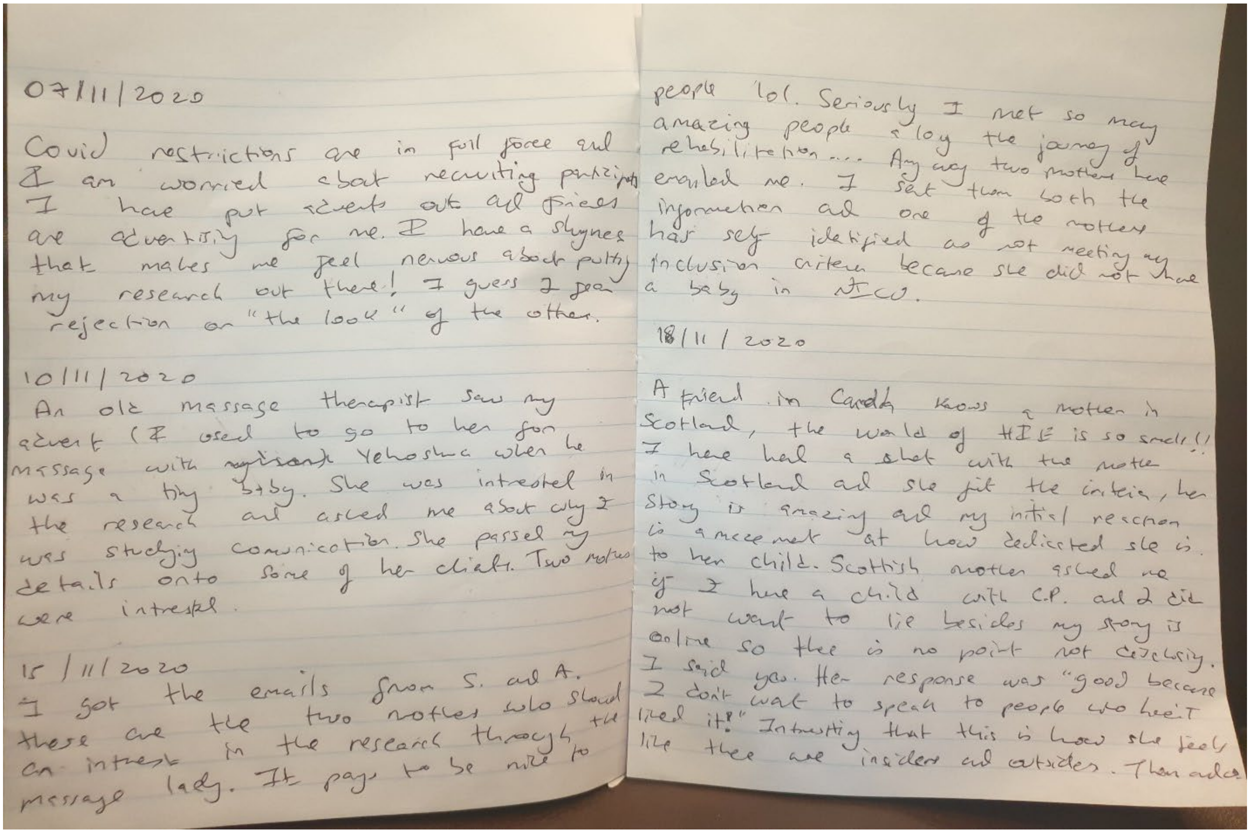
Trauma upon a trauma		N	
Having EMDR for trauma		N	
Maternal Isolation and Disconnection		**N**	
Communicating in therapy		N	
Mothers struggle to communicate her experience		N	
Suppressed Emotions		N	
Mother feeling heard		N	
Mother feeling not understood		N	
Responsibility and Relatedness			**Choice to communicate**
Desire to communicate	Y		
Taking responsibility to enable child to communicate	Y		
Transcendence and acceptance	Y		Communication over time?

Final Theme Explication

Findings	Mandy	Judy	Bunty	Jackie	Tracy	Jinty	Sandie	Tammy
The choice to communicate								
Desire to communicate	✓	✓	✓	✓	✓	✓	✓	✓
Taking responsibility to enable child to communicate	✓	✓	✓	✓				
Communication Over Time								
The communication of first few days	✓	✓	✓	✓	✓	✓	✓	✓
The communication of the first year	✓	✓	✓	✓	✓	✓	✓	✓
Communication Turning point	✓	✓	✓	✓	✓	✓	✓	
Accepting the limitations of the communication	✓		✓			✓	✓	✓
Impediments to Communication								
Temporary visual impairment	✓	✓	✓				✓	✓
Temporary Hearing loss	✓						✓	✓
Certainty and Uncertainty								
Establishing a yes and no	✓	✓	✓	✓	✓	✓		
Frustration around communications	✓	✓	✓	✓				
Uncertainty of understanding	✓	✓	✓			✓	✓	✓
Physical aids for communication	✓	✓	✓		✓			
Embodied Communication								
Idiosyncratic bodily communication	✓	✓			✓		✓	✓

Involuntary movements								✓
Tiredness	✓	✓					✓	✓
Medication or Diet that interferes with communication			✓		✓		✓	
Dualism- mind/body of communication					✓			
Being Towards Communication								
Somatic communication	✓		✓		✓		✓	✓
Intuitive communication	✓	✓	✓		✓	✓	✓	✓
Mediated communication					✓			
Enmeshed communication			✓		✓		✓	
Mother as interpreter	✓		✓		✓		✓	
Time to communicate	✓	✓	✓	✓	✓			
Fighting for communication	✓	✓		✓		✓	✓	✓
The relentlessness of this communication	✓	✓	✓	✓				
Being in the World with Others								
Professional support for independent communication	✓	✓	✓	✓	✓	✓	✓	✓
Travelling the world for therapies for communication			✓		✓		✓	
Communicating for your child	✓					✓	✓	
Parents supporting parents with communication.	✓	✓	✓	✓	✓	✓	✓	

Appendix 5 Sample of Journal Kept:



07/11/2020

Covid restrictions are in full force and I am worried about recruiting participants. I have put adverts out and friends are advertising for me. I have a shyness that makes me feel nervous about putting my research out there! I guess I fear rejection or "the look" of the other.

10/11/2020

An old massage therapist saw my advert (I used to go to her for massage with ~~my son~~ Yehoshua when he was a tiny baby. She was intrested in the research and asked me about why I was studying communication. She passed my details onto some of her clients. Two mothers were intrested.

15/11/2020

I got the emails from S. and A. these are the two mothers who showed an interest in the research through the message lady. It pays to be nice to people lol. Seriously I met so many amazing people along the journey of rehabilitation.... Anyway two mothers have emailed me. I sent them both the information and one of the mothers has self identified as not meeting my inclusion criteria because she did not have a baby in NICU.

18/11/2020

A friend in Cardiff knows a mother in Scotland, the world of HIE is so small!! I have had a chat with the mother in Scotland and she fit the criteria, her story is amazing and my initial reaction is amazement at how dedicated she is to her child. Scottish mother asked me if I have a child with C.P. and I did not want to lie besides my story is online so there is no point not disclosing. I said yes. Her response was "good because I don't want to speak to people who haven't lived it!" Interesting that this is how she feels like there are insiders and outsiders. Then adds

Ethical Approval

Appendix 6a Recruiting Advertisement

The Department of Health and Social Sciences
Middlesex University
Hendon
London NW4 4BT

"Mothers Who Listen, With More Than Ears"

This research requires participants- would you be interested?

The research is being led by a D-Psych student at the New School of Psychotherapy and Counselling accredited by Middlesex University: This research is exploring each mother's experience of communication between herself and her complex non-verbal Cerebral Palsy Child.

This research is looking for mothers of children with complex Cerebral Palsy, who are:

- *Unable to communicate consistently using their voice, hands or feet*
- *Over 3 years of age and has external nursery provision or a care package of support in place*
- *Not yet a legal adult.*
- *Not in a critically unwell condition currently*
- In addition to this your child was:
- *Diagnosed at or around birth with Cerebral Palsy or given some indication that Cerebral Palsy was a possibility from the start*
- *Unresponsive and unable to feed at birth*
- *In intensive care at birth*

This researcher is interested in mothers' experiences and would like to learn about their experience of communication with their child.

If you feel emotionally able to share your experience in an interview, then this research might be something you will be able to contribute to. Part of the interview will include producing some form of artwork (no art skills are necessary.)

For more information, please contact me.

Miriam Tasgal

Email: MJUDY006@live.mdx.ac.uk

Appendix 6b Participant Information Sheet

The Department of Health and Social Sciences
Middlesex University
Hendon
London NW4 4BT

Participant Information Sheet

Date: 28/01/2020

Title: "Mothers Who Listen, With More Than Ears"

The Phenomenological Experience of The Non-Verbal Communication Between Mothers and their Child with Complex Cerebral Palsy.

Invitation paragraph

My name is Miriam Tasgal and I am an Existential Counselling Psychotherapy Doctoral student at the New School of Psychotherapy and Counselling affiliated with Middlesex University, London. I would like to invite you to take part in my research project. The research project is about mothers who have children with complex cerebral palsy that affects their child's ability to speak or communicate consistently. Through this research I hope to learn more about the experience of communicating for the participant mothers. This is an opportunity for mothers to share their experience. In addition, the research hopes to inform health care professionals about mothers within this experience of non-verbal communication. Before you decide if you want to take part, it is important that you read the inclusion and exclusion criteria.

Inclusion Criteria

- You have a child with complex Cerebral Palsy.
- Your child cannot communicate consistently.
- Your child was diagnosed at or around birth with Cerebral Palsy or given some indication that Cerebral Palsy was a possibility from the start.
- Your child was unresponsive and unable to feed at birth.
- Your child spent time in intensive care at birth.
- Your child is over 3 years of age and has external nursery provision or a care package of support in place.
- You do not mind doing some artwork as part of the research (no art skills are necessary).

Exclusion Criteria

- Your child did not spend the early part of life in intensive care
- Your child can consistently use a communication device even when they are unwell
- Your child who is in a critical condition currently
- Your child is not yet an adult.
- You do not have enough care support in place to participate
- You don’t feel emotionally able to share your experience.

Please ask any questions if you are uncertain about the inclusion and exclusion criteria.

What is the purpose of the research?

This research aims to shine a light on level 5 complex childhood Cerebral Palsy, exploring what the internal world and life experiences of the mother is like, in relation to the complex non-verbal communication with her Cerebral Palsy child. There is no hypothesis, simply a quest to explore the lives of these mothers in the context of their experience.

Why have I been chosen?

You have been chosen because your experience is valuable to the contribution of knowledge and raising awareness on how mothers experience non-verbal communication. You have also met all the criteria above and wish to be a part of this project.

Do I have to take part?

Please consider the information sheet carefully and talk about it with your family or friends.
You do not have to take part; it is your decision. If you do want to take part, you will be
asked to sign a form giving consent. You will be given a copy of this information sheet and
your signed form to keep. You are free to stop taking part at any time during the research
without giving a reason.

What will happen to me if I take part?

You will be contacted by researcher to check that you have met the criteria.
A place, date and time will be arranged for an in-depth interview.
The researcher will make sure that you have understood the aims of the study and provide written consent. The interview will last for 1 hour, it will be audio digitally recorded and stored in a password

protected computer. You will also be asked to do a piece of artwork (no art skills are required). You will be asked to describe what the artwork or photograph means to you something the viewer can't know unless the viewer is told. The "art" contribution will be photographed after you have been interviewed and used as part of the data for this research.

You will be debriefed after the interview and you will have an opportunity to ask any questions. Details will be given of avenues of further support as well as contact details of the researcher and supervisor.

Right to stop the interview

You will be free to pause or stop the interview at any time during the interview. No reason is needed.

Right to withdraw

Participants are free to withdraw at any time up until analysis which will be in December 2020, with no reason needed, all data will be destroyed.

What will happen to my data?

Data will be transcribed by the researcher and seen by the research supervisor.

All reasonable measures will be taken to anonymise data and all identifying features removed such as name and location etc.

Data will be coded and original recording destroyed.

Data will be kept on a password protected file on an encrypted USB.

Paper copies will be stored in a locked cabinet in researcher's own home.

Identifying data stored separately and not linked.

Only the researcher and supervisor will have access to data.

Data will be destroyed after 10 years.

What are the possible disadvantages to taking part?

Participating in this research takes 2 hours of your time, when having a disabled child takes up a lot of time. You may find yourself feeling emotional at times as you think back through your journey of communication, so having a good support system in place is very important. A list of agencies, organisations etc. will be offered as part of the debrief after the interview.

What are the possible advantages of taking part?

Taking part in this research may contribute your experience to a wider audience, especially professionals. The artwork you produce will be yours to keep. Sharing an experience often gives deeper meaning and insight into the experience.

Consent

Through complete transparency every step of the way you will be fully informed and know what you are consenting to. Only once you have fully understood everything and raised any questions you may have will consent be obtained from you. You can withdraw at any point up until the data has been analysed. This should take place in December 2020.

Who is organising and funding the research?

This research is self-funded under the guidance of Middlesex University. There is no commercial gain from this project and there is a genuine interest in investigating this experience to understand it better.

What will happen to the data?

Your data will be stored on a password protected file on the researcher's personal computer for up to 10 years. It will be used for research and education purposes only. All reasonable steps will be taken to ensure that all names and identifying details are changed.

Who has reviewed the study?

All proposals for research using human participants are reviewed by an Ethics Committee before they can proceed. The NSPC Ethics sub-Committee have reviewed this proposal.

Concluding section

I consider this research important and hope that it could potentially support mothers with their children who have Cerebral Palsy.

I would like the opportunity to explore together with my participants what it is like to communicate non-verbally. Thank you for your interest and participation.

Researcher: Miriam M. Tasgal
MJUDY006@live.mdx.ac.uk

First supervisor: Dr Charlotte Harkness

Appendix 6c Participant Consent Form

61-63 Fortune Green Road,
The Burroughs,
West Hampstead,
London NW4 4BT

Middlesex University School of Science and Technology
Psychology Department

Written Informed Consent

Title of study: “Mothers Who Listen, With More Than Ears”
The Phenomenological Experience of The Non-Verbal Communication Between Mothers and their Child with Complex Cerebral Palsy.

Academic Year: 2020

Researcher: Miriam (Mazal) Tasgal MJUDY006@live.mdx.ac.uk
Supervisor*:* *Charlotte Harkness*

- I have been fully informed of the details of the research, including the risks and benefits, as explained to me by the researcher and confirm that I consent to act as a participant.

- I have been given contact details for the researcher in the information sheet to keep.

- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from participating in the project up until data is analysed in December 2020 without any obligation to explain my reasons for doing so.

- I consent to being recorded for the purposes of data collection and understand that my recording will be destroyed upon transcription.

- I understand that the transcript will be coded and anonymised and all reasonable steps will be taken to ensure my data will not be identifiable. I further understand that my data will be stored in password protected files or in a locked cabinet in the researcher's own home for up to 10 years.

- I understand that I can ask for my data to be withdrawn from the project until data analysis begins in December 2020.

- I further understand that the data I provide may be used for analysis and subsequent publication, such as psychology journals, speech and language journals or PowerPoint presentations for educators, medical doctors and policy makers. I provide my consent that this may occur.

- I also consent to the researcher contacting her supervisor should any concerns for my wellbeing arise.

Print name_____________________ Sign Name______________________

Date: _________________________

To the participant: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ___________

Appendix 6d Participant Debriefing Form

NSPC
61-63 Fortune Green Road,
West Hampstead,
London NW6 1DR

Middlesex University London
The Burroughs,
Hendon,
London NW4 4BT

The New School of Psychotherapy and Counselling (NSPC) and the Psychology Department, Middlesex University, School of Science and Technology

Debriefing Form

Title of study: “Mothers who listen with more than ears”: The phenomenological experience of the non-verbal communication between mothers and their child with complex cerebral palsy.

Academic year:

Researcher: **Miriam Tasgal**
MJUDY006@live.mdx.ac.uk

Academic Supervisor: **Charlotte Harkness**
NSPC, 61-63 Fortune Green Road, West Hampstead,
London, NW6 1DR
020 3515 0223

Thank you for participating in this research by taking part in the interview.

The interview in which you participated was designed to explore how you experience communication with your non-verbal complex cerebral palsy child. To give you the opportunity to voice your experience which may help other mothers who have felt isolated by their experience. It is hoped that this research will inform multi-disciplinary professionals about what is helpful to new parents who will only be at the start of their journey and how to offer them more suitable support.

Please let me know:

- If you would like to add anything we discussed during the interview
- If you have any questions about this research and its aims?
- If there was anything you found useful or not so useful about the interview.

- If you wish to withdraw at any time from the study, until data analysis starts in December 2020.

- If you wish for the findings to be shared with you.

The data that results from this research project will be anonymised and you will be identified with a code and not your name. The data will be stored on a password protected computer and stored in a locked filing cabinet. This data will be stored for 10 years. The data generated will be used for my doctoral thesis and for other academic purposes including journal articles.

If anything discussed in this interview has caused you any distress, you can contact the many support services available that have been listed below. This experience may have brought up the need for having someone to talk to in a therapeutic setting. How to find therapeutic emotional support is also listed below. Additionally, free therapy is available on the NHS. To find out more about this contact your registered GP.

Please find a list of support agencies should you need additional support

For Therapeutic Emotional Support:

UKCP Psychotherapy Register - http://members.psychotherapy.org.uk/find-a-therapist/

BACP Psychotherapy Register - https://www.bacp.co.uk/about-therapy/how-to-find-a-therapist/

Samaritans (24 hour helpline)

Telephone: 08457 90 90 90

Email: jo@samaritans.org

For Practical Information and Support:

The Communication Trust – Every child understood https://www.thecommunicationtrust.org.uk/
Contact a Family- https://contact.org.uk/
Cerebra - https://cerebra.org.uk/
Family Fund- https://www.familyfund.org.uk/
Scope -
https://www.scope.org.uk/?gclid=CjwKCAiA98TxBRBtEiwAVRLqu_LC9FbCc5Aund9UCq7XLVxM28a7nyuWdNf9LsqzkM1r3EKfd2l5-hoC5-EQAvD_BwE

Appendix 7 Ethical Approval Forms

Middlesex University Data Protection Checklist for Researchers

REC no:______

Project title: "Mothers Who Listen With More Than Ears"

The Phenomenological Experience of The Non-Verbal Communication Between Mothers and their Child with Complex Cerebral Palsy.

PI/Supervisor: Charlotte Harkness **Date: 29/01/2020**

There are **8 Data Protection Principles**, which states that information must be:

1. Fairly and lawfully processed;
2. Processed for specified and lawful purposes;
3. Adequate, relevant and not excessive;
4. Accurate and kept up date where necessary;
5. Not kept for longer than is necessary;
6. Processed in accordance within individuals' rights under the DPA;
7. Kept secure;
8. Not transferred to countries without adequate protection.

Section 33 of the Data Protection Act 1998 (DPA) provides exemption to some of the eight data protection principles for processing personal data for 'research purposes' including statistical or historical purposes. These are noted in the checklist below.

For guidance on the Data Protection Act for Social Research please see the MRS/SRA Data Protection Act 1998: Guidelines for Social Research, April 2013 which can be accessed using the following link: http://www.mrs.org.uk/pdf/2013-04-23%20MRS%20SRA%20-%20DP%20Guidelines%20updated.pdf

Guidance on large data sets can be found at the Information Commissioner's Office website – Big Data and Data Protection July 2014. http://ico.org.uk/news/latest_news/2014/~/media/documents/library/Data_Protection/Practical_application/big-data-and-data-protection.pdf

You may also find JISC Legal Information on Data Protection and Research Data Questions and Answers, Aug 2014 helpful. http://www.jisclegal.ac.uk/ManageContent/ViewDetail/ID/3648/Data-Protection-and-Research-Data-Questions-and-Answers-21-August-2014.aspx

Note: Personal data which is anonymised[i], permanently, is exempt from compliance with the DPA and registration process. See endnotes for further details.

Conditions which must be met for a research exemption to apply under section 33 of the DPA 1998	**Please indicate**		
1. The information is being used **exclusively for research** purposes?	Agree		
2. The information is not being used to **support measures or decisions relating to any identifiable living individuals**?	Agree		
3. The data[ii] is not being used in a way that will **cause** or **is likely to cause, substantial damage or substantial distress** to any individuals or very small groups? *If you 'Disagree' please provide details why an adverse effect is justified:*	Agree		
4. The results of the research, or any resulting statistics, will **not be made available in a form that identify individuals**? *If you 'Disagree' please provide details why identification is intended:*	Agree		
If you 'Agree' to all of the above conditions then the use of personal data is exempt from the Second Principle and the Fifth Principle, but you must comply with First, Third, Fourth, Sixth, Seventh and Eighth Principles of the DPA. If a research exemption does not apply then you must ALSO comply with the Second and Fifth Principles of the DPA			
First Principle: Fairly and lawfully processed			
5. Will you have appropriate **informed consent**[iii] secured from participants for the **personal data**[iv] that you will be analysing? i.e., **inform participants** of a) What you will **do** with the data? b) Who will **hold** the data? (Usually MU, unless a third party is involved) c) Who will have **access** to the data or receive copies of it? (e.g., for **secondary data sets**, are you sure that appropriate consent was secured from participants when the data was collected?) *If 'no' please provide details and any further actions to be taken:*	Yes		
6. If you plan to analyse **sensitive personal data**[v], have you obtained **data subjects'**[vi] **explicit informed consent**[vii] (as opposed to **implied consent**[viii])? *If 'no' please provide details:*	Yes		
7. If you do not have the data subjects' explicit consent to process their data, are you **satisfied that it is in the best interests of the data subject** to collect and retain the sensitive data? *Please provide details:*		NO	
8. If you are processing[ix] personal data about **younger individuals or those with reduced capacity**, have you put a process in place to obtain consent from parents, guardians or legal representatives, if appropriate? *Please provide details:*			N/A
9. Will you have a process for managing **withdrawal of consent**? *If 'no' please provide details:*	Yes		

10. Will it be necessary or desirable to work with external organisations e.g., charities, research organisations etc. acting as **a third party** i.e., directly providing a service for us or on our behalf that involves them accessing, collecting or otherwise processing personal data the third party will become a data processor under the DPA? *If 'yes' then you will be using a third party as a data processor you must take advice from the Middlesex University Data Protection Officer about the planned contractual arrangements and security measures.*		No	
11. If you hold or control personal data, will you **register and/or inform** the Middlesex University Data Protection Officer when: i) A new dataset has been established, ii) The purpose for which personal data stored in a dataset has changed, iii) A networked dataset of personal data is being used, iv) Extracting personal data from a networked dataset to create a new dataset.	Yes		
Second Principle: Processed for limited purposes			
Will personal data be obtained only for **one or more specified and lawful purposes**, and not further processed in any manner incompatible with the purpose(s)? (Research data subjects should be informed of any new data processing purposes, the identity of the **Data Controller**[x] and any disclosures that may be made.) **Research Exemption Note** (section 33(2)): Personal data can be processed for research purposes other than for which they were originally obtained if that processing does not lead to decisions being made about an individual and is not likely to cause substantial damage or distress to an individual. That data may also be held indefinitely (Section 33(3)).			NA
Third Principle: Adequate, relevant and not excessive			
12. Will you only collect data that is **necessary** for the research? *If 'no' please provide details and any further actions to be taken:*	Yes		
Fourth Principle: Accurate and where necessary, kept up to date			
13. Will you take reasonable measures to ensure that the information is **accurate**, **kept up-to-date** and **corrected** if required? *If 'no' please provide details:*	Yes		
Fifth Principle: Not kept for longer than is necessary			
14. Will you check **how long data legally must be kept** and **routinely destroy** data that is past its retention date and **archive data** that needs to be kept? **Research Exemption Note** (section 33(3)): Personal data processed for research purposes can be kept indefinitely.			NA

Sixth Principle: Processed in accordance with individuals' rights under the DPA[xi]			
15. If you are intending to publish information, which could **identify individuals**, have you **made them aware** of this when gaining their informed consent? *If 'no' please provide details:*	Yes		
16. Will you allow **access to all personal data** held about a data subject if an individual makes this request? **Research Exemption Note** (section 33(4)): Where the results of processing personal data for research purposes do not identify a data subject, that data subject does not have a right of access to that data.	Yes		
17. Will you ensure that all researchers who have access to **personal data** understand that it **must not be provided to any unauthorised person or third party** (e.g. family members etc.) unless consent has been given?	Yes		
Seventh Principle: Kept secure			
18. Will you ensure that personal data will be **stored in locked cabinets, cupboards, drawers** etc. (regardless of whether data is on paper, audio visual recordings, CDs, USBs, etc.)?	Yes		
19. Will you ensure that if personal data is to be **stored electronically** it will only be kept on **encrypted devices**?	Yes		
20. Will you ensure that individuals who have access to the personal data are aware that **email is not a secure method** of communication and should **not be used for transferring the data**?	Yes		
21. Will you ensure that **disposal of personal data** will be via **confidential waste services** or in the case of **electronic media and hardware** should be **destroyed** in line with Middlesex University guidelines and procedures?	Yes		
Eighth Principle: Not transferred to other countries without adequate protection			
22. Will you **ensure that personal data is not transferred outside the EEA** unless one of the following applies? i. The country you are transferring the data to has been approved as providing adequate protection ii. You have obtained explicit informed consent from the individual(s) iii. You have a contract in place with the recipient of the data, which states the appropriate data protection requirements. iv. You have completely anonymised the data.	Yes		

Any concerns in relation to compliance with the DPA should be discussed with the Middlesex University Data Protection Officer.

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[i] **Anonymous data** is prepared from personal information but from which, an individual cannot be identified by the person holding the data. **Anonymisation** is a **permanent** process. Personal data must be treated so that it cannot be processed in such a way as to link the data to a specific individual (e.g., using an identifier). Coded data is not anonymised and therefore not exempt from compliance or registration.

[ii] **Data** covers information that is held on computer, or to be held on computer to be processed. Data is also information recorded on paper if you intend to put it on computer.

[iii] **Informed consent** means providing participants with a clear explanation of the research project in order for them to give informed consent regarding the use of their data. Individuals should be informed that their involvement is voluntary and that they have the right to refuse or withdraw at any time without any negative consequences.

Informed refers to the following information being provided to the data subject/participant:

- i) Who you are, the organization you work for and who else is involved in the research project or using the data.
- ii) What data will be collected and how.
- iii) Who will hold the data, control access to the data and how it will be stored and kept safe and whether it will be transferred to a third party.
- iv) How the data will be used.
- v) How long it will be kept and what will happen to it at the end of the project.
- vi) Risks related to any aspects of the research project and data, benefits of the research project and any alternatives.

[iv] **Personal data** (sometimes referred to as personal information) means data which relate to a living individual who can be identified from those data whether in personal or family life, business or profession, or from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller. The data is of biographical significance to the individual and impacts an individual in a personal, family, business or professional capacity. It includes any expression of opinion about the individual and/or statements of fact.

[v] **Sensitive personal data** means personal data consisting of information about the **data subjects'**,

1. Racial or ethnic origin,
2. Political opinions,
3. Religious beliefs or other beliefs of a similar nature,
4. Trade union membership
5. Physical or mental health or condition,
6. Sexual life,
7. Criminal matters

   Also personal financial details are vulnerable to identity fraud and should be handled confidentially and securely although not defined as sensitive under the Act.

[vi] **Data subject** is a living individual to whom the personal data relates. If an individual has died or their details have been anonymised then their data does not fall within the Act. Personal data relating to deceased individuals may still be owed a duty of confidentiality.

[vii] **Explicit informed consent** is where an individual actively opts to participate.

[viii] **Implied consent** is where an individual must inform the researcher that they wish to opt out.

[ix] **Processing** of personal information includes collecting, using, storing, destroying and disclosing information.

[x] **Data controller** is the person who either alone or jointly on in common with other persons determines the purposes for which, and the manner in which, any personal data are or are to be, processed. The fact that an individual or institution holds or processes personal data does not make them a Data Controller if they do not determine the purpose and manner of that holding or processing. (This is probably one of the most widely misunderstood definitions of the Act.) In most cases the Data Controller will be Middlesex University, however further guidance and clarification can be sought from the Middlesex University Data Protection Officer.

[xi] **Data subject rights** include rights to access, for accuracy, to prevent processing likely to cause damage or distress, to prevent direct marketing, to prevent automated decision making, to seek compensation and for no third party access. Access means an individual can make a subject access request for all copies of all personal data held about them and ask to whom it has been disclosed. An individual potentially has access to personal comments written about them. It is an offence to deliberately edit or destroy data once a subject access request has been received. Third parties do not generally have access to subject data unless an exemption applies or there is overriding public interest. There may be limited third party access to ordinary personal data relating to a business or professional capacity in the public interest through the Freedom of Information Act.

Middlesex
University
London

Research Fieldwork Risk Assessment

This form is for students and staff undertaking any type of research fieldwork

The Principal Investigator/Supervisor is responsible for completing a risk assessment of their research activities i.e., identifying any potential hazard which could occur during data collection activities and determining appropriate actions to minimise the risk of harm, accident or illness. The results of risk assessments should be shared with all project staff. All team members should be given a copy of the completed risk assessment(s) to ensure that they have a full understanding of all issues identified and addressed.

PLEASE NOTE: applicants completing data collection in an external institution/organization may need to complete and submit the risk assessment documentation provided by the institution/organization, as required for insurance purposes.

Project Title/ Reference/ID No.	Project Title: “Mothers Who Listen With More Then Ears”	Reference/ID no:	
Researcher details:	Name: Miriam (Mazal) Tasgal Student no. if applicable: M00665747	Role: Principal Investigator/Supervisor/Data Collector	
Researcher details:	Name: Student no. if applicable:	Role: Principal Investigator/Supervisor/Data Collector	
Next-of-kin for …………………………	Name: [redacted]	Contact Details: [redacted]	
Next-of-kin for …………………………..	Name: [redacted]	Contact Details: [redacted]	
Date of risk assessment:	30.01.2020	Review Date:	

DECLARATION: By submitting this form you are agreeing to allow us to be in contact with your next-of-kin in the case of an emergency.

Please give details where the research/data collection will be completed:

Location	**Name/position of contact**	**Place for fieldwork/organisation**	**Address**	**Tel:**	**Email:**
1.	In the Participants area in a hired interview room		Not yet known		

2.	Researchers home		[redacted]		MJUDY006@live.mdx.ac.uk
3.	Face to Face Or Zoom		Address online		

POTENTIAL HAZARDS: please inform us of any hazards you may face whilst on location

Examples of Potential Hazards:

i) Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

1. Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.
2. Demolition/building sites, assault, getting lost, animals, disease.
3. Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.
4. Lone working: difficult to summon help, alone or in isolation, lone interviews.
5. Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders.
6. Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.
7. Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.
8. Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.
9. Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.
10. Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

Location	Potential risk/hazard	Who might be harmed and how?	Precautions to be taken to control this risk	Additional safety measures/ equipment that may be needed	Action by who?	Action by when?	Done
1a	Doing research away from home or University Campus	Researcher	Using a well set up interview room in a populated area during the day light hours.	Doing research in a safe way See Appendix 1: for check list.	Researcher	At the start of the journey.	
1b	Meeting strangers (Participants) Conduct during visit Risk of verbal/physical abuse/harassment	Researcher	Participants might be aggressive or volatile	Being vigilant and making sure to not be alone in a building or go to the participants own home Appendix 2 for full check list.	Researcher	During the interview	
2a	Travel to/from location	Researcher and Participant	Transport may not be running participants may struggle to find location ect.	Send google map directions in advance. See Appendix 3 for full checklist	Researcher	Before the interview	
2b	Traveling in Bad weather	Researcher and participant	Insure to be dress appropriately for the weather in the event of it being a hot day ensure water is available	If any delays are caused by weather phone and let the participant know you might be delayed See Appendix 4 for full checklist	Researcher	On the day of the interview	

2c	Adequate facilities	Researcher and participant	Call up the location and ask for details.	Ask for photos or google for photos on trip advisor.	Researcher	Before booking the room	
2d	Disabled access if needed	Researcher and participant	Call up the location and ask about access	Ask participants about additional needs.	Researcher	Before booking the room	
2e	Health and safety checks	Researcher and participant	Ask site manager for a copy of health and safety certificate	Always check	Researcher	Before booking the room	
2f	Comfort, dignity and confidentiality	Researcher and participant	Insure that as much as possible the rooms are fit for purpose	Read online reviews of these rooms.	Researcher	Before booking the room	
3a	Art materials may be messy or might not be appropriate	Researcher and Participant	In sure that adequate cleaning supplies are at hand	Because of point 1. No sharp objects will be used during the art session	Researcher	Before the interview starts	
3b	Check with participants that they have no allergies to art materials	Participants	Look at the ingredients of art supplies	Only bring art supplies that the participant is not allergic to	Researcher	Will ask participants over the phone	
3c	Layout and equipment	Researcher and Participant	Check the room insure it is safe	Look for potential hazards see Appendix 5 for full checklist. Arrive early to do so and contact the building manager	Researcher	On the day	
4a	Participants may have to cancel in the last minute due to ill health of their child	Researcher	Ask for an alternative date to rebook the interview	Check that there is a cancellation policy with hired interview room See Appendix 3 for full checklist	*Researcher*	*On the day*	
4b	If a participant brings a child to the interview	Researcher and participant	Terminate the interview	Explain that an interview with a child present will not be possible	*Researcher*	*Before the interview. During the preliminary phone call remind participant that no children may be present*	
5	Researcher's safety	Researcher	Do as much as possible to minimise risk	Explore what risks might arise. See Appendix 6 for full checklist	*Researcher*	*Before embarking on any interviews*	
6	In the Event of an accident or emergency	Participants and Researcher	Think about potential unforeseen accidences or sudden ill health	Have a crisis plan in place. Let participants know what the emergency procedures are See Appendix 7 for comprehensive checklist	*Researcher*	*Before interview*	
7a	Covid19	Participants and Researcher	Consider social distancing by doing fieldwork online via Zoom or Skype	Following government and Middlesex University guidelines (see appendix 8a)	*Researcher*	*Before interview*	
7b	Zoom or Skype	Participants and Researcher	Risk of being hacked or data stolen	Think about security measures e.g. passwords, firewall (see appendix 8b)	*Researcher*	*Before interview*	

Examples of precautions:

i) Providing adequate training, information & instructions on field/location work tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use.

4 Assessing individual’s fitness and suitability to environment and tasks involved.

5 Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.).

6 Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances.

7 First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements).

8 Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.**

9 Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations.

10 Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of field/location work area.

FIELD/LOCATION WORK CHECK LIST

i) Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:

Safety knowledge and training?

Awareness of cultural, social and political differences?

Physical and psychological fitness and disease immunity, protection and awareness?

Personal clothing and safety equipment?

Suitability of field/location workers to proposed tasks?

1. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed regarding:

Legal access to sites and/or persons?

Political or military sensitivity of the proposed topic, its method or location?

Weather conditions, tide times and ranges?

Vaccinations and other health precautions?

Civil unrest and terrorism?

Arrival times after journeys?

Safety equipment and protective clothing?

Financial and insurance implications?

Crime risk?

Health insurance arrangements?

Emergency procedures?

Transport use?

Travel and accommodation arrangements?

Important information for retaining evidence of completed risk assessments:

Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the field/location worker participating on the field course/work.

Appendix 1:
Offsite checklist:

- site visit is appropriate and necessary
- conduct introductory phone call to participant to confirm attendance.
- Depending how far the location Researcher will check onsite prior to interviewees
- conduct off-site visits within normal working hours (have a plan of action if this is not possible)
- Check train timetables and train delays.
- Interview only in daylight hours
- gather only as much information as is necessary to complete risk assess of location and relevant background info on participant
- plan routes and transport in advance/carry maps and timetables as appropriate

- wear appropriate, non-offensive clothing
- Avoid carrying any confidential material
- ensure CRB clearance if working with children or vulnerable adults
- always display NSPC/Middlesex ID card
- Avoid carrying large amounts of cash, jewellery or valuables
- Don't leave valuables in the open (lap top, ;purse etc)
- Only walk to public transport on will lit streets and try to finish before dusk.
- consider strategies that may reduce risks (travel by taxi, disguising laptops in non laptop bags)
- carry a mobile phone to call for help
- carry charging pack in case phone on low battery
- make sure phone is fully charged before leaving home
- leave an expected schedule (location, time of interview, time of return) with supervisors have an agreed plan of action with your next of kin in the event you do not return
- carry small amount of cash in case of car breakdown and need to get taxi, bus etc.

Appendix 2
In counting volatile behaviour checklist:

- position self with access to the door
- terminate interview immediately
- bring mobile phone
- ensure non-offensive clothing/jewellery
- use sensitive language not to offend religious/cultural/political beliefs
- make not of exit plan/escape route
- minimise presence of potential weapons (heavy or sharp objects)
- permit participant to terminate interview at any time without being required to justify it
- terminate immediately if concerned re. Risk
- ensure designated person knows your location and has their phone with them in case you call
- notify designated person when you have competed the offsite visit and confirm your safety
- have a plan of action agreed with designated person in event no call is made
- terminate interview immediately with participant under the influence of alcohol and drugs

Appendix 3
Check list for travel issues that may arise getting to the interview room.

- send thorough directions well ina dvance of interviw time. Ensure participant knows where they are going
- confirm date/time/location in writing
- include a map with confirmation of interview
- offer to reimburse travel expenses
- ensure participant has researcher's contact details in case they get lost
- arrange to greet participant at reception/entrance and display ID badge clearly
- only conduct interview within normal working hours where there are people around
- only conduct interviews in daylight hours
- keep a diary of appointments for participants who are visiting the premises
- contact the participant immediately if you are unable to honour the appointment (due to ill-health, accident or emergency)

Appendix 4
Travel and location checklist

- Ensure adequate facilities in place for disabilities (wheelchair ramp/easy access/lift available)
- ensure comfort – adequate seating, lighting. Provide water/tissues
- run through health and safety – appraise participant of fire exits and emergency procedures
- make sure participant knows where conveniences are
- makes sure participant knows how to get out of the building
- inform them they can leave at any time-tables
- ensure you guide them to the exit if /when they want to leave
- ensure privacy – place 'in use' sign on door to prevent interruptions
- Ensure privacy and confidentiality as much as is practically possible
- check sound-proofing of room – can participant be heard?
- Do not lock the door

Appendix 5

Health and safety of the layout and equipment being used.

- Conduct risk assessment of room beforehand to identify any trip hazards (loose leads, clutter etc)
- Consider optimal layout of physical environment to reduce potential participant anxiety (adequate distance between chairs/access to exit/ windows that open/availability of tissues and water/minimal office debris/tidy space/privacy
- arrange furniture so that access to door is available to both researcher and participant
- minimise presence of potential weapons (paperweights, letter openers etc)
- minimise hazards of clothing (scarves, ear-rings etc)
- equipment regularly maintained and checked to sure they work properly
- use equipment only in accordance with manufacturer's instructions

Appendix 6

Risks to the researcher checklist

- position self, close to door

- carry safety alarm (if available)
- ensure receptionist or other person on-site knows where you are
- keep mobile phone with your to call for help if needed
- do not conduct interview if participant is under influence of drugs or alcohol
- report any concerns immediately afterward to supervisor/manager
- if distressed as a result of the interview – ask for support from supervisor

Appendix 7

Accident and Emergency checklist

- know where the nearest hospital is
- know the location of the nearest defibrillator
- know if there is a designated first aid responder on site
- know location of nearest fire extinguisher
- know where the fire exits are
- carry a phone to call 999
- know where a landline is situated in case there is no mobile network
- have written access to contact details for participant's next of kin to contact in case of emergency
- In the event that the researcher feels ill terminate the interview immediately and seek help independent of the participant

Appendix 8a

Covid19 Emergency Checklist

- The safety and well-being of participant and researcher is the utmost priority continuing to follow official guidance from the UK Government and Public Health England carefully with regard to social distancing.
- To help combat the spread of COVID-19, implementing prevention steps:
- Ensuring washing hands more frequently and thoroughly
- Ensuring sanitizing hand soap is provided.
- Social Distancing
- Moving field work online.

Health Guide for COVID-19

COVID-19 is a new illness that can affect your lungs and airways. It's caused by a virus called coronavirus.
What's the risk of coronavirus in the UK?
The UK Chief Medical Officers have raised the risk to the public from low to moderate.

Health professionals are working to contact anyone who has been in close contact with people who have coronavirus.
Symptoms of coronavirus
The symptoms of coronavirus are:
• a cough • a high temperature • shortness of breath

But these symptoms do not necessarily mean you have the illness.
The symptoms are similar to other illnesses that are much more common, such as cold and flu.
How coronavirus is spread
Because it's a new illness, we do not know exactly how coronavirus spreads from person to person.
Similar viruses are spread in cough droplets.
It's very unlikely it can be spread through things like packages or food.
Do I need to avoid public places?
Most people can continue to go to work, school and other public places.
You only need to stay away from public places (self-isolate) if advised to by the 111 online coronavirus service or a medical professional.

How to avoid catching or spreading coronavirus
Do

• wash your hands with soap and water often – do this for at least 20 seconds • always wash your hands when you get home or into work • use hand sanitiser gel if soap and water are not available • cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze • put used tissues in the bin straight away and wash your hands afterwards • try to avoid close contact with people who are unwell

Don't

• do not touch your eyes, nose or mouth if your hands are not clean

Check if you need medical help
NHS 111 has an online coronavirus service that can tell you if you need medical help and advise you what to do.
Use this service if:
• you think you might have coronavirus • in the last 14 days you've been to a country or area with a high risk of coronavirus – see our coronavirus advice for travellers • you've been in close contact with someone with coronavirus

For further information please follow this link:

https://www.nhs.uk/conditions/coronavirus-covid-19/

Appendix 8a
Zoom security Checklist:

- Each time researcher sets up a meeting for a participant, use the 'generate automatically' option rather than your Personal Meeting ID.
- Use a password for each meeting you set up. If you go to Account>Settings>Schedule Meeting, you can turn on the option for the password to be embedded in the meeting invitation. This means that as long as the participant enters the meeting by clicking on the link in the email rather than typing in the meeting ID number, they won't have to physically enter the password.
- Use the waiting room option. This means that you physically admit your participant into the meeting rather than them just popping in whenever they are ready.
- Turn off all recording options. On Account settings, click 'recordings' along the top and turn off the options for both local and cloud recording. Even though research is obviously are recording meetings, this just eliminates the options for anything to be stored in the cloud where Zoom can access it.
- Establish internet connection before interview.
- Either post consent documents before the interview or email the document some days before.

NSPC
61-63 Fortune Green Road,
West Hampstead,
London NW6 1DR

Middlesex University London
The Burroughs,
Hendon,
London NW4 4BT

Application for Ethical Approval

Section 1 – Applicant Details

1. Details of Applicant

Given Name Miriam (Mazal)

Family Name Tasgal

1.1 Is this an application for a student research project?

☒ Yes

☐ No

Resubmission

1.2 Please indicate below:

☒ This is a NEW Application, not submitted before.

☐ This is a RESUBMISSION of the application to address issues raised by the reviewers.

☐ This is a resubmission to address MINOR AMENDMENTS.

Co-investigator/collaborator details

1.3 Are you the Principal Investigator? (Supervisors are usually the PI, unless the applicant is a doctoral student)

☒ Yes

☐ No

Section 2 – Details of proposed study

2..1 Project Short Study Title (max of 5-6 words)

“Mothers Who Listen…”

2..2 Project Full Time (This should be consistent on all documents relating to this research study)

The Phenomenological Experience of The Non-Verbal Communication Between Mothers and their Child with Complex Cerebral Palsy.

2..3 Proposed start date (This must be a minimum of 10 working days after submission of your application to allow for the review process.)

March 2020

2..4 Proposed end date

Jan 2022

Aim(s)

2..5 Please state the main aim(s) and research question(s) with references and citations (where applicable.) (The word limit is 250 words)

This research aims to shine a light on level 5 complex childhood CP. Exploring what the internal world and life experiences of the mother is like, in relation to the complex non-verbal communication with her CP child. Where these, mothers of children with complex CP face limited or no responsiveness from their child, how do they experience meaningful two-way communications? There is no hypothesis, simply a quest to explore the lives of these unique mothers in the context of their experience.

2..6 Would you like to include a document with further information?

☐ Yes

☒ No

Section 2 - Summary of research study and rationale

2..7 Please provide full details of the method(s), study design, data to be collected, how data will be obtained, with rationale and information about participants, hypotheses, data analysis and benefits of the research, with references and citations (where applicable)

Methods

There will be two parts to the interview with the mother's part 1 will be 1 hour long split into 2 thirty-minute time frames. The mother will spend 30 minutes producing a piece of art to mimic the experience of non-verbal communication, or analyze a photograph if they are unhappy to do a creative piece, followed by 30 minutes of the mother giving an interpretation of what she was trying to convey through her artwork. The second part of the interview will be the semi structured interview.

The interviews and artwork will be performed face-to-face for 2 hours with each participant. Face to face interviews will allow me to document and read the body language of the participants to build a more cohesive interpretation (Braun and Clarke, 2013). The interview will take place in a privately hired therapy room where nothing can be over-heard, near the participants home. However due to coronavirus it may no longer be possible to conduct interviews face to face. Participants may be shielding as advised by the government and social distancing might still be in effect. Therefore, whilst social distancing is necessary interviews will have to move online using Zoom.

The interview will be based on semi structured questions with the aim of getting the narrative of each mother's relational experiences as the communication evolves with their children. In this way the interview will facilitate the participants free speech. Being the parent of a disabled child is stressful and their time is limited so I want to ensure each mother feels that I value her contribution (Pousada et al., 2013). Therefore, I hope the interview will be a self-reflective experience for the mother that might in some way leave each mother feeling her experience has been actively listened to.

Artifacts generate rich material that is not readily available through more conventional methods of data collection. The artwork itself can tell its own story as well as follow the process and content and content focused nature of a heuristic enquiry (Sultan 2019).

Study Design

Heuristic enquiries work on finding the unique factors specific to each participant, and the ways in which these are similar or different from the others interviewed. Therefore, it is significant that the sample is small and that the mothers used for the research have similar situation (Smith, Flowers, 2009). There is no out-and-out sample size for a heuristic study in the literature (Smith, 2007). Rather that sample size reliant on idiographic factors and tries to create an equilibrium between being small enough to find possibly refined nuances of meaning (Collins and Nicolson, 2002) whilst being great enough to have sufficient data to work with. Griffiths, Camic and Hutton 2009, propose that having 8 participants is in accord with other Heuristic inquiry sample sizes.

This research does not employ a hermeneutic method because the researcher will not be formulating any interpretation of the data produced, rather this research is exploring the phenomenological experience of mothers who interpret their child's unique way of communicating. There is also the possibility that some mothers will not be able to understand their child.

Data to be collected

Audio recordings and transcripts produced through 1:1- interviews with participants. Photographs of the artwork that each pariticipant will produce.

Data to be obtained

Transcripts of interviews for analysis. Interviews will be audio recorded digitally. Due to Coronovirus the interviews may be done online on zoom or face to face depending on government guidelines. Participants will need to have access to a computer with a camera and microphone. Participants will also need to have a comfortable and private space for the interview.

Photos of artwork produced

Data to be anonymised

All information that could possibly identify the participants will be removed or changed. Data will be encoded and stored on a password protected computer file or held in a locked filing cabinet.

Rationale:

The reason for this research is to give voice to unheard mothers who are full-time carers of their children. With enough research, professionals, including psychotherapists, can learn how to better care for those who are caring for the most vulnerable in our society. This work will give a view into the hidden lives of these mothers. Ultimately this research should enlighten professionals who work with these mothers to insure they are adequately supported. The findings might be expanded to include other complex medical conditions with similar implications.

Information about Participants

The participant will be mothers of a child with complex cerebral palsy who communicate non-verbally. The mothers must have a child older than the age of three but not yet legally an adult. The mothers must have experienced caring for her child whilst it was in neo-natal intensive care.

Hypotheses

This is a Heuristic Inquiry and as such no hypothesis has been predicted rather this research is an exploration of the lived experience to see what might emerge.

Data Analysis

The data will be analyzed using the Heuristic theme explication which involves four methods of representation: individual representations, composite depiction, exemplary portraits, creative synthesis (Sultan,2017).

Benefits of the Research

Participants being interviewed about their experience of communication with your non-verbal complex CP child has no direct benefit, although some participants may find it an opportunity to reflect on their experience, which could find this beneficial. There is a wider more societal duty around questions of capacity and challenging how medical models measure output in its non-verbal population, that this research is hoping to bring wider attention to this topic through readers reflections on this population.

References:

Braun and Clarke (2013) Successful Qualitative Research A Practical Guide for Beginners. 1st edn. London: Sage Publications Ltd.

Collins, K. and Nicolson, P. (2002) ‘The meaning of “satisfaction” for people with dermatological problems: Re-assessing approaches to qualitative health psychology research’, Journal of Health Psychology. doi: 10.1177/1359105302007005681.

Griffiths, K., Camic, P. M. and Hutton, J. M. (2009) ‘Participant experiences of a mindfulness-based cognitive therapy group for cardiac rehabilitation’, Journal of Health Psychology, 14(5), pp. 675–681. doi: 10.1177/1359105309104911.

Pousada, M. et al. (2013) ‘Impact of Caring for a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of the Literature’, Journal of Developmental and Physical Disabilities. doi: 10.1007/s10882-013-9332-6.

Smith, J. A. (2007) ‘Hermeneutics, human sciences and health: linking theory and practice’, International Journal of Qualitative Studies on Health and Well-being, 2(1), pp. 3–11. doi: https://doi.org/10.1080/17482620601016120.

Smith, J. A. Flowers, P. and L. M. (2009) Interpretative Phenomenological Analysis: Theory, Method and Research. 1st edn. London: Sage Publications Ltd.

Sultan, N. (2017) ‘Embodiment and the Therapeutic Relationship: Findings From a Heuristic Inquiry’, Journal of Humanistic Counselling. doi: 10.1002/johc.12052.)

Sultan N. (2019) Heuristic Inquiry Researching Human Experience Hollistically SAGE publication USA ISBN 978-1-5063-5548-1

2..8 Would you like to include a document with further information?

☐ Yes

☒ No

Section 3 – Method(s) and Data Source(s)

3.1 **Step 1**: Please indicate design/methods included in the study (Please tick all that apply)

☐ Simulation, computational, theoretical research, product design/build

☐ Analysis of existing/available data e.g. digital forensic investigation techniques etc.

☐ Case study (in-depth investigates of a single person, group, event or community, may require observations and interviews)

☐ Direct observation(s) and/or taking photographs, video recordings etc. of participants

☐ Action research, insider/participatory research, ethnography

☐ Questionnaire(s)

☒ Interview(s) / Focus group(s)

☐ Field study

☐ Lab-based study (excluding computer lab)

☐ Experiment/quasi-experiment (e.g., with control groups/interventions

3.2 **Step 2**: Please indicate data source(s) below. (Please tick all that apply)

☐ Simulation, computational, theoretical research, product design/build

☐ Existing/archived data or documents, e.g., from UK Data, external organization, internet site, social media site, mobile device(s), app(s) etc.

☐ Human participant(s) – children (under 18yrs), vulnerable adults or with impaired mental capacity to give consent

☒ Human participant(s) – non-vulnerable groups, but may include adults in an unequal power relationship to the researcher e.g., students/employees

☐ Human participant – ONLY my own data (e.g., personal data)

☐ Archived human tissue samples stored under MU HTA licence

☐ Collective or use of human tissue/products (e.g., blood, saliva)

☐ Genetically modified/engineered organisms (GMO's)

☐ Primary human cell lines (directly cultured from their source organ tissue or blood cells

☐ Imported human and or non-human samples

☐ Human or non-human materials requiring transfer between UK Institutions

☐ Materials from UK tissue banks

☐ Animal(s) or animal parts (not included in above categories)

☐ Flora, foliage, minerals or precious artefacts

Section 3 – Risk Assessment to be completed by ALL Applicants

Evaluation of risk level - The level of risk will determine the number of reviewers required to consider your research ethics application. (A higher risk application does not mean that the application will not be approved)

3.3 'Higher Risk' research ethics applications include the following activities. Please tick whether your research involves any of the following:

☐ Animal or animal parts

☐ Genetically modified / engineered organisms

☐ Possibility of causing serious harm to others or the environment

☐ Primary cultured human cells (not commercially available)

☐ Collection/analysis of human tissue/blood

☐ Non-compliance with legislation

☐ Potential to adversely affect the reputation of the university

☐ Concerns security sensitive research e.g., terrorist or extreme groups

☐ Radioactive materials

☐ Drugs, placebos or other substances (e.g., food, caffeine) given to participants

☐ Adults who lack mental capacity to give consent

☒ None of the above

Research Location

3.4 Will the research, or any part of it, require travel to another country?

☐ Yes

☒ No

3.5 Will this research require in-country travel and/or be conducted in a location that may present potential hazards? (e.g., fieldwork)

☐ Yes

☒ No

Approval from an External Research Ethics Committee

3.6 Do you HAVE evidence of research ethics committee approval from an EXTERNAL UK Research Ethics Committee for this research study? (e.g., another Higher Education Institution etc.)

☐ Yes

☒ No

☐ N/A

Section 3 - Supporting Research Conducted by an External Organization within Middlesex University

3.7 Is this research being conducted within Middlesex University by an EXTERNAL organization?

Research conducted within Middlesex University by other Higher Education Institution (HEI) or organization which requires access to data for/about Middlesex University staff and/or student's needs to be supported by a Middlesex University Senior Manager or delegate.

☒ No

☐ Yes, and I can upload the Middlesex letter of agreement for support and access now

☐ Yes, a letter of agreement is required, but this will be provided after Middlesex ethics approval is obtained. I have a letter confirming this requirement which I can upload.

Compliance with Existing Legislation

3.8 Will you ensure that the data/outputs from the research (e.g., products, guidelines, publications etc.) will comply with existing legislations, e.g., not breach copyright, privacy, use of computer networks etc.

☒ Yes

☐ No

3.9 Could the data/outputs from the research (e.g., products, guidelines, publications etc.) cause harm to others directly, or through misuse?

☐ Yes

☒ No

Security Sensitive Categories

3.10 Does your research fit into any of the following security-sensitive categories? If so, indicate which:

☐Commissioned by the military

☐Commissioned under an EU security call

☐Involve the acquisition of security clearances

☐Concerns terrorist or extreme groups

☒None of the above

Section 4 - Materials/Equipment

4.1 Would you like to upload further information/copies of materials/details of equipment to be used in the research?

☒ Yes

☐ No

Possible Issues

4.2 What possible data collection issues do you anticipate that have not been covered so far and how will these be managed?

The main concern around data collection was finding enough participants to fit a very specific inclusion criterion. Some thought was put into this issue and spreading the recruitment across the whole of the UK was thought to resolve this issue. The question of how to conduct the interviews was then explored and the conclusion was not to use skype as nuances pertaining to body language will be lost over skype. The collection of all data will be face to face with an interview room being hired for the purpose of interviewing participants in a safe location.

I would like to mention in case traveling further afield becomes unrealistic, that more children are surviving with more complex CP, so I have been made aware by other professionals that a sufficient number of the sort of mothers I am looking for might all be found in and around London.

There may be mothers who fit my criteria but will be unwilling to do a piece of “artwork” for this reason I have expanded the term to include anything symbolic such as a photograph (Not of people) that is meaningful to the participant.

Section 5 - Incentives and Payments to Researchers

5.1 Are there likely to be any personal payments, benefits or other incentives that the Principal Investigator and/or other research collaborators may receive for conducting this research?

☐ Yes

☒ No

Section 6 - Safety Issues

6.1 Are there any adverse risks or safety issues (e.g., from potential hazards) that the research may present to you and/or for your participants or others?

☒ Yes

☐ No

Potential Impact of the Research

6.2 Are you going to be selecting data that may not accurately represent the wider data set and/or participants' views which may cause bias?

☐ Yes

☒ No

6.3 Please state any negative impact(s) that might result from your research, and how this might be managed?

Thought went into the well-being of the participants. There is a possibility that emotional content may surface as they talk about their children. This has been addressed by a comprehensive debrief that signposts participants towards organizations, UKCP and BACP trained therapists and NHS provisions for mental health through the GP.

As this is a Heuristic Inquiry the researchers own self care is of great importance and competent personal therapy has been put in place and open honest communication between the researcher and the research supervisors will take place throughout the process.

Section 7 – Research Funding and Resources

7.1 Is the research part of an application for external funding or already funded e.g., by the ESRC?

☐ Yes

☒ No

Resources for Research

7.2 Provide details of any additional resources required for your research (e.g., equipment, travel costs, devices needed to access data etc.) how these resources will be obtained, estimated costs and who is covering the cost.

The cost for research resources will be covered by the researcher. There may be some cost for travel if participants live further away in the UK then London Train tickets cost between £30 to £150 depending on the distance and booking availability. There will be a cost for hiring and interview between £40 to £60 depending if this is in or out of London. I will be paying for additional security software for my computer to store my data this will be a payment to a high street provider and will cost £150. One off purchase of art supplies not more than £20 for all 8 participants. As a dyslexic student I already own a digital recorder to record lectures so I will not need to buy one. I will not need to purchase a USB stick as my recorder connects directly to my computer.

Section 8 – Other Issues – to be completed by ALL Applicants

8.1 Does the research involve any ethical and/or legal issues not already covered that should be taken into consideration?

☐ Yes

☒ No

8.2 Are there any other documents you would like to attach?

☐ Yes

☒ No

Other Ethical and/or Legal Issues

8.3 Does the research raise any other risks to safety for you or others, that would be greater than you would encounter in everyday life?

☐ Yes

☒ No

Conflict of Interests

8.4 Are there any conflicts of interests to be declared in relation to this research?

☐ Yes

☒ No

Section 8 - Data Management, Ownership and Intellectual Property

8.5 Who will be the owner of the data from this research?

Usually the owner will be the Principal Investigator and the supervisor for undergraduate and master's level students' projects. Doctoral students are usually considered to be Principal Investigators and the owners of their data. However, such issues are worth clarifying and you may need to check who owns the data if collecting data within an organization.

The data will be owned by the principle researcher. Miriam Tasgal

8.6 If there are any intellectual property issues regarding any documents or materials you wish to use, provide details below:

All pieces of art produced will belong to the participant. There are no other known intellectual property issues.

Signatures:

Researcher		18.02.2020.
Supervisor		13/2/20
Chair of Ethics	Please ensure you enter an electronic / handwritten signature. **(do not just type in name)**	Click here to enter a date.

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16th June 2020

Dear Miriam

Re: Ethics Approval

The panel have reviewed your ethics amendments and your application has been approved by Chair's action and ratified by the ethics board.

Yours sincerely

Prof Digby Tantam Chair Ethics Committee NSPC