Mothering a Child with a Physical Disability:
An Intersubjective Exploration of Maternal Subjectivity

A PhD “including publications”

by Clare Harvey

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Declaration

I declare that this thesis is my own, unaided work. It is being submitted for the Degree of Doctor of Philosophy in Psychology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at another university.

Signed: _____

Clare Harvey

Date: _____ of _____2019

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Background

Introduction

What does it mean to mother a child with a visible physical disability? How, in a world sharply inflected by a particular idealisation of motherhood and by dominant, often unquestioned and unfiltered discourses of disablism, do non-disabled mothers navigate their subjectivities and their relationships with their disabled children? In this complex landscape, how can we understand the potentially conflicted internal worlds of mothers in this position? The research reported in this thesis focuses on the subjectivity of non-disabled mothers raising visibly physically disabled children.

As the research interviews and subsequent data analysis unfolded, another question became more prominent than was initially anticipated. The research experience highlighted the importance of understanding mothers as their own subjects and of creating space to hear their personal feelings and thoughts. The process also showed that disabled participants, and those who stand in a relationship with disabled people, need to be encountered as human subjects with personal ideas and emotions to share, rather than as entities that can be objectified by researchers. This particular research study was also powerfully shaped by the fact that I have a physical disability myself, and I am the mother of a child with a physical disability. As the research progressed, it became clear that extensive exploration of this intersubjective aspect of the research encounter was warranted. Such an exploration has the potential to shed light on the experiences of mothers, as well as on the ethical and advocacy demands of researching disability. Thus a second core research focus arose, emphasising not only the experiences of mothers, but also the process of conducting

research with mothers of children with physical disabilities.

Hence, this project offers a dual, complementary focus. The primary focus is a psychoanalytically informed exploration of maternal subjectivity in women with physically disabled children: an exploration of the maternal within the realm of disability. In addition, there is an explicit focus on the process of research in this area, holding up an intersubjective lens to the research enterprise. Although the process of research is arguably always important, this project gives sustained attention to a reflexive exploration of the research endeavour[1]. This dual focus is intended to allow for an interrogation of the experiences of mothers, as well as of the implications of conducting research in this area.

Focus of the Study

The aim of this qualitative study is to explore the subjective experiences of mothers of children with a visible physical disability by inviting mothers to engage in interviews about their experiences, thoughts, and feelings. The purpose is to gain an in-depth experiential understanding of the meaning-making process and intrapsychic resonances of mothering a child with a disability. In particular, the study considered the process involved in becoming a mother to a child with a disability. The focus is on how women make sense of their self as a person, as a mother, and of their child's disability. Attention is paid not only to everyday aspects of maternal experience, but also to those aspects that are more forbidden, more difficult to articulate and sometimes painful to explore.

The research focuses on visible physical disability. Some disabilities can be hidden and kept undisclosed from others, while other disabilities are always seen. Mothers with children with a visible physical disability are continually forced to confront what is "other" about their child(ren) and how they themselves perceive this "otherness". Visible physical

[1] For this reason, some chapters are devoted to an analysis of the process of research (Chapters Four and Five), while others are devoted to an analysis of mothers' accounts (Chapters Six and Seven).

disability also invites a social dimension that mothers need to manage psychologically. It is likely that a visible physical disability will evoke certain social responses in other people, prompting mothers continually to confront their child's difference. Consequently, these mothers' maternal subjectivities are continually challenged by social experiences of othering, disablism, and stigmatisation. Thus, the physicality and visibility of their children's disability is likely to place these mothers in positions of constant renegotiation of their own meaning-making around disability and motherhood.

The visible, physical focus of this project brings into sharp focus the embodiment of disability. Various authors in the field of disability studies, including Garland-Thomson (2005) and Shakespeare (2006), have called for the body to be re-focused. Embodiment is understood as an experience within and through the body. It includes how the body functions within and between the physical experience(s) of living and societal settings and structures (Garland-Thomson, 2005; Sherry 2006). According to Garland-Thomson (2005, p. 1568), regrettably, disability is seldom "presented as an integral part of one's embodiment, character, life, and way of relating to the world". Embodiment is deeply relational, since one's physicality is frequently shifting as one interacts in the world (Bynum, 1999). Indeed, Bendelow and Williams (1995, p. 147) describe embodiment as "both personal and impersonal, objective and subjective, social and natural". Maternal subjectivity is also fundamentally embodied: it is experienced both psychically and physically (Schmied & Lupton, 2001). For Kristeva (1982), female subjectivity and embodiment are intertwined. The embodiment of a child is central to mothering, as are the embodied practices of childcare (Tonkin, 2017). The embodiment of maternity and disability are thus potentially deeply intersubjective.

The research is situated at the intersection of three bodies of literature:

psychological research specifically interested in the experience of mothering a child with a disability, feminist research on motherhood, and research in the field of disability studies. By exploring maternal subjectivity in mothers of children with a disability, the study is intended to add to the currently limited body of psychoanalytic research on mothering a disabled child, and specifically, a child with a visible physical disability. It must be acknowledged that some important general psychological research has already been published on mothering children with a variety of disabilities – this literature, which is discussed in detail in the literature review section of the thesis, hints at meaningful experiences. However, in these prior studies, a focus on the complexities of this maternal experience is often absent. The existing research has highlighted mothers' encounters in society and accompanying experiences of disablism, stigmatisation and their feelings associated with these engagements (Ryan & Runswick-Cole, 2008; C. Thomas, 1999). A range of maternal emotions has been reported in the literature, including joy, sadness, anger and stress (Bower & Hayes, 1998; Ryan & Runswick-Cole, 2008; Sadat Nurullah, 2013), but this research has not hitherto been expanded on to explore in greater depth how these feelings contribute to mothers' subjectivities.

The focus on motherhood is central to the current research. Since the 1970's, feminist scholars have accorded great importance to women's reflecting on their experiences and speaking for themselves (Bassin, Honey, & Kaplan, 1994; Kruger, 2003). The aim is to focus on their subjectivity and to view mothers as subjects with their own thoughts and feelings rather than as objects. This approach is intended to demystify the "myth of motherhood" (Glenn, 1994, p. 9) which has arisen from some of society's rigid guidelines and expectations. Price (1988, p. 17), for example, refers to "the fantasy of the perfect mother". The current study addresses the question of maternal subjectivity from the

perspective of mothers. The intention is to remain cognisant of what maternal encounters are like for the women themselves, and not only in relation to their babies.

Furthermore, this project aims to centre disabled people in research by accessing the voices of those closest to disabled children. The intention is that the study not be experienced as alienating (Lester & Nusbaum, 2017), a criticism raised against some of the existing research, in which non-disabled researchers have positioned themselves as "experts" and disabled people as objects. Related to this aim is a commitment to celebrate the complexities of the subjectivities of the participants to ensure that ableist practices are not reproduced. Thus, the intention is to understand the experience of motherhood and disability without trying to remediate it. In this regard, it is useful to consider Saville Young and Berry's (2016) sensitively worded reminder of the difficult, yet necessary tension of allowing mothers' experiences to be explored, while acknowledging that this might at times be a voyeuristic act, as Goodley and Runswick-Cole (2013) have cautioned. Simultaneously, taken-for-granted ideas around motherhood and disability need to be highlighted.

The research is also expected to contribute to the broader psychological disability literature. This aim is important, given that disability research has only recently moved back towards a psychological perspective, after having been relegated to the medical realm for decades. It is anticipated that this knowledge will contribute to the practice of psychology, particularly for psychotherapists working with mothers, mothers of children with disabilities, and with disabled children in general.

The Research Process

There has been limited theorisation of non-disabled people's intimate experiences with disabled people. For the purposes of this research study, the conceptual tools of psychoanalysis are employed, because they offer in-depth ways of thinking about intimate

experience(s). The central emphasis within psychoanalysis is on the unconscious – the part of the mind that always tries to remain hidden, but nonetheless expresses itself in a different configuration (Frosh, 2002). Since very little literature could be found addressing the topic of mothering a visibly physically disabled child through a psychoanalytic lens, the "how to" of the project became a central aspect to the overall study. Reflection on the implications of employing a psychoanalytic method as a disabled researcher interviewing non-disabled participants about their emotional experiences in the realm of disability became the second aim of this project. A further particularity that needed to be considered was that the researcher and the participants are all mothers.

A psychoanalytic paradigm, including the method of data collection, analysis, and theoretical interpretation, is well-suited to assist in understanding the participants' deep-seated intrapsychic aspects and the relational complexities of motherhood. Hence, a psychoanalytically informed research interview method is used, adapted from Cartwright (2004), Kvale (1999), and Strømme, Gullestad, Stänicke and Killingmo (2010). The study applies psychoanalytic theoretical concepts to make sense of the interview material in order to establish a psychoanalytically based understanding of how the participants make sense of themselves intrapsychically as mothers when they have a disabled child. Psychoanalysis provides a rich vocabulary to capture the emotional realm of the participants' worlds (Saville Young & Berry, 2016).

Psychoanalysis can not only focus on the internal world and on what is said, but can also provide a valuable tool to access intersubjective encounters. As Marks (2002) argues, psychoanalysis is well positioned to bridge the split between the social and the psychic within disability studies. Moreover, Kristeva (2010, p. 267) suggests that "psychoanalytical listening to vulnerability" is the optimal way in which disabled and non-disabled people's

experiences can be heard, bringing these two groups closer together. Thus, a psychoanalytic lens in the current study pays attention to the complexities of lived maternal experiences. Accordingly, a meaningful understanding of women's intrapsychic responses to their selves as mothers, to their children, and to other people's responses to their children and to themselves, is discussed.

Women were interviewed about their meaning-making process(es) and their experiences of mothering a child with a disability. Furthermore, the process involved in becoming mothers to a child with a disability was explored. How mothers make sense of their children's disability, and how they make sense of their selves as mothers in relation to this disability was also explored. Thus, the women's subjective experiences of mothering in relation to their disabled children was a focus in the interviews. Aspects of their intrapsychic worlds were also considered, for example, their conscious and preconscious object relating and what they may defensively disown.

Researcher Personhood

A study on disability would be incomplete without clarifying the researcher's positionality. My position as a person with a disability, as well as a woman and a mother, needs to be openly acknowledged, partly because the participants themselves brought these aspects of my personhood into the study. Furthermore, this is a qualitative, psychoanalytic project, and thus I play a role in the entire research endeavour.

I am a woman who was born with a visible physical disability, achondroplasia. This form of human dwarfism results in physical disproportion from a gene mutation which results in markedly short arms and legs. The average height of adults with achondroplasia is four feet (Little People of America, 2013). Other complications of this disability include spinal deformities and a prominently large head (Ornitz & Legeai-Mallet, 2017). I am the

only one with dwarfism in my family of origin. I have a mother, father, older sister and younger brother. I am married to a non-disabled man, and we have two children – a daughter who also has achondroplasia, and a son who does not have a disability.

The relationship between a researcher and participant(s), as with all relationships, is interpenetrative and intersubjective (Harvey, 2017b). The intersubjective nature of the interview process, and how participants responded to me, in various (sometimes unanticipated) ways, compelled me to be much more reflexive than I had originally foreseen myself needing to be. Some of the participants looked to me as someone who could provide guidance and answers regarding their motherhood- and disability-related anxieties. They also saw me as someone who provided hope and reassurance for their own and their children's futures. I became a vessel into which they projected some of their more difficult emotions and experiences. Such emotional encounters needed to be carefully traversed. The "how" of the process of writing this thesis has, in many ways, become as important as reporting on these mothers' experiences, because of the reflective, recursive nature of this process, involving a back and forth process between psychoanalytic theory, practice, and reflection. Thus, where there are or were moments when my personhood serves or served to illuminate the participants' maternal subjectivities, their responses to and interactions with their disabled children, and their social encounters as mothers, including their encounters with me, I share and reflect carefully on a consideration of my presence in the study.

Rationale for the Current Study

The current study contributes to the growing area of disability studies, particularly from a psychoanalytical perspective.

People with disabilities are increasingly recognised and included in mainstream

society. As Garland-Thomson (2005) points out, disability is no longer merely a medical problem or a personal misfortune that requires charity. Rather, disability is a diversity issue, an inclusion issue, and a civil rights issue. Disabled people are the world's largest minority group (Garland-Thomson, 2005). World disability figures are estimated to be over one billion people, translating to approximately 15% of the world's population (Disabled World, 2018). More disabled people reside in the southern hemisphere than in the northern hemisphere (E. Stone, 1999), with an estimated 60 to 80 million people living with disabilities on the African continent (Disabled World, 2017a). These numbers suggest that 10% of the African population has a disability, although it is suspected that this number may be as high as 20% in the poorer regions of the continent. Disability affects everybody, since it transcends class and wealth (Goodley, 2011a). It is estimated that over 5% of the world's child population has a disability (WHO, 2011) and that this percentage is growing, because women often have children at an older age than in previous generations, which increases the risk of genetic or chromosomal disabilities (Shakespeare, 2005a). In addition, while the survival rate of premature babies has increased due to advances in medicine, up to half of these babies are disabled (Watermeyer, 2013). The number of people classified as people with disabilities is also increasing because of the steep rise in psychiatric, administrative and educational labels (Goodley, 2011a).

According to Goodley (2011a) and Sinason (1992), psychology has historically had a predominantly negative reputation in the area of disability studies, because of a long-held deficit model of treatment, rehabilitation, cure and/or therapy. Recently, some significant literature on the topic of disability from a psychological perspective has been written, notably by Marks (1999a, b), Saville Young and Berry (2016), Sinason, (2002), Watermeyer (2012, 2013) and Watermeyer and Swartz (2008). Although these contributions are

noteworthy for providing psychological and at times psychoanalytical theoretical underpinnings to enhance understanding of the experience of disability, this body of work is still small. Moreover, although it has been argued that psychoanalysis is able to provide a different lens to illuminate the experience of disability, thus far psychoanalytic analyses have not been consistently or comprehensively applied to the often discomfiting aspects of disability (Harvey, 2015a). The existing literature tends to focus on people with a disability, and there is little focus on people who are not disabled, but find themselves in an immediate and intimate relationship with a disabled person. This is the unique, exacting position many mothers find themselves in – not belonging to the "outgroup" of society, yet mothering someone who does (Harvey, 2015a).

Reeve (2008) has argued for a psychology of disability to illuminate non-disabled people's anxieties emanating from social interactions with disabled people, and Marks (1999b) has described how disabled people disrupt the expected norm, causing distress for those who are not disabled. Consequently, disabled people can feel psychically wounded through their interactions with non-disabled society, especially when they internalise society's difficult feelings around disability. Shakespeare's (1994, p. 287) description of disabled people as "dustbins for disavowal" captures the argument that non-disabled people may project the more unwanted, difficult aspects of humanity, including feelings of weakness and dependence, onto disabled others. However, this literature has not yet been applied to the situation of non-disabled mothers. Research is thus warranted to explore the intrapsychic experiences of people with a disability and, by implication, of individuals who care for disabled children.

Thus far, there is a dearth of research on the relationship between disability and gender (including womanhood) (Mohamed & Shefer, 2015). Some useful research has

examined mothers' general experiences of raising a child with a disability (e.g., Ferguson, 2001; S. E. Kelly, 2005). Most of this research has tended to take a general psychological perspective on mothering and parenting children with disabilities.

Moreover, this research has not necessarily focused on physical disabilities. For example, some studies have concentrated on the everyday practical aspects and experiences of mothers of children with various disabilities (e.g., Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Weiss, 2002). Other research has focused on children with cognitive disabilities, including Autism Spectrum Disorders and learning disorders (e.g., Khushabi, Farzad Fard, Kakasoltani, Pouretemad, & Nikkhah, 2010; S. Ryan, 2005), and deafness (e.g., Bosteels, Van Hove, & Vandenbroeck, 2012). Researching focusing on developmental disability[2] and mothering includes a paper by Sadat Nurullah (2013). The literature on mothering physically disabled children is even more limited, although some meaningful general psychological research has been carried out, including that by Green (2001), and by Ryan and Runswick-Cole (2008). There is a dearth of studies from a more complex psychological, and specifically psychoanalytical, perspective on mothering a child with a disability, and in particular, a child with a visible physical disability.

Mothers of disabled children have been placed in a "complex, contradictory and marginal position" (Ryan & Runswick-Cole, 2008, p. 199) in the disability literature. An ongoing debate has arisen in disability studies about how the field should focus on the experiences and perspectives of disabled people themselves, as their own subjects. Non-disabled mothers are often included in this debate, since they can offer insights into the experience of disability, while not being disabled themselves. It is also important to focus on

[2] According to Wang and Jong (2004, p. 334), a developmental disability is "a chronic disorder that has a significant and continuing impact on the developmental progress of children" and results in varying degrees of dysfunction in the areas of motor, cognitive, speech, and/or social skills.

mothers in their own right, as their own subjects – an argument made in feminist theory (e.g., Bueskens, 2014; Hollway, 2015; O'Reilly, 2006) and by a small number of psychoanalytic writers (e.g., R. Parker, 1996; Pines, 1997; Raphael-Leff, 2010). This existing body of literature highlights the intrapsychic processes of mothers, including unconscious and preconscious facets that are defensively managed. The focus in this thesis on the processes of mothers of disabled children potentially contributes a unique lens to this body of psychoanalytic literature.

Early psychoanalytic theory (e.g., Bowlby, 1958; Klein, 1940; Winnicott, 1960) claiming a focus on mothering was more interested in the child and the mother's childrearing practices (Kruger, 2006; Woollett & Phoenix, 1991). Deutsch (1932, 1933, 2018), an early psychoanalytic writer in the field of motherhood, amongst other topics, focused on the mother, but with a strong focus on sexuality, reproduction and a mother's relationship with her own parents. Psychoanalytic literature on motherhood has been criticised for focusing too much on pregnancy and the birthing process, often ignoring the ongoing impact on women of raising a child (Hollway, 2001). This critique includes an initial failure to focus on maternal subjectivity (Benjamin, 1988). The primary mother-baby bond has historically been idealised in the literature as the "most perfect, the most free from ambivalence of all human relationships" (Freud, 1933, p. 133). Consequently, a mother's more difficult feelings for her baby have been given limited attention. Indeed, Raphael-Leff (2010, p. 3) has criticised feminist psychologists for failing to explore "painful maternal experiences of ambivalence, persecution and hatred".

There is a growing call for motherhood to be researched from women's perspectives (Kruger, 2006). A theoretical shift is apparent from a focus on the impact of the mother on her child towards an emphasis on the mother's self, and the physical and psychic impact of

mothering (Kruger, 2006; Schuker & Shwetz, 1991). R. Parker (1996) helpfully introduced the notion of maternal development in an attempt to focus on mothers in their own right.

Baraitser (2009a), Hollway (2001), R. Parker (1996) and Raphael-Leff (2010) began to explore the complex concept of maternal subjectivity, and more specifically, maternal ambivalence. Baraitser (2009a) argues that existing psychoanalytic theorisation of mothers, as withstanding their babies' destructive impulses and remaining the same subject they have always been, is greatly flawed. Rather, maternal subjectivity encompasses "a distinctive subject-position" (A. Stone, 2012, p. 167). In the current study, it is argued that such a position can be most directly accessed through the personal accounts of mothers regarding their experiences. Benjamin (1995) contends that if mothers' subjectivities are not recognised, their children's primary psychic needs for recognition will not be met. Importantly, although the current thesis focuses on maternal subjectivity, this does not exclude a focus on the child's sense of self. Rather, this project aims to add to ways to achieve the difficult, yet necessary, balance of keeping both mothers and children in mind.

The existing psychoanalytic literature on maternal subjectivity in general has not yet been applied to the experience of mothering a child with a disability – indeed, psychoanalytic writing on disability has been questioned. Watermeyer and McKenzie (2014) have criticised psychoanalysis for traditionally emphasising parental responses of trauma, grief and depression to the birth of disabled children. Davis (1997), Marks (1999b), and Watermeyer and McKenzie (2014) have lambasted psychoanalysis for often taking an uncritical, individualistic lens, ignoring the effects of the wider social context on constructing disability. These authors make a plea for a more complex and nuanced understanding of disability. Such a nuanced understanding calls into question how such material can be grasped: how indeed can one research maternal subjectivity in the realm of disability? In

this regard, Goodley (2011b) has proposed a psychoanalytic understanding of subjectivity, as encompassing psychic, relational, and social aspects, which could greatly assist in a theorisation of disablism. Other writers (e.g., Frosh, 1987; Marks, 2002) have also stated that subjectivity is moulded in and through the impact of social encounters on the conscious and unconscious. Furthermore, De Groef and Heinemann (1999) point out that the focus in psychoanalysis on emotional states could provide insight into the conscious and unconscious psychic backdrop of disabled children's lives.

A very limited number of studies do explore the nuanced psychoanalytical processes mothers may undergo and/or undertake in negotiating and understanding their maternal role and identity in relation to their children's disability, and specifically physical disability. Sinason (2001, 2002, 2010b) has meaningfully focused on a psychoanalytical analysis of the experience of disability; but looked at the perspective of disabled adults and children, focusing on intellectual (but not necessarily physical) disability. Burkhalter (2010) discusses the psychodynamic world of parenting a disabled child, writing from the subjective position of being the father of a disabled child, rather than from a mother's point of view. His focus is also primarily on cognitive disability, although his child had both a physical and a cognitive disability. Watermeyer and McKenzie (2014) wrote an interesting article attempting to synthesise a psychoanalytic approach with the social model of disability. They call for a reconstruction of mothering a disabled child, with a focus on both the emotional relationship and the contextual reality of this practice. It is a theoretical paper that draws on a variety of writings in the field of various disabilities and parenting generally, aiming at destabilising the historical tendency of psychoanalysis to pathologise the parents of disabled children. Saville Young and Berry (2016) integrate two different theoretical frameworks, the social model of disability and contemporary attachment literature, to make sense of the

subjectivity of one mother who has a child with a disability. They successfully provide a nuanced psychosocial perspective on the maternal within the realm of disability. However, their focus is on one mother of one child with an undisclosed physical and developmental disability.

Given the above limited review, the current research project's intention is to address the gap in the psychoanalytic literature on mothering a child with a visible physical disability and to comment on the process of conducting research in the fields of disability and motherhood. Thus, this study aims to explore the complexities of the maternal experience of raising a child with a visible physical disability. The project is intended to do justice to shared emotional experiences of people with disabilities, and by implication mothers of disabled children, while also acknowledging their different subjective experiences (Grue, 2013). The investigation of the complexity of the maternal experience that the project aims for entails an in-depth exploration of mothers' conscious and pre-conscious thoughts and feelings – hence the need for a psychoanalytical focus. An understanding of the participants' pre-conscious thoughts, affects and fantasies required a willingness to work within the transference-countertransference situation throughout the research enterprise. This willingness in turn is related to the necessity of an awareness of and reflection on the intersubjectivity between the various mothers and myself throughout the project. This intersubjective approach allows for a deep engagement with the data and with the field of disability and motherhood studies.

Research Questions

The study attempts to answer the following two questions:

1. What are the subjective experiences of mothers of children with a visible physical disability?
2. What are the implications of researching the maternal subjectivity of mothers with disabled children?

Introduction to Core Concepts of the Thesis

At this stage, it is helpful to introduce briefly two concepts that underpin the thesis, namely disability, and motherhood and maternal subjectivity.

Disability. The question of how *disability* is assessed and designated as a label needs to be clarified.

Disability can be visible or invisible; congenital (a person is born with it) or acquired (Couser, 2005; Disabled World, 2017b). Disability can be physical, intellectual, psychosocial and/or sensory (auditory or visual) (Disabled World, 2017a). Disabilities can be static or progressive (Couser, 2005). The range of the impact of a disability can also vary, from little to a profound impact across a person's life.

Definitions of disability, and the act of defining disability at all, are highly debated, partly because the field of disability studies is a developing area which has witnessed great theoretical shifts and growth. The long-held medical model considered disability in a pathological light, as a flaw or psychical trauma residing in an individual that needs to be remediated or cured (Barnes, 1990; M. Oliver, 1990; S. Ryan, 2005; C. Thomas, 2007). The word *dis*ability suggests that something is missing in the person – either physically or mentally (Davis, 1995).

One definition of disability is that provided by the Americans with Disabilities Act of

1990 (Chrvala & Sharfstein, 1999), which states that a person is disabled if that person is substantially impaired to the point that it limits that individual in one or more areas of functioning. Thus, physical disability would imply a substantial impairment within the body, preventing the individual from fully participating in major life activities. Although it is helpful, this definition has undertones of the medical model of disability, with its focus on impairment, and thus it is limited in its application. Disabled people began to challenge this medical outlook and their consequent exclusion from various social spheres.

As disabled people started the struggle for full equality, the field of disability studies became politicised (C. Thomas, 2004) and the social model arose (Barnes, 2012; Finkelstein, 1981; M. Oliver, 1990). Disability was reconfigured from an overarching, individualised defining category into a contextual phenomenon (Barnes, Mercer, & Shakespeare, 1999; Grue, 2013). The social model defines a disability as emanating from how society responds to an individual's impairment (Finkelstein, 1980; M. Oliver, 1983), thus separating bodily impairment from socially produced disablement (Paterson & Hughes, 1999). The United Nations Convention on the Rights of Persons with Disabilities (2007, p. 1) defines disability according to this social perspective: disability is perceived to emanate "from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others". Thus, a person is only disabled if society's structures and members respond to the person as impaired.

The International Classification of Functioning, Disability and Health developed by the World Health Organisation (WHO) describes a causal relation between the biological and social, with a focus on disease leading to impairment and disability. Impairment is defined as a "loss or abnormality in body structure or physiological function (including mental functions)" (WHO, 2001, p. 213). Disability is "an umbrella term for impairments,

activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)" (WHO, 2001, p. 213). According to this definition, disability is a label that resides at the interface between health conditions (including diseases, disorders and injuries), contextual factors (including social attitudes, architectural characteristics, legal and social structures), and internal personal factors (including coping mechanisms) (WHO, 2002).

The shift towards a social model and perspective introduced an ownership aspect to the field – and the slogan "Nothing About Us, Without Us" (Charlton, 1998, p. 3) was born. Scholars who are also disabled have become increasingly invested in the area of disability studies (e.g., Shakespeare, 1998; Watermeyer, 2012) ever since the field has dislodged disability from its medicalised and moral origins (Herndon, 2002). The personal became the political (Barton & Oliver, 1997) in this move – this is a notion adopted from the feminist movement to portray the fact that the exclusion of disabled people was not only an individual experience (B. Ryan, 2007). Perhaps inevitably, this social shift led to the denial of intimate experiences of disability – this aspect of the model is critiqued by Morris (1992), and by Shakespeare and Watson (1996) for neglecting the everyday reality of lived experiences of disabled people, and the complexities of being a person.

Various scholars, including French (1993), Marks (1999a, 199b, 2002), Reeve (2002, 2008), Shakespeare (2006), C. Thomas (2001, 2007) and Watermeyer (2006), advocate a refocus on the body, which, they argue, is often disregarded in the social model of disability. This shift has seen a renewed, more holistic focus on the experience of disability incorporating the embodiment of disability, as well as the personal experience of disability. This call has facilitated a developing critical lens to the field: critical disability studies aims to

examine how disablism is enacted at the level of the psyche, culture, and society (Goodley, 2011a). In this context, C. Thomas (2007, p. 73) defines *disablism* as "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being". Goodley (2011a) and Marks (2002) therefore suggest an interdisciplinary approach, incorporating physical, social, cultural and psychological aspects of disability. Saville Young and Berry (2016) also call for a psychosocial lens to the field. Psychoanalysis offers the tools to access conscious, and potentially unconscious, experiences, feelings, fears and fantasies about disability to enable greater understanding of the relationship between the subjective experiences of disabled and non-disabled people and their social context (Marks, 1999b, 2002). This potentially enables a more holistic conception of disability to be generated.

These developments in the critical disability studies field have also facilitated the emergence of a feminist lens (see e.g., Garland-Thomson, 2005; Morris, 1992). The core aim of feminist disability studies is to conceptualise disability as a variation in humanity, rather than as a bodily inferiority (Garland-Thomson, 2005). The field of critical disability studies attempts to re-centre the body and disability, since the body is the space where the self and society meet (Goodley, 2011b, 2013). This critical psychoanalytic lens explores conscious and unconscious subjective experiences of disability, along with the impact of disabling social structures and policies (Marks, 1999b). Today, the field of disability studies is a developing matrix of theories, pedagogies and practices (Garland-Thomson, 2002).

Marks (1999a, p. 611) has provided a fairly encompassing definition of disability as "the complex relationship between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs". As Lourens (2016, p. 3) points out, "disability cannot be

divorced from the body". Marks's (1999a) definition of disability is adopted for the current thesis, because it avoids an either/or approach, negotiating the space between the individual and the social. Thus, disability is not perceived to reside only in a particular body or environment. Rather, disability is seen as "an embodied relationship" (Marks, 1999a, p. 611) – it is an experience within the body, where the mind and body are understood to be inherently connected.

In the field of disability studies, there is an ongoing debate regarding whether to use person-first language (*a person with a disability*) or identity-first language (*a disabled person*) (Dunn & Andrews, 2015). The politics of disability led by the social model has argued for person-first language. Identity-first language was initially driven by the minority model. This drive was carried further by the field of disability studies, which positions disability as "a function of social and political experiences occurring within a world designed largely for nondisabled people" (Dunn & Andrews, 2015, p. 259).

The current thesis deliberately alternates between person-first and identity-first language. I argue that the subjectivity of disability for those with a disability (and for those in immediate relationships with disabled people) is experienced within the body, social encounters and the environment, and between and beyond these two, in often raw, unprocessed affective responses. Furthermore, I maintain that the experience of disability cannot be separated from the person. The focus of this study is on non-disabled mothers of disabled children, and therefore both identity-first and person-first terms are used interchangeably to also acknowledge the perspectives of non-disabled people when they encounter disability. Thus, the current research does not support either the medical or the social model of disability, but rather argues for a more integrated and critical psychoanalytic model of disability.

Motherhood and maternal subjectivity. According to much of the psychoanalytic literature, a *mother* is the primary (usually biological) caregiver of a child (Hollway, 2001). Although mothers and mothering can be practised across genders, the current project focuses on women as mothers – specifically, biological mothers. While there are many types of mothers, including birth mothers, adopting, fostering, and surrogate mothers, biological (or birth) mothers remain the most common (Hollway, 2016).

With the birth of a child, a woman's selfhood is altered – a "messier, more inter-dependent new maternal self" (Wolf, 2001, p. 6) emerges. *Motherhood* is often understood to be a transformational experience (Baraitser, 2006). Indeed, motherhood has been described as one of "the most common and powerful transformations in human experience" (Trad, 1990, p. 341). It is a time of great development, and may engender even "psychic crisis" and internal conflict for women when they are re-confronted with their own psychological complexities in their relationship with their child (Baraitser, 2006, p. 217; Hollway, 2010). The very nature of motherhood suggests a time of introspection, since women psychically grapple with notions of independence and dependence (Trad, 1990).

Mothering is the maternal activity of caring for children, and includes Ruddick's (1989) notion of *maternal practice* – a way of being that women develop in relation to their children. This practice includes women's maternal intellectual capacities, attitudes, and values. Schwartz (1993) has identified three central maternal functions that women engage in – security functions, regulation and recognition. Security functions include mothers' provision of nourishment, comfort, soothing and protection from real and imagined psychological threat. The second function, regulation, involves mothers' moderation of their children's emotional world. Schwartz's (1993) third function, recognition, is based on Benjamin's (1988) work – mothers' recognition validates their children's developing selves.

These maternal functions form conscious and unconscious aspects of the maternal self.

Bassin et al. (1994) describe different models of motherhood. In this regard, Kruger, Van Straaten, Taylor, Lourens, and Dukas (2014) discuss implicit and historically, scientifically and culturally embedded discourses on motherhood. Such discourses have a strong influence on women's often unrealistic expectations and idealised fantasies about being a mother. The "good mother" is one such model and discourse, articulating an "ever-bountiful, ever-giving, self-sacrificing mother" (Bassin et al., 1994, p. 2). Attachment theory and notions of bonding have had a powerful impact on such thinking (Widding & Farooqi, 2016). This "good mother" model presupposes that mothers of this type have no needs of their own (Gillies, 2007), and that mothers are indispensable primary caregivers (Arendell, 2000; Choi, Henshaw, Baker, & Tree, 2005; T. Miller, 2007). Hence, existing theorisation on mothers can place enormous pressure on women. Furthermore, mothers are rarely considered to (or believed to be allowed to) have their own existence and perspectives (Woollett & Phoenix, 1991). Consequently, mothers develop complex maternal subjectivities in their attempts to try to achieve this "unspoken ideal of motherhood" (Kruger et al., 2014, p. 463). All these factors have an impact on mothers' subjectivities.

According to Weedon (1987), *subjectivity* is comprised of conscious and unconscious thoughts and feelings, a sense of the self, and an understanding of the self in relation to the world. Subjectivity is one's personhood, which entails a blend of psychological depth and internal (conscious and unconscious) life (Murray & Finn, 2011).

Maternal subjectivity is one aspect of a woman's overall subjectivity, "a specific form of subjectivity that is continuous with the maternal body" (A. Stone, 2012, p. 3). Hollway (2001) correctly points out that women who are mothers are not only mothers. Juhasz (2003) describes multiple subjectivities, comprising a plethora of subject positions that form

a person's sense of self. Baraitser (2009a, 2009b) has also helpfully defined maternal subjectivity. She sees this form of subjectivity as comprised of what women reap from being mothers and being in a maternal space, as well as what is generated from the relationship with their children. This form of selfhood has a particular emotional flavour to it.

Hollway (2001) understands maternal subjectivity as encompassing unconscious intersubjectivity. A. Stone (2012, p. 147) appropriately describes a mother as a "relational subject". Maternal subjectivity includes all the ways "fantasy, meaning, biography and relational dynamics inform individual women's positions in relation to a variety of discourses concerning motherhood" (Featherstone, 1997, p. 7). Thus, maternal subjectivity includes the effects of what Ruddick (1980, 1989) termed *maternal work* (ensuring children are cared for in all domains) and *unconscious emotional work*, including managing one's child's and one's own maternal feelings, and the intersubjective dynamics between the two (Hollway, 2001).

The current thesis adopts this combined definition of maternal subjectivity – as encompassing the dynamic which develops from the needs of the woman's baby, and the consequent capacities within the woman to manage these needs, and her accompanying emotional responses. This definition of maternal subjectivity suggests an embodied subjectivity, a "concept of self that allows for differentiation from as well as connection to her children" (A. Stone, 2012, p. 410).

The focus in this thesis is on the *maternal subject* and the process of being a mother from the perspective of the mother. The project explores how women think about being a mother, what resulting affects arise, and what they do with such thoughts and emotions, "how the mother feels about what she feels and what she does with how she feels" (Kraemer, 1996, p. 765). Thus, subjectivity entails both conscious and unconscious aspects.

Structure of the Thesis

This thesis is structured as a PhD "including publications". This requires that a minimum of four published, and/or submitted papers to research journals appear as chapters. Because each journal article requires a literature review, method and discussion, this thesis is not traditionally structured, in an attempt to avoid repetition as far as possible[3].

Chapter One provides the introduction to the study, considers the research aims and research questions, and outlines the rationale for the project. A brief overview of the core concepts of the thesis is also given.

Chapter Two presents a critical literature review. This journal article, "Maternal subjectivity in mothering a child with a disability: A psychoanalytical perspective", was published in 2015 in *AGENDA: Empowering Women for Gender Equality*. The paper reviews the existing literature to explore the question of what maternal subjectivity may entail, and what conflicts and feelings one might expect, based on the currently available literature. It serves as the main literature review of the study.

Chapter Three describes the methodological approach of the current study, and was not published as an article.

Chapters Four and Five present an analysis of the process of undertaking this research; thereby addressing the second research question. **Chapter Four** is entitled "Ethical emotional encounters: Contemplating challenges in psychoanalytically informed research" and it was published in *Psycho-analytic Psychotherapy in South Africa* (2017). The paper discusses the implications of using a research method that is based on psychoanalytic

[3] Articles have been reformatted to be consistent with the remainder of the thesis in terms of font, without altering the wording, content or structure (hierarchy of headings) in the articles, as published or submitted (where the publication is still in progress). The references are not given separately per article, but are consolidated at the end of the thesis. Chapters which are comprised of manuscripts have been named with the same title as that of the manuscript.

principles and practices. The ethical implications of using such a method are explored.

Chapter Five focuses on "The intricate process of psychoanalytic research: Encountering the intersubjective experience of the researcher-participant relationship". Published in 2017 in the *British Journal of Psychotherapy*, it emphasises emotional encounters *between* a researcher and participants. The paper focuses specifically on the implications of the researcher's personhood for the research and offers an introspective account of the research process.

Chapters Six and Seven present an analysis of maternal subjectivity, thereby addressing the first research question. Both chapters focus specifically on those aspects of maternal subjectivity that are more forbidden, more difficult to articulate and sometimes painful to explore. **Chapter Six** draws on Freud's (1919) concept of the uncanny, as well as concepts of maternal ambivalence, to explore "The uncanny effect of disability: Uncomfortable maternal love for a disabled child". Complex maternal processes of encountering familiarity but also a sense of the unfamiliar in one's child and oneself are described, and the process of working through this specific manifestation of maternal ambivalence is suggested. The paper has been accepted for publication in *Contemporary Psychoanalysis*.

Chapter Seven is entitled "Subjectivity and the return of the abject in mothers of physically disabled children". It has been submitted to *Studies in Gender and Sexuality*. Drawing on Kristeva's (1982) concept of the abject, the paper explores the links between abjection and disability, as well as the implications of this for maternal subjectivity. The process of disavowing the abject, but also of reconfiguring the abject so as to develop maternal love and acceptance, is explored.

Chapter Eight concludes the thesis by examining the implications of the study for

understandings of maternal subjectivity in the realm of physical disability. A final reflection on the process of the research is undertaken, including a reflection on the challenges encountered and implications for further research.

Chapter Two:

Maternal Subjectivity in Mothering a Child with a Disability:

A Psychoanalytical Perspective

Introduction

This chapter focuses on what has been written on the topic of maternal subjectivity when a mother's child is visibly physically disabled. Thus far, there is very little in the literature that addresses the in-depth psychological experience of disability, either for disabled people, or for people living with those who are disabled – including non-disabled mothers raising disabled children. Furthermore, although women, and mothers, are beginning to be realised as their own subjects (e.g., Raphael-Leff, 2010), there have been few attempts to access their subjectivity in research in general. In particular, psychoanalytically focused literature has neglected the selfhood of "other" mothers, including those raising disabled children. Hence, this research endeavour began with a critical review of the literature on maternal subjectivity in the face of disability, and this review constituted the published theoretical article overleaf, "Maternal subjectivity in mothering a child with a physical disability: A psychoanalytic perspective". The paper was published in 2015 in a special issue on gender and disability in *AGENDA: Empowering Women for Gender Equality*.

The article stands in lieu of a literature review for the thesis, but it does not claim to provide an exhaustive account of the literature pertinent to this study. The articles included in the thesis as Chapters Six and Seven, as well as the final (discussion) chapter, Chapter Eight, also review and comment on the prior literature in order to develop an understanding of subjectivity in women whose children are disabled.

Given the dearth of published research in the combined fields of motherhood and disability studies using a psychoanalytical lens, the article overleaf begins by examining the developments in the disability-focused literature, moving towards a psychological, and specifically psychoanalytical, understanding. The paper discusses the psychoanalytical literature on motherhood in general, before honing in on the limited prior research available on experiences of motherhood in the face of disability.

The paper starts to address the first research question of the thesis by providing a basic sense of the subjective psychological experiences of mothers of children with a visible physical disability. The second research focus, namely how to access material on the topic of motherhood within the realm of disability, is also considered to some extent, as the article addresses suggestions in the literature regarding accessing mother's voices, including approaching them as their own subjects. Thus, the paper attends to some of the aims of the study, as it builds on the existing general psychological literature on the experience of disability, as well as on motherhood in the face of disability. It also adds to the limited psychoanalytically focused literature on mothering when a mother's child is visibly physically disabled.

Article:

Maternal Subjectivity in Mothering a Child with a Disability:

A Psychoanalytical Perspective

Abstract

This focus offers a psychoanalytical understanding of the maternal subjectivities of mothers of children with a disability. The deficit assumptions and apparent splits in the existing literature on disability in general, and on mothers' experiences of raising a disabled child, will be discussed. Specificities of this maternal subjectivity include mothers' engagement in unconscious defence mechanisms, including part-object relating (splitting), minimisation, denial, as well as engaging in compensatory and reparative impulses in order to manage the intense emotions of this mothering experience. Mothers of disabled children are forced to confront and tolerate their own preconceived notions and uncomfortable feelings of disability that they have introjected from society's deficit view of disability. Once women have a baby that belongs to the "outgroup" of society, they have to tolerate society's projections of the disavowed aspects of disability. Mothers are left with intense feelings of shame and guilt. They also experience loss for their fantasised ideal object, the non-disabled baby. This is a vastly under-researched area and it is apparent that there is a need for further engagement with the maternal subjectivities of mothers with children with a disability.

Introduction

The number of mothers raising children with a disability is increasing. It is difficult to gain an accurate estimate of the worldwide prevalence of children with disabilities due to the different definitions and assessment measures of disability that are used across different countries (WHO, 2011). *The global burden of disease: 2004 update* (WHO, 2008)

estimates that over 5% of the world's child population has a moderate to severe disability. This figure suggests that the prevalence of disability in general is quite high, and therefore that it is an area that requires greater attention. Further, the number of children with various disabilities is growing due to ongoing advances in medicine increasing survival rates of children born with disabilities (Watermeyer, 2013).

A child with a disability is likely to require additional and specific care around their disability that falls within the role of parenting. While it is noted that it is no longer purely a woman's role to care for children, and that men also actively take up this role today, continued gender stereotypes and gendered caregiving practices across global contexts continue to locate women as primary caregivers for children. For this reason – and given that there is little research on the women who are primary caregivers in relation to caring for disabled children – this paper will focus on mothers. My area of interest lies in exploring the affective and psychological experiences of these mothers.

From a current feminist perspective on motherhood, many women choose to be active mothers – this being vastly different from the historical perspective and assumption that women were automatically placed in this domestic role. There is a lacuna in the literature on the specificity of motherhood, in general, as an experience. Very little psychoanalytical literature could be found on the experiences of mothers of disabled children, and therefore research that includes a focus on the more general experience of parenting of such children will also be discussed where relevant. Specifically, a helpful paper by Burkhalter (2010) on the father's perspective will be discussed. Further, much of the existing psychoanalytical literature focuses on how the mother's sense of self affects her child. Very little research focuses on a mother's subjectivity in its own right; and this is even more the case when the mother's child has a disability. The focus here is rather on the

implications of a child's disability for the mother.

Although the number of women mothering a child with a disability is on the increase, there remains a lacuna in research focusing on this maternal experience. Indeed, only very recently has maternal subjectivity research begun to appear in the psychoanalytical literature. This focus piece will consider pertinent aspects of both the existing disability literature, as well as the literature on maternal subjectivity, so as to begin to understand this particular maternal experience for such mothers.

Much of the existing disability literature assumes ideological and theoretical deficit, arising from the medical model understanding of disability (S. Ryan, 2005). This focus presumes that a mother's internal, psychological world, including aspects of her internal psychodynamics, determines how her maternal subjectivity will be affected. However, notably, there is a deficit in the current literature on motherhood and disability. Specifically, there is a paucity of research on mothers' internal, affective psychological experiences. Further, much needs to be inferred from the existing literature regarding the experiences of individuals with disability on the one hand, and on mothers' subjectivities on the other. This is because certain ideas are suggested in the literature which are not always fully named or expanded on in meaningful ways. These ideas have a psychoanalytical undertone, and thus I argue that an integrated, critical, psychoanalytical framework and perspective is deemed most appropriate when focusing on maternal subjectivity when the mother's child is disabled.

While I cannot unpack everything from the existing literature here, I will focus on the most pertinent themes for the discussion at hand. These include characteristic psychoanalytical maternal defence mechanisms, including part-object relating, or splitting, which mothers of disabled children appear to engage in. Mothers also seem to be receivers

of their child's projections, as well as the projections of others around them. Feelings and experiences of maternal trauma and loss, as well as maternal guilt, shame and anxiety regarding their children, is evident in some of the literature. Finally, maternal ambivalence is an important aspect of these mothers' subjectivities. This psychoanalytical perspective offers a different reading of the existing literature on motherhood and disability, and in this way the affective components of maternal subjectivity can begin to be understood.

Although psychoanalysis is felt to be helpful in this respect, it has not been applied to these often intolerable and uncomfortable aspects that the topic of disability can engender. In this paper I propose that this subject has largely been avoided because the topic of disability in general is often viewed in an ambivalent manner. Individuals perceive disability as either a very positive or a very negative phenomenon, as something the disabled individual can master and "overcome", or as something that needs to be pitied in the disabled person (Harvey, 2015b). This defensive strategy of splitting is unconsciously engaged in to manage the feelings of intolerable anxiety that a disability in others ignites in non-disabled individuals.

In this way non-disabled individuals continue to avoid their own shameful feelings of vulnerability, fallibility and potential for bodily flaws and dependence (Harvey, 2015b; Marks, 1999b). It seems that the defence mechanism of projection is engaged when confronted with disability in others, as these difficult aspects of human experience are projected onto disabled individuals. In another paper (Harvey, 2015b), I argue that disability (as well as disabled individuals) need to be viewed in a more integrated manner and incorporated into the fabric of general human experience, rather than split off and disavowed.

The existing literature has not explored in any great depth these disavowed aspects

of disability in non-disabled individuals, as they are unpalatable. In this focus piece I will attempt to undo some of these splits found in the deficit-focused literature. I will offer a psychoanalytical understanding of aspects of maternal subjectivities that are hinted at in research on mothers raising disabled children, including what it might mean for mothers who are mothering a child that is different to them due to the child's disability, and how the splits in society regarding disability impact on a mother's maternal subjectivity.

Theoretical Understandings of Disability

Before these issues can be explored, the semantic and conceptual demarcation of disability needs to be considered. The WHO (2011, p. 5) defines disability as a difficulty that encompasses a range of human functioning, which include impairments or "problems in body function or alterations in body structure", activity limitations, which "are difficulties in executing activities", and participation restrictions, which "are problems with involvement in any area of life". Thus disability implies a substantial impairment in the physical body and/or mind preventing the individual from participating fully in major life activities.

Historically research on disability has taken a medical model perspective (S. Ryan, 2005). This paradigm focuses on the biological, often pathological, aspects of disability (Watermeyer, 2012). Such an understanding positions disability in a particular way in a mother's mind, before she has even conceived her baby, namely as something that is deviant. This deficit model does not view a child with a disability in a holistic manner, focusing instead on the child's non-normativity. This conveys the message that disabled children are "incomplete" or "defective" (McKenzie & Müller, 2006, p. 313), which may cause mothers of disabled children to feel that their children will never be good enough (McKenzie & Müller, 2006). This deficit model focus may leave mothers feeling helpless and inadequate as they unconsciously introject these projections, reactions and attitudes from

proponents of this model. Mothers thus fall prey to two waves of exposure to this way of thinking: before they have their baby, as well as once they are mothers to their baby.

At this point it is helpful to suspend considerations of maternal intrapsychic processes and to contemplate work by authors who have analysed the aforementioned sociocultural constructions of disability. Proponents (e.g., S. Ryan, 2005) of the social model consider disability to be situated within a social context that oppresses difference. Disability is thus defined as a restrictive set of associations imposed on the individual's existing impairment(s) by society's structures (Sheldon, 2014). P. Thomas (2004, p. 2), writing as a disabled person, argues this tendency: "[S]ociety does not take account of people with impairments and creates separate, segregated 'special' systems to keep us on the margins of society and pressurises us to conform to some mythical idea of 'normality'".

This model is helpful in understanding the notion of "disablism" (in keeping with "sexism"), which is the practice of not fully recognising people with impairments (P. Thomas, 2004). This perspective offers an understanding on how mothers of children with disabilities may be left to tolerate such projections from society. But what about these mothers' own introjections from past exposure to social constructions of disablism, and the mothers' own projections onto their babies?

Neither the medical nor the social model of disability has addressed disabled people's internal, affective psychological experiences; for example, what disability means for their fantasy life and object relational formations. Traditionally only one of these models has been used to understand disability, resulting in a limited understanding of disabled people's experiences and, for the purposes of this paper, of those people in immediate contact with disabled people – mothers of disabled children.

A Psychoanalytical Understanding of Disability

More recently a psychological and specifically psychoanalytical conceptualisation of disability is being argued for (e.g., Marks, 1999b; Watermeyer, 2012), but at present psychoanalytical studies on disability are sparse. Marks (1999b) argues that psychoanalysis seems especially fitting as an explanatory theory for understanding the internal, affective experiences of mothers of disabled children. Psychoanalytical concepts could provide disability studies with a way to begin to make sense of the internal emotional processes of disabled people (Watermeyer, 2006). These concepts are also likely to be helpful in understanding the experience of non-disabled people who find themselves in the immediate context of a disabled individual. Watermeyer (2012) suggests that psychoanalytical theory is well suited to assist in understanding and connecting the societal distortions and experiences of disability with the lived, psychological accounts of disabled people, thus accounting for disabled people's psychological experiences of disablism.

Emotional experiences and disability: "Dustbins for disavowal". The emotional experiences of non-disabled people in relation to disability are in themselves highly complex and often contradictory, causing many individuals to be both fascinated and repelled (Sinason, 1992). Anxiety is the over-arching emotion (Watermeyer, 2006). Watermeyer (2013, p. 52) writes that "disability awakens discomforting feelings" in non-disabled people, which activates psychological defence mechanisms, which can distort reality and result in a warped perception of the disabled person. Authors in the area (e.g., Harvey, 2015b; Marks, 1999b) suggest that aspects of disability in others, including experiences of vulnerability and dependency, cause non-disabled individuals to feel anxious as these aspects are experiences which many people have difficulty with. This in turn will affect how a non-disabled individual responds to someone who is disabled.

This has implications for non-disabled mothers of a disabled child in terms of their own prior "discomforting feelings" about people with disabilities, as well as their sense of how other people might feel about and react to their disabled child, and to them as mothers. Shakespeare (1994, p. 287) expands on this notion, describing disabled people as "dustbins for disavowal", as non-disabled people "throw" and project their unwanted psychological characteristics onto disabled people. Projection is a psychoanalytical term to describe the psychological defence of unconsciously disowning difficult feelings and experiences by "putting" these into other people, which are then identified as being part of that other person. In this way these parts no longer belong to one's self (Klein, 1946). It can be extrapolated from the above literature that this would have an effect on a mother's psychodynamics, as disabled children might become unconsciously attached to their mothers' unbearable and difficult emotional aspects.

Where does all of this leave maternal subjectivity, when a mother must hold in mind all of the disavowals of her culture and herself? According to psychoanalytical theory mothers are required to "hold" their babies in mind by thinking about them and being attuned to their emotional needs (Bion, 1962), in order for babies to develop into thoughtful, emotional individuals capable of engaging with and expressing affects appropriately. According to Bion (1962), a baby, because of its initially very rudimentary consciousness, depends on his or her mother to mature, mentally and emotionally. This is partly achieved through a mother's capacity for maternal reverie, which involves a mother receiving and reforming her baby's unprocessed sensations so that her baby can understand these experiences. However, as Watermeyer (2013) argues, because disability is difficult to think about due to the intense emotions it evokes, this "normal" and expected maternal behaviour might be negatively affected when mothers have a child with a disability. It may

be that, due to their child's disability, the process of maternal identity formation is particularly complicated, it being a complicated process in any case (Murray, 2008). Watermeyer (2013) describes disability in a baby as being generally unexpected and unknown, which can heighten the already present anxieties which new mothers experience. Individuals appear to struggle to reflect on the meaning of a disability in others, with the result being an "immediate, unmediated and paranoid" (Watermeyer, 2013, p. 66) response.

This will more than likely have implications for mothers faced with a disability in their child, and may affect the quality of psychological adjustment these mothers are able to make. It is likely that a variety of defence mechanisms come to be activated in such a mother, in order to manage anxieties about raising and managing such a child. Further, Sinason (2010a, p. 76) found that a disabled individual's sense of identity can feel threatened at times as they find themselves in a social outgroup. These mothers may also feel vulnerable as they raise a child belonging to the "unwanted minority" of society.

The abovementioned literature, although helpful, is limited in scope, as for the most part these studies focus on the experience of the individual with a disability and not of those within their immediate vicinity, namely mothers.

Motherhood and Psychoanalysis from the Maternal Perspective

Psychoanalytical theory has not yet been applied to the intrapsychic processes of mothers of disabled children. Because of this dearth, I need to be content with a consideration of the literature concerning women's experiences of motherhood.

The birth of maternal subjectivity. Until very recently there was a surprising lack of literature on mothers' subjective perspectives and internal affective psychological experiences. This is a significant lacuna given that motherhood is defined as "a normal

characteristic of a woman's female identity" (Phoenix, Woollett, & Lloyd, 1991, p. 40). The experience of motherhood, "mothering", includes the idea of the "emotional closeness of the idealised mother-child relationship" (Phoenix et al., 1991, p. 6). Baraitser (2009a, p. 46) provides a useful definition of the experience of motherhood, "as a particular form of female subjectivity". It is striking how the word "normal" is used by Phoenix et al., yet it is very possible that these mothering experiences will be profoundly affected and different when the mother's child is born with a disability.

Further, these definitions are bound in predominantly Western culture, which perceives mothers as needing to meet specific and idealistic containing roles for their children. This is in contrast to the non-idealised, non-Western cultural perspectives of mothers as meeting the functional aspects of this parenting role.

Phoenix et al. (1991) argue that psychological writings in general have tended to take quite a narrow focus on motherhood. These authors state that women's perceptions and understandings of motherhood have been largely absent in traditional psychoanalytical theory, suggesting that holistic understandings of maternal experiences have been neglected in the service of foregrounding more positive and "normal" aspects of mothering. This has by implication resulted in a negative social construction of "other" groups of mothers, including mothers of disabled children. A. Stone (2014) goes as far as to say that psychoanalysis is incapable of recognising or theorising mother's psychical structures and relational positions. However, psychoanalytical constructs have the potential to offer extremely helpful ways for thinking about maternal subjectivity.

Maternal subjectivity refers to mothers' lived experiences of their relations with their children (A. Stone, 2014). This is a distinctive subjective and psychic position, encompassing how a mother feels about her maternal emotional aspects (Kraemer, 1996).

Baraitser (2009a) describes it as a subjectivity that is founded on both being for the self and for another – one's child – and thus as something that is paradoxically connected and separate.

Many psychoanalytical writers, including attachment theorist Bowlby (1958), have focused on motherhood from the child's experience. Other psychoanalytical literature on motherhood has tended to focus on motherhood in relation to the child, on the mother-child dyad (e.g., Winnicott, 1960). While Winnicott's (1960, p. 587) well-known phrase "'there is no such thing as an infant', meaning, of course, that whenever one finds an infant one finds maternal care, and without maternal care there would be no infant", is true, very little attention has been given to maternal experience in its own right, purely from the mother's perspective. Again it is noted that this phrase is specifically commenting on Western cultural meanings of the maternal.

Long (2009), writing about HIV-positive mothers, is one of the few authors who emphasises the importance of understanding maternal experiences through mothers' accounts. A small number of other authors have also supported this focus, including A. Stone (2012), who argues for maternal subjectivity to be explored from the standpoint of the mother looking at her sense of self and identity as individual rather than primarily through her relationships with either her child or her mother.

"Everybody has had a mother" are Birksted-Breen's (2000, p. 23) words, suggesting that women carry conscious and unconscious memories of their experiences of being mothered, as well as their own long-developed fantasies about wanting to be a mother. There is an interesting extra dimension when a mother is not disabled and yet her child is. Her memories of having been mothered will have a different experiential element to the role she now finds herself in.

Pines (1997), and Fraiberg, Adelson and Shapiro (1975) also write about the important process of a mother's developing identification and working through of her own relationship with her mother when she becomes a mother. Birksted-Breen (2000) views the birth of a baby as a developmental opportunity for a woman, offering her the opportunity to psychologically process her relationships, as well as her psychological conflicts and self-perception. If the relationship with her own mother was predominantly "good-enough" (Winnicott, 1953), the mother's psychological identity may develop further through her own motherhood experience. However, in "not good-enough" mother-child relationships, where painful experiences have been psychologically defended against, the transition into motherhood can be a difficult experience (Pines, 1997). What about this maternal experience when the transition into motherhood occurs when the baby has a disability?

Winnicott (1956/2012) wrote about what he termed "primary maternal preoccupation" to describe a mother's complete devotion to her infant. He described how not all mothers could achieve this temporary state, and suggested that the ramifications of this are potentially very damaging for the child. R. Parker (1996) critiqued Winnicott for, perhaps unintentionally, naming a set of ideals which if not met would, by implication damage the child, imposing a heavy burden on mothers to meet this ideal.

The "good-enough mother" was another phrase coined by Winnicott (1953). Winnicott believed that the mother can, and should, adapt less and less to the developing baby's needs so that the baby experiences some manageable frustration and begins to develop some ego strength. Freud (1949) conceptualised the ego as a symbolic internal mental structure. Psychoanalytical theory defines ego strength as the capacity for healthy, adaptive personal functioning. Winnicott's "good-enough" notion was posited as positive in that the baby can learn that the mother is a complete object whom they can love and hate.

This potentially could give mothers some respite from the ideal of needing to be all loving and perfect, and allow them to engage with their more natural maternal instincts. However, Segal (1992) critiqued this "good-enough" concept as a measure which mothers judge themselves on. Further, other mothers, as well as the parenting industry, also judge mothers according to this concept. A. Stone (2014) strongly criticises the parenting industry for largely overlooking mothers' feelings in their own right, and as a result reiterating and continuing the long-standing social tendency to view mothers as merely the background to their children's developing subjectivity.

The feminist movement has criticised psychoanalysis for tending to reduce the mother's perspective to that of the child (A. Stone, 2014). Contemporary psychoanalytical feminist theorists (e.g., Baraitser, 2009a; De Marneffe, 2009; A. Stone, 2014) have moved towards focusing on mothers' own perspectives and experiences of their relations with their children. Importantly, it has begun to be recognised that mothers undergo their own psychic development that does not always coincide with their children's development (A. Stone, 2014). Writings are beginning to emerge that focus on mothers as subjects and not just as objects meeting their children's needs.

Maternal ambivalence: "Eternal and natural". Winnicott did attempt to address a mother's more difficult experience in an aspect of his theory that is not often acknowledged due to its raising difficult emotions in most individuals – that of maternal ambivalence. He wrote about mothers' inevitable hate for their children (Winnicott, 1949, p. 356): "The most remarkable thing about a mother is her ability to be hurt so much by her baby and to hate so much without paying the child out, and her ability to wait for rewards that may or may not come". This might be especially pertinent in the case of a mother who has a child with a disability, as the rewards are perhaps not those envisaged in her initial fantasies. R. Parker

(1996, p. 49) writes about “the unacceptable face” of maternal ambivalence, which is an experience all mothers share – that of feeling both love and hate for their children. She draws links to the difficulty psychoanalytical theory has had in addressing this important area adequately.

Raphael-Leff (2010) also explores this largely ignored topic. She argues that painful maternal emotions, including hatred towards one’s baby, remain under-researched. Describing a different type of maternal experience to that which Winnicott described, which she calls “primary maternal persecution”, Raphael-Leff’s concept gives space for a consideration of ambivalence about the maternal role.

Indeed Raphael-Leff (2010, p. 9) believes that some mothers may feel “exploited”. This may be further complicated if the sense of “exploitation” occurs from a disabled baby – one that was most likely not wished for.

More recently Tuval-Mashiach and Shaiovitz-Gourman (2014) have researched maternal ambivalence amongst Jewish Israeli mothers. They have described it as an aspect of a mother’s internal psychological experience, encompassing the ideal maternal role (and object) that a mother tries to achieve. The wider the gap between the type of mother a woman is pursuing and the actual kind she is able to achieve, the greater her distress and frustration. It is very possible that this will have implications for mothers who very unexpectedly have a child that is different to their initial fantasy.

Tuval-Mashiach and Shaiovitz-Gourman’s (2014) work is important in that they view maternal ambivalence as positive, an outlook originally taken by R. Parker (1996). R. Parker importantly distinguished between manageable and unmanageable maternal ambivalence. A mother’s accompanying feelings of guilt and anxiety can become problematic, resulting in her not embracing her ambivalence. This is often a result of internalised social norms that

forbid a mother from experiencing feelings of aggression and hostility towards her baby. Tuval-Mashiach and Shaiovitz-Gourman (2014) provide a much more complex and accurate account of motherhood compared to earlier authors, as involving love, difficulty, responsibility and burden. This is important, as all mothers inherently and naturally experience complicated, mixed feelings. As Lazarre (1997, p. xii) states: "[T]he only thing which seems to me to be eternal and natural in motherhood is ambivalence".

Baraitser (2009a) is another author who has taken this new direction in maternal studies. She describes the motherhood experience as neither positive nor negative, but as something that involves both times of struggle as well as pleasure and fulfilment. She views motherhood as a paradoxical experience, consisting of "both liberation and trap, exquisite pleasure and appalling drudgery" (Baraitser, 2009a, p. 2). Her work on maternal subjectivity suggests that women have a unique opportunity of reformulating and transforming the self in relation to their child. A mother's subjectivity is thus forever altered and the mother is rightfully seen as a subject and not as an object (in relation to her child). T. Miller (2005) describes how women self-transform and readapt to form different and more complex internal psychical relations when they give birth. A new subject position as mother develops, and is claimed over time.

While these authors have opened the way for an exploration of the more complex feelings experienced by mothers, these theories have not been applied to research on mothers of children with disabilities. However, these ideas have the potential to be very helpful in understanding maternal subjective experiences and the meaning-making process for such mothers.

Research on Experiences of Mothers of Children with a Disability

There is a small but significant body of general psychological literature that examines

the experiences of mothers of children with various disabilities. Much of the literature in this area conflates “parents” with “mothers” and the notions of “parenthood” with “motherhood”. While mothering is an aspect of parenting and mothers do parent, fathers do not appear in any significant manner in the existing literature on parenting. Further, this conflation is another deficit of the existing research, as mothers in their own right and their subjectivities, including womanhood, are not always given their own dues. As a result, some aspects from general parenting, as well as fathering literature (most notably a paper by Burkhalter, 2010), will be drawn on where they have relevance to maternal experiences of mothers of disabled children.

A social experience: A visible maternal role. Susman (1994, pp. 15,16) states that individuals’ experiences of disability are largely shaped by prior negative perceptions of differences – what she termed “deviance” – as well as the adverse responses these perceptions evoke, namely stigma. She went on to define stigma as “any persistent trait of an individual or group which evokes negative or punitive responses”. Thus stigma comprises the negative reactions towards and treatment of people with disabilities by non-disabled individuals or groups.

Ryan and Runswick-Cole (2008) found that mothers with children with a disability experience disablism as they experience their children’s encounters of stigmatisation directly and vicariously. A sense of rejection as a result of this social stigma was found to be a major factor in Sadat Nurullah’s (2013) study of parents of children with a developmental disability. This resulted in very high levels of stress in these parents. Interestingly, Ryan and Runswick-Cole (2008) considered how mothers of children with a disability find themselves within a context of disabling practices. They suggested that the mothering role becomes particularly visible due to engagement with various professionals, and thus maternal

competencies are felt to be questioned.

Similarly, C. Thomas (1999) wrote about parents' sense of disablism in the new role identity they find themselves in. These parents experience stigmatisation with and through their disabled child as they witness the many discriminatory practices and attitudes their children are faced with. This research, although involving parents in general, suggests a maternal experience that involves receiving and having to tolerate others' projections. Thus this particular maternal subjectivity is complex, given that a mother also has to receive and tolerate her own baby's projections.

Ryan and Runswick-Cole (2008) describe mothers of disabled children as finding themselves in a strangely marginalised position, as they are not themselves disabled but negotiate their identity within the disability realm. Green (2002) helpfully expands on how she experiences her daughter's disability from an outsider's perspective, looking in at her daughter's life as she is not disabled herself. This leaves her with a great sense of sadness, as she feels she will never fully understand her daughter's lived experience. A process of maternal identification and dis-identification, involving an experience of loss of the idealised object (the non-disabled baby) is thus evident in these mothers. This also refers back to a previous point in this paper of a mother's initial exposure to the idea of disability as "bad" and different from oneself and thus as something to split off. However, when a woman has a baby with a disability, she finds herself in the peculiar situation of not having the disability herself but having an intimate connection to, and having to mother, someone who belongs to the disavowed group. This threatens to undo a mother's splits, which are previously based on a sociocultural split along the lines of normal and different.

Kittay (1999) writes about the role of caring for dependent children and how mothers of disabled children are faced with society's fears. These mothers are challenged to

socialise themselves to accept their child, establish who they present as socially, as well as to socialise others to accept their child. These mothers therefore need to manage their own anxieties in order to "defend" their child, which suggests that they engage in certain defensive strategies. Landsman (2003) discusses this maternal experience as involving mixed feelings of love and disquiet, related to wishing to eradicate the disability and the social experiences it brings. This intimates to an experience of maternal ambivalence towards their babies.

Bosteels et al. (2012) found that social reactions forced parents to confront their child's disability and their own related feelings of parental guilt. This resulted in needing to be seen as "good" parents, an indication that defence mechanisms are engaged in order to cope with their more difficult feelings, including displaying compensatory and reparative impulses. I believe that this would also be the case specifically for mothers of such children. Further, Watermeyer and McKenzie (2014) describe how parents of non-disabled children are not culturally sanctioned to admit the burden of childrearing, and that this is even more the case for parents of disabled children.

Emotional Experiences Engendered by Mothering a Child with a Disability

Ambivalence. Sadat Nurullah's (2013) study on parents raising a child with a developmental disability makes reference to the highs and lows produced by this experience. Joyful feelings as well as stress, burden, sorrow and mental exhaustion were reported. Parents described feelings of self-blame, as well as being judged by society, which left them feeling overwhelmed and rejected. Acknowledging and accepting their child's difference and personal characteristics affected by the disability assisted these parents in managing the daily physical and emotional challenges. Further, mixed feelings of concern, as well as hope for their child's future, were reported.

Although this research was conducted with mothers and fathers, these findings suggest that some mothers experience a sense of shame, maternal ambivalence and persecution, suggesting a denigrated self-object concept. Kohut (1977) used the term "self-object" to refer to another person who performed a function that the self could not do yet. For example, the first self-object is the mother who empathically supports the baby's internal sense of being so that the baby can develop a strong, cohesive self. In this way a baby is protected from fragmenting as it organises itself around this self-object. A denigrated self-object arises when the reflection of the self is not affirmed, often resulting in an experience of shame.

In Ryan and Runswick-Cole's (2008) general research, maternal feelings involved anger and a sense of unfairness that this was not the child they had expected. Bower and Hayes (1998) found that a high level of stress and exhaustion comes with mothering a child with an intellectual and physical disability. Some of the more positive experiences included the fact that these mothers felt that they had grown personally from mothering a child with a disability. As a counterpoint, Ryan and Runswick-Cole (2008) suggest that being given a diagnosis can be a helpful experience, giving mothers some refuge and protection from being viewed as inadequate mothers, as their child's functioning can now be better understood in relation to the disability. This implies that mothers of disabled children feel shame and guilt as a result of being "dustbins of disavowal" (Shakespeare, 1994, p. 287) as they introject others' projections regarding the more unpalatable aspects of disability.

Further, Bosteels et al. (2012) describe parenting a deaf child as similar to riding a roller coaster, with many ups and downs leaving parents feeling confused and overwhelmed. Being a new parent and feeling the intense emotions this brings was often overshadowed by medical advice and procedures, resulting in feelings of doubt and fear. It

seems that the “usual” learning process a parent (and for the purposes of this paper, a mother) embarks on with the arrival of a child is intensified and accompanied by other, more difficult feelings that are disability-specific, resulting in a sense of questioning of maternal identity. The early experiences of mothering a child with a disability may be that much more psychologically complex as they raise feelings of inadequacy, promoting an experience of ambivalence towards one’s baby, one’s self, one’s partner, and society.

Less psychic space. One of the emotional challenges for these mothers might be less time or psychic space to allow for reflection on their present situation due to the complexities and demands on them. In this regard, Bosteels et al. (2012), writing about parents of hearing-impaired children, report that the common pressure to intervene medically as early as possible left parents little space to reflect on their personal experiences and meaning-making processes. There is a danger that due to the inherent psychological complexities, mothers of children with disabilities may end up not being as emotionally available for their child as they could have been, resulting in a difficulty in maternal reverie and containing their child’s unmanageable experiences.

At times the focus was on diminishing the disability as much as possible, resulting in a loss of perspective for the entire child. The professional attention solely on their child’s deafness caused them to focus on this defective aspect, at the expense of seeing the whole child. The defences of part-object relating (splitting), as well as minimisation and denial are apparent in these parents, and thus another aspect of maternal subjectivity for mothers of disabled children.

A hint at management of maternal anxiety was also noted by Greenspan (1998, p. 57), writing about her own experience of raising a disabled child. She describes it as “parenting without a developmental map”, as it is often accompanied by contradictory

advice and negative aspects. Green (2002) states that she has to develop a much more present orientation to mothering her child with cerebral palsy, as she cannot rely on established practices and advice that perhaps mothers of non-disabled children can. She does not look too far into the future, as she has no guide as to how her daughter – and thus herself as her mother – will cope with the next stage.

A further significant point raised by Ryan and Runswick-Cole (2008) is that these mothers often mother for longer, as their children are dependent on them in complex ways. This can result in these mothers struggling to develop other identities and interests alongside their mothering position, which has implications for the "usual" process of separation and individuation between a mother and a baby and a mother's development of autonomy. However, some mothers find this expanded role enriching.

An "all-consuming experience". This focus piece has highlighted various questions from the perspective of maternal subjectivity for the reasons previously outlined. Psychodynamic psychotherapist Burkhalter (2010, p. 24) has written about his experience of fathering a child with an intellectual and physical disability. Aspects of his fathering experience can be helpful in understanding the equivalent maternal experience. Fathering his child was only later thought about by him in any meaningful way, as initially his parenting approach was predominantly experiential. One of his dominant parenting experiences was of multi-layered trauma – the intense trauma associated with learning of his child's disability, and the ongoing trauma from daily events, that mobilised a sense of powerlessness as he slowly realised this disability would remain. He describes it as "an all-consuming experience". Ryan and Runswick-Cole (2008), as well as Green (2002), also describe this sense of little psychological space to work through some of the intense emotions and encounters that this mothering experience brings. This maternal trauma and

loss of the fantasised, idealised object seems to be initially defended against as the emotions it evokes are very painful.

Burkhalter (2010) expands on how parents cope with these traumas, which often manifest in an external form as a means of defence, including attempts to "correct" the disability. Bruce and Schulz (2002) describe a process of mourning in a parent when a child with a severe disability is born. Expanding on this, Green (2002) writes about the sense of loss a mother of a disabled child feels, which is unique as the object of loss continues to be present in the mother's life. The mother is left with a chronic sense of sorrow which is intertwined with grief for the child she had imagined. P. S. Miller (2006) describes this experience of a parent's realisation that this is not their idealised child as accompanied by feelings of disappointment, anger and grief. Indeed, Green (2002) suggests that such mothers continually have to transform their perspectives and, it seems likely, their meaning-making processes as well, in order to raise their child in a manner that meets all of their child's needs.

Burkhalter (2010) also discusses the various painful psychological experiences of parenting a disabled child, including intense vulnerability and issues of separation and dependency. The emotional implications include loss and mourning, as well as rage, shame, vulnerability and anxiety. Such an emotional experience, he argues, challenges a parent's very essence of who they are and how they make sense of their internal and external experiences. Thus, mothers are likely constantly to grapple with the external, tangible aspects of their child's disability, and at the same time with how this resonates with their psychological fantasies and internal object relations.

Conclusion

This paper offers an understanding of the maternal subjectivities of mothers of

children with a disability. Mothers formed the focus of this paper as universal gendered practices and stereotypes continue to place women as primary caregivers of their children. Further, very little literature exists for understanding the psychological process for the individual who primarily cares for the child with a disability. A psychoanalytical perspective of the existing general disability literature and of the research on mothers of disabled children was given. The deficit assumptions in the existing literature were discussed in as far as they impact on the subjectivity of these mothers.

By reading the literature with a psychoanalytical lens, a different understanding of this specific maternal subjectivity is inferred. Mothers of children with a disability were seen to engage in unconscious psychoanalytical defence mechanisms in order to manage the intense emotions of this mothering experience. These mothers carry with them their preconceived notions and uncomfortable feelings of disability according to society's view of disability as non-normative – something that is managed by defensively splitting off related intolerable emotional aspects. Mothers are re-confronted with these attitudes and beliefs when they mother a child with a disability.

It was discussed how mothers are then left having to tolerate their own prior introjections, as well as society's projections of these disavowed and unpalatable disability aspects, leaving them to experience feelings of shame and guilt. Further, a disabled child is thought to become unconsciously identified with their mother's projections from society, as well as with their mother's own unbearable psychodynamics. It was also inferred from the existing research that mothers of disabled children experience a chronic sense of loss of and grief for their fantasised idealised object – a non-disabled baby. A mother's existing splits around disability are threatened to be undone as she has a baby belonging to the "outgroup" of society.

Defence mechanisms appear to be activated to manage this, including engaging in compensatory and reparative impulses. It was suggested that this may impede mothers from being able to enact necessary maternal reverie and adequately contain their babies. Part-object relating (splitting), as well as minimisation and denial were other defensive strategies that became apparent in such mothers. The intense vulnerability that was alluded to in such a maternal subjectivity is thought to challenge a mother's core identity and meaning-making in terms of the external tangible and psychological aspects of her child's disability, as well as her internal object relations and fantasies.

I have attempted to undo some of the splits in the existing deficit-focused literature on the topic of maternal subjectivity and disability. However, given the apparent lacunae in research on maternal subjectivities when the mother's child is disabled, further research is called for.

Chapter Three:

Method

Introduction

This chapter provides an outline of the dual method approach used in this research venture. The one side of this approach is developing the research method of the study and analysing the process of using this method. The other is accessing and analysing the participating mothers' accounts of their maternal subjectivity.

This chapter starts with a description of the qualitative research design which forms the backdrop to this project. Thereafter, an account of the participants and sampling strategy used is provided. The project required a particular methodological approach in order to answer the research questions. I therefore tailored the method used for the study by adapting a number of methodological paradigms within the broad area of psychoanalysis – the description of the data collection includes a discussion of the adapted psychoanalytic research interview. I reflect on and discuss the method of data analysis in the current chapter before considering ethical aspects that are pertinent to this study.

A published paper on the adapted psychoanalytic research interview method and the associated ethical considerations in interviewing participants while using this technique forms the extended focus of the next chapter. Given the intersubjective centrality of this study, I also include a detailed discussion on researcher reflexivity in a separate chapter, Chapter Five, as part of the published paper presented there.

Research Design

Qualitative research attempts to understand human experiential phenomena in their context. Qualitative data takes the form of language, words and expressions of experiences

(Levitt et al., 2018). One of the ways in which this type of data can be acquired is by using the researcher as the primary instrument, or research tool, both in the data collection and data analysis stages of the research process (Terre Blanche, Durrheim, & Painter, 2006). Qualitative information is collected in a particular context using various techniques, including research interviews, which involve "an interpersonal situation, a conversation between two partners about a theme of mutual interest" (Kvale & Brinkmann, 2009, p. 123). The researcher is active in this process, asking follow-up questions and interacting with the participants. The researcher needs to be knowledgeable about the topic, and must have sufficient understanding and experience of human interaction (Kvale & Brinkmann, 2009) to elicit nuanced and meaningful information from the participants. My use of myself as a research tool was thus central throughout the study. My training and experience in psychoanalytically focused psychotherapy was helpful in enabling the intersubjective focus required in the project, because I am skilled in enabling others to talk openly.

In planning the research method, I was influenced by prior research following an interpretative methodological approach (e.g., Smith, 2004, 2011), which aims to describe and interpret individuals' feelings and experiences. This approach assumes that researchers can come to understand people's meaningful experiences by interacting with them and listening to their stories (Terre Blanche et al., 2006). Interpretive-based research explores "in detail how participants are making sense of their personal and social world" (Smith & Osborn, 2015, p. 25). An interpretive researcher is interested in understanding what meanings participants accord to certain experiences and events in their lives.

This study is also influenced by the phenomenological psychological research paradigm, which aims to gain an understanding of people's everyday life situations (Giorgi & Giorgi, 2008). Phenomenology is a philosophical approach which examines people's

personal experiences (Smith & Osborn, 2015). This study's goals are to understand the psychological meanings that constitute the phenomena that I am studying – experiences of motherhood in the face of mothering a child with a disability – and to offer a psychoanalytic explanation of these phenomena. These aims were achieved by staying as close as possible to the lived experiences of the participants.

Smith (2011, p. 9) is "concerned with the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience". Such an approach is well suited to a psychoanalytic way of thinking, since both paradigms (the interpretative methodological and the phenomenological approaches) recognise the central role that a researcher plays in analysing and understanding the personal experiences of participants (Smith, 2004). Hence, I adopted a "double hermeneutic" (Smith, 2004, p. 40) process, because the participants are attempting to make sense of their experiences, and in addition, I wanted to understand how the participants are making sense of their personal and social worlds.

In this context, it is important to consider the influences of my personhood as a researcher throughout the entire research process, which is akin to psychoanalytic thinking and its emphasis on countertransference. Furthermore, while interviewing and reading the interview texts, it is possible that a researcher may engage with areas that have arisen, but that the participants are unable, or unwilling, to acknowledge (Smith, 2004). Such unacknowledged areas suggest access to some of the participants' preconscious and unconscious processes, which suggests more similarities with psychoanalytic practice. This form of engagement with participants and the interview material can result in a more profound and thorough understanding of the participants' experiences. Moreover, this way

of engaging with participants and accessing data supports the prominent intersubjective focus of the current study.

Participants

The data source for this project were obtained from two sources – the narratives of mothers, and from the intersubjective encounters that the participants and I shared. In a prior study, R. Parker (1996, p. 8) fittingly states that, "theorising motherhood seem[s] to demand the raw material of maternal voices". Mothers were asked to enter into a conversation in the form of interviews to elicit their subjectivity. It was the intention of this research to treat mothers as their own objects, and not "as their children's objects" (R. Parker, 1996, p. 9).

Nine non-disabled women who have children with a visible physical disability were interviewed. I chose only mothers who are not disabled, because I wanted to explore what particular types of lived responses and meaning-making processes they would bring to the research area, as non-disabled mothers do not have personal lived experiences of disability to draw on to make sense of their children's and their own experiences. Only mothers with biological children with a disability were included, since carrying and giving birth to a child with a disability would arguably elicit particular responses from mothers (these may be different from those experienced by mothers of an adopted baby, for example).

The participants' children have various forms of visible physical disability. A visible manifestation of a physical disability apparent from birth, or shortly thereafter (in the first year of life), constituted a key inclusion criterion. I decided to include only children whose disabilities cannot be hidden from view, because I wanted to gain insight into the influences of other people's perceptions on the mothers' formations of their maternal identity. Furthermore, I anticipated that a visible disability would elicit particular responses from the

mothers regarding issues of disablism and stigmatisation, as well as a meaningful engagement with aspects of their maternal identity that are a product of their children's disabilities.

This criterion excluded children who may have developed a disability later on in their childhood, for example, after an accident or due to a childhood illness. I hypothesised that the genetic or syndrome basis to the participants' children's disability would elicit further maternal feelings and fantasies. The mothers' meaning-making processes could be affected by the congenital aspect of their children's disabilities. Disabilities resulting from a birth complication or difficulty at the time of the birth were also included, for the same reasons.

The intention was to focus on mothers whose children have only a physical disability, without a comorbid intellectual disability. The physical manifestation of the disability was predicted to initiate particular social responses from those around the mothers, resulting in unique experiences for the participants. Subsequently, these social experiences could influence the mothers' sense of identity and function in relation to their disabled children. Moreover, the physical aspect of the children's disabilities was likely to have a serious and unique impact on the type of relationship these mothers have with their children (compared, for example, to that of mothers who have a child with an intellectual disability).

The level of functional independence the participants' children can potentially achieve in life was a useful initial criterion to consider for participants' inclusion in the study. The degree to which mothers need to adapt their hopes and expectations for their children's futures would also be affected by the presence and degree of a physical disability. Children with physical disabilities often require particular physical assistance in daily living, and for longer, compared to children with cognitive disabilities or non-disabled children (Horton & Wallander, 2001). It is often thought that it is more likely that people with

physical disabilities who do not have a co-morbid cognitive disability can achieve independence, because they are intellectually more able. Yet the presence of a physical disability raises the question of what this independence might look like. The potential independence that the participants' children could achieve might elicit particular maternal fantasies. The mothers' would also perhaps have specific feelings to share regarding their adjustment of their future aspirations for their children because of the complex balance between dependence and functional independence in people with physical disabilities (Horton & Wallander, 2001).

Mothers of children with physical disabilities that include a degenerative aspect and/or shortened lifespan were not included, but a further initial sample criterion for inclusion was mothers of children who have a physical disability that cannot be "cured" or completely "fixed". Hence, it is not a temporary disability. The participants' children will be disabled for all of their lives. Again, this criterion potentially implies a particular adjustment by the participants regarding their hopes and expectations for their children's futures.

The various disabilities of the participants' children are cerebral palsy, dwarfism or restricted growth – specifically achondroplasia, children with cleft lips and cleft palates, Pierre Robin syndrome, and spondylocostal dysostosis. These disabilities are listed in Table 1, in the next subsection, which details the participants and sampling strategy.

With regard to the ages of the children of the participants, the inclusion criterion was that the children should be past infancy and toddlerhood. Mothers whose children fall into this older age group would potentially have had a wider range of experiences and emotions relating to their children's disability. They would also have had some time to make psychological adaptations. Women whose children are past toddlerhood often have a more complete sense of their children, in terms of their potentials, strengths and struggles – in

contrast to the mothers of babies who may primarily hold fantasies of who and what their babies may one day become, as babyhood is a period of great maternal preoccupation (Winnicott, 1956/2012), or what Stern (1998) termed the motherhood constellation. Children who are no longer infants or toddlers are usually also less demanding than a baby, in that they are usually a little more independent and more receptive to external experiences, including education and social relationships. This may allow mothers somewhat greater psychic space to think more clearly and meaningfully about their children and the relationship they share (Baraitser & Noack, 2007). Thus, it was hoped that applying this criterion would allow an in-depth sense of the mothers' meaning-making processes and internal psychic world to be elicited, without running the potential risk of disrupting the important adaptation process of new mothers.

Sampling Strategy

A non-probability sampling strategy was used in this study. This is a sampling technique where participants are intentionally chosen because they are identified as being likely to be able to answer the particular research questions (Ritchie, Lewis, Nicholls, & Ormston, 2013). Thus mothers of disabled children were chosen to elicit information on mothering a physically disabled child and the consequent impact on maternal subjectivity. The specific type of non-probability sampling that I used is the purposive sampling technique. Purposive sampling involves choosing participants who meet particular criteria which should allow for in-depth exploration of the research topic (Ritchie et al., 2013).

Ethical clearance was obtained from the relevant authorities (see also the last section of this chapter). Once ethical clearance had been obtained for the project, potential research participants were contacted and invited to take part in the study. Participants were accessed by contacting professional services for people with various physical disabilities.

First, support groups for people with physical disabilities and their caregivers were contacted, including the Smile Foundation[4], enquiring whether they had members who met the criteria and who might be interested in participating in the study. Two participants were suggested. Next, professionals working with physically disabled children were contacted to inform them of the project and ask whether they could suggest any potential candidates. Counsellors and geneticists at the Genetic Counselling Services at the University of the Witwatersrand suggested two mothers who might be interested in participating. Various physiotherapists who specialise in treating children with a range of physical disabilities were also contacted to suggest potential participants; three mothers were accessed from this referral source. Finally, two participants were identified by word-of-mouth.

Once I had received the names and contact details of potential participants, I contacted them via telephone, introducing myself and the project. All the women whom I contacted were willing to be interviewed. I provided each of them with the Participant Information Sheet (please see Appendix A). A time and location for each participant's first interview was then arranged.

After I had repeatedly interviewed the nine participants, the data was found to be adequately rich to address the research questions so the sample was capped at nine participants.

The table overleaf provides an outline of the participants in this study. All the participants are middle class South Africans. While the various demographics of the participants are listed, not all of these were the focus of the study.

[4] A non-governmental organisation for children who require corrective facial reconstructive surgery and treatment (Smile Foundation, 2019).

Table 1

Participant information

Participant's pseudonym	Participant's race	Child's pseudonym	Child's age	Child's gender	Child's disability	Age at diagnosis	Referral source
Patsy	White	Nicky	3 years	Girl	Cerebral Palsy[5]	14 weeks	Physiotherapist
Jessica	White	Cameron	5 years	Boy	Achondroplasia	6 weeks	Word-of-mouth
Sandra	Mixed race	Emma	5 years	Girl	Achondroplasia	Day of birth	Genetic Clinic
Lara	Mixed race	Kim	6 years	Girl	Pierre Robin Syndrome[6]	2 days	Smile Foundation
Becky	Mixed race	Simon	6 years	Boy	Spondylocostal Dysostosis[7]	2 days	Genetic Clinic
Chloe	Indian	Joshua	6 years	Boy	Achondroplasia	32 weeks in utero	Word-of-mouth
Janet	Indian	Ashley	7 years	Girl	Cerebral Palsy Spastic Diaplegia[8]	1 year	Physiotherapist
Kirsty	White	Thomas	7 years	Boy	Bilateral cleft lip and palate[9]	33 weeks in utero	Smile Foundation
Joan	White	Sarah	16 years	Girl	Cerebral Palsy	9 months	Physiotherapist

[5] Cerebral palsy is a disability of posture and movement control with multiple presentations, including coordination and balance difficulties, and/or irregular movement patterns. Cerebral palsy is caused by damage to the brain, from various sources, e.g., preterm delivery, congenital malformations, intrauterine infection, foetal growth restriction, multiple pregnancy, and placental abnormalities (MacLennan, Thompson, & Gecz, 2015; Miller & Bachrach, 2017).

[6] Pierre Robin syndrome, or sequence, is present from birth and results in a smaller than expected lower jaw. The tongue is far back in the throat, which causes difficulties in breathing (Breugem & Van der Molen, 2009).

[7] A group of conditions known as spondylocostal dysostosis are characterised by abnormally developed and fused vertebrae, and sometimes ribs. The result is a short torso and rigid neck, yet normal length limbs. Another term for this disability is short-trunk dwarfism. Fatal complications include breathing difficulties (Turnpenny et al., 1999; Whittock et al., 2004).

[8] A specific form of cerebral palsy, diaplegic cerebral palsy, or spastic diaplegia, manifests during infancy and early childhood, usually due to brain damage before, during, or shortly after birth. Symptoms include stiff and contracted muscles in the limbs (Rosenbaum et al., 2007).

[9] Bilateral cleft lip and palate is an undeveloped roof of the mouth with an opening into the nose (Watkins, Meyer, Strauss, & Aylsworth, 2014).

Data Collection

Two in-depth, one-on-one, open-ended interviews were carried out with each participant, resulting in eighteen interviews.

An adaptation of the technique of the psychoanalytic research interview, as described by Cartwright (2004) and Kvale (1999), was used. This technique argues for an iterative interview process. The method used in the current study was also inspired by Hollway's and Jefferson's (2000) free association narrative interview method, which similarly advocates for repeated interviews. These authors believe that inviting participants to narrate their experiences grants researchers access to information on participants which may not necessarily be gained using a traditional question-and-answer interview technique. The method is based on the realisation that participants should be understood as genuine people with lived experiences. In arguing for the use of the free association narrative interview method, Hollway and Jefferson (2000, p. 32.) point out that "while stories are obviously not providing a transparent account through which we learn truths, story-telling stays closer to actual life-events than methods that elicit explanations".

I was interested in how participants construct and reconstruct past and present occurrences, since this provides some access, albeit limited, to the participants' deeper psychic dynamics (Cartwright, 2004). A psychoanalytic research interview outline is the research data collection instrument that was therefore adopted in the current study. This is an instrument of psychoanalytic inquiry. The outline employs an analytically based interview technique aimed at accessing conscious, and some preconscious and unconscious meanings, intrapsychic processes, object relations, fantasies and defences associated with the focus of the research (Cartwright, 2004). Thus, this method is very apt for an attempt to elicit

detailed, rich and nuanced material on participants' maternal experiences and aligns well with a psychoanalytic paradigm.

Before starting the first interview, I asked the participants to sign a consent form giving written consent to be interviewed and audio-recorded (please see Appendices B and C for these forms). Each participant was interviewed twice over the course of approximately two months. Interviews varied in length, in line with the open-ended, unstructured data collection technique. The interviews lasted from one hour to three hours each, with an average time of one and a half hours. Interviews were conducted in various locations which were convenient to the participants, including in participants' homes, places of work, and my psychotherapy practice rooms. Each interview was audio-recorded and then transcribed verbatim.

Research Instrument

A semi-structured interview schedule was used to provide some structure to the interview process and formed the basis of the interviews in this project. Such schedules vary in the degree of structure they provide, and may consist of some broad topics to be covered in the interview, or may entail a carefully formulated sequence of specific questions (Kvale & Brinkmann, 2009). It is a guide or script listing pre-decided topics and sub-topics that form the foci of the researcher-participant encounter (Terre Blanche et al., 2006).

For the purposes of the current project, the term psychoanalytic research interview outline is applicable to describe the instrument used, because a traditional semi-structured interview schedule might imply that the researcher adhered to certain pre-planned questions to ask the participants. Such a schedule can be restrictive in the type of information it elicits from participants, since it guides the direction of the interview (Hollway & Jefferson, 2008). By contrast, a psychoanalytic research interview outline can be changed

freely, and it usually does change, as the interview progresses, in order to match the participants' intentions to relate their experiences. Furthermore, with a traditional semi-structured interview schedule, the interviewer remains in control, highlighting certain aspects of the topic. These aspects may be different to those the participants might believe are important. Instead, this study was influenced by Hollway's and Jefferson's (2008, p. 302) suggestion that "the researcher's responsibility is to be a good listener and the interviewee is a storyteller, rather than a respondent".

In developing their free association narrative interview method, Hollway and Jefferson (2008) provided some suggestions for a psychoanalytic research interview outline. The current study is guided by some of these suggestions, but this doctoral project is not a psychosocial project (Hollway & Jefferson, 2008; Saville Young, 2011) and thus a distinctly psychoanalytic research method was developed. The suggestions by Hollway and Jefferson (2008) include asking questions in as open-ended a manner as possible, and eliciting stories from participants which help to anchor participants' experiences and feelings to actual events. Researchers are required to adapt questions about certain research topics into story-telling invitations. Another suggestion is to follow up on participants' stories by employing the same phrases and order that the participants use (Hollway & Jefferson, 2008). The researcher needs to listen attentively, and possibly write some notes during the interview, to explore certain aspects of the participants' stories in the same order in which they are narrated. This enables the participants' meaning frames to be preserved and further information to be elicited.

In the current research endeavour, participants were invited to share their experiences of being a mother to their physically disabled children. This implies that the participants were invited into a kind of free-associative process, which is a psychoanalytic

method that encourages a person to say whatever comes to mind (Hollway & Jefferson, 2008). Freud first referred to this technique in *Studies on hysteria* (Breuer & Freud, 2000, p. 56), when he discussed his patient, "Anna O", who "was making use of our conversation, apparently unconstrained and guided by chance, as a supplement to her hypnosis". The kind of response that is elicited in a free-association method is structured according to "unconscious logic, that is, the associations follow pathways defined by emotional motivations, rather than rational intentions" (Hollway & Jefferson, 2008, p. 309). In the current study, the participants' free associations were followed in whatever direction they took. However, some participants struggled with such an open process, and then there was room to take a more structured interview approach.

The level of structure was tailored to each participant, based on my intuition, during the interview process. Some broad themes were created before the data collection phase, with possible follow-up, open-ended questions. These themes were based on my review of the relevant literature. The psychoanalytic research interview outline consisted of a number of questions grouped into the following four themes:

1. Mothering experience
2. Diagnosis of child's disability
3. Support systems
4. Social aspects of mothering experience

However, with all nine participants, very few structured questions were required.

Interview Structure

In order to maximally facilitate the collection of rich data, each participant was interviewed twice.

The first interview. At the start of the first interview with each participant, the mother's and child's relevant personal details were recorded. Next, I explained the process that I would follow, and briefed the participant on the purpose of the interviews, as suggested by Kvale and Brinkmann (2009). The briefing consisted of the following information:

> As you can see I have a physical disability. The area of disability and mothering has always been an interest of mine. I am really interested in hearing about your experiences of mothering your child with a physical disability, in as much detail as you would like to give. I would like you to be as honest and as open as feels comfortable for you. I would like you to feel at ease in this interview on the topic of your mothering experiences. Please feel free to tell me anything that comes to mind; or that you may wish to share, however small or irrelevant you may feel it is.

Next the interview was conducted, using the outline (see Appendix D for the full psychoanalytic research interview outline).

The second interview. The second interview gave participants a chance to reflect on what they had shared in our first encounter. Additionally, participants often shared some memories and thoughts that had arisen after the initial interviews. In some cases, the second interview was more structured than the first one, in order to clarify the information already gathered. Any contradictions, conflicts and defences that had arisen in the previous interview were also explored at this stage, as suggested by Cartwright (2004). By the end of the second interview, participants had been invited to engage in free association on all the aspects of interest to the research topic.

Data Analysis

Once an interview was completed, it was transcribed. Participants were given pseudonyms and identifying details were omitted or disguised in the process of transcribing to ensure confidentiality and the final anonymity of each participant. The interview data were then formally analysed to understand the participants' experiences and meaning-making processes better. In fact, the process of analysis already began during the interview encounters themselves, because of the markedly intersubjective nature of these meetings. The participants' various and particular engagements with me to meet their own needs required a certain level of psychoanalytic thinking on my behalf to engage ethically with them and to hear the specific data that arose from such a process. It is for this reason that in this study the analysis stage consisted of two, complementary parts – the analysis of the process of the practice of the research, and the analysis of the accounts of the participants.

The analysis of the psychoanalytic research interviews is based on the assumption that knowledge is produced in a relationship and in the conversation process between two people – the researcher and participant (Kvale, 1999). According to Cartwright (2004), analysis of this interview format broadly involves three steps, and these steps do not necessarily constitute a linear process. These steps influenced how the participants' interview transcripts in the current study were analysed. Other psychoanalytic concepts were also taken into account, notably the transference-countertransference situation (Ogden, 1994). I sought further inspiration from the intersubjective school of thought, because of the prominent influence of my presence in the interviews. The notion of thirdness (Britton, 1989; Ogden, 1997) was most helpful in this regard. Thus, I also needed to analyse the actual process of this research study. The data analysis steps, broadly based on Cartwright (2004), are the following:

- **Step 1: Careful attention to feeling states and corresponding thoughts or perceptions.** Paradoxically, the analysis of each interview started before it was conducted. It started when I began to explore my personal motivation for researching the topic of this project. The analysis continued throughout the interviews, and was then taken up more formally once they were completed (Cartwright, 2004). I was constantly vigilant, considering personal emotional responses from the interview interactions which might provide valuable information on the participants' relationships with their internal and external objects. I then compared this information with the object relations and representations present in the transcribed interview texts.
- **Step 2: The search for core narratives.** In this step, a search for story lines in the interview texts that are related to the topic of the research was conducted. In this way, coherent narratives were discovered. I engaged with the entire interview text, allowing all aspects of the interview to influence the analysis. With each new reading of the text, questions were formed about the nature of the story being narrated. Thus, I returned to the text in a circular manner, deriving a more informed reading each time. This iterative process entailed an attempt to refine prior understandings, ultimately resulting in a more accurate and complex analysis. Hence, I did not merely confirm what I was expecting to find in the data. This second step was accomplished once all the coherent core narratives had been constructed (Cartwright, 2004). These core themes in the data were then aligned with significant transference and countertransference impressions.
- **Step 3: The exploration of identifications and object relations.** In this step, I established significant identifications and object relations apparent from the

> narratives. The aim was to gain an understanding of how the participants, consciously and unconsciously, placed themselves in their narratives in relation to external objects in their life – including me. In this way, I began to gain an understanding of the participant's objects, fantasies, and defensive organisations (Cartwright, 2004).

While analysing the narratives, I paid particular attention to my feeling states, which I recorded in the form of personal notes during and after each interview, as recommended by Cartwright (2004). Specifically, I was interested in understanding why these feelings and thoughts appeared when they did. My intention in doing so was to provide some meaningful context to the participants' words and to how they related to me and my particularities. Working with my emotional responses and with how these interacted with those of the participants during the research process provided additional insight into some aspects of the participants' object relationships. However, these thoughts and feelings were also found to be the product of my own psychological processes and internal world. I committed myself to a free associative writing process in personal reflective note-taking, writing down my emotional responses to each interview. This material was immensely valuable and formed data for the thesis. (This material is discussed more fully in Chapter Five). These notes not only formed part of the data, they also informed the analysis of the interviews (Saville Young & Berry, 2016). Although these personal impressions are grounded within the text and interview encounters, they do reflect my subjective experiences, suggesting the "psychoanalytic notion of understanding as depending on 'the subjective exploration of one person by another'" (Frosh & Saville Young, 2008, p. 115). Hence the emphasis on the intersubjectivity of this study.

Countertransference data were also constantly noted and analysed. Clear non-verbal cues and strong transference responses of the participants were meticulously recorded. Thus, the participants' emotional responses to the process, to me, and to follow-up questions are also used as countertransference data. These data are carefully evidence-based, for example, noticing when a participant shifted positions. Many of the participants in the current project were overt in their encounters with me, providing direct access to their most intimate thoughts and feelings because of our perceived shared identities. The level of interpretation of participants' preconscious and unconscious processes from interview material is of necessity limited (I explore this topic in the published paper in Chapter Four). However, the intersubjective nature of this project provided greater access into these processes than I had initially expected they would.

Themes in the narratives began to appear and repeat themselves, which seemed to indicate the participants' intrapsychic organisation (Cartwright, 2004). The analysis technique followed in this study assumes that the core narratives form symbolic representations of the participants' internal psychic structures, that is, how the participants have created meaning around certain happenings in their lives. This implies that the participants' internal sense of themselves and their objects was gleaned (Cartwright, 2004). I reread the narratives repeatedly so that I could refine previous understandings and impressions. The ultimate aim was to make sense of the narratives, with as few contradictions and gaps in meaning as possible. These precautions are necessary to protect against over-interpretation and my personal projective process. Furthermore, extensive quotations to express participants' exact words are used in the writing up of the interview material to ensure the participants' narratives are accurately heard (Kruger et al., 2014).

The method of analysis for the current project also drew on ideas from Braun and Clarke (2006), who suggest identifying and analysing themes by discovering the patterns and links between them, resulting in a rich and detailed account of the data source. A theme is defined as something that captures an area that is important in the data in relation to the topic of the study (Braun & Clarke, 2006), and can be likened to what Cartwright (2004) calls a core narrative. Analysis at the latent level (Braun & Clarke, 2006) was carried out in this study – this involves analysing research material using an interpretative lens to uncover the underlying ideas and thoughts in the participants' words.

Another feature of the analysis of the data, which was inspired by both Cartwright (2004) and Braun and Clarke (2006), is a circular approach. The data were repeatedly revisited in order to review the themes and to understand how they fit in with the rest of the data and themes. This hermeneutic circle describes how a researcher's presuppositions shape interpretations of the data (Cartwright, 2004). One of the many advantages of drawing on ideas from Braun and Clarke (2006) is the theoretical flexibility of their ideas, which could be successfully applied to the current psychoanalytically based study.

The analysis was binocular (Saville Young & Berry, 2016), as I used both top-down and bottom-up approaches. Top-down interpretations involve applying central psychoanalytical concepts, while also grounding interpretations in the texts and the research encounters. Saville Young and Frosh (2010) describe the process as a concentric reflexive approach, because repeated readings of transcribed interviews and research encounters result in a larger analysis with each revisiting of the data. This implies that the data are circular, in that parts of the material are understood in the context of the whole interview and vice versa (Cartwright, 2004).

Integrity of This Research Project

It is important to consider how the method employed in this study and the resulting data can be used and analysed in a reliable and verifiable manner. The task of establishing whether an interpretation is credible is not a minor consideration (Schwandt, Lincoln, & Guba, 2007). This section follows on from the discussion of the methodical analysis technique above, where I have already discussed precautions to avoid misinterpretation of the data. This section should also be read in the context of the next two chapters, in which the published articles explore ethical considerations when using the psychoanalytic interview technique (Chapter Four) and my reflexivity (Chapter Five). I continuously needed to maintain a fine balance between aiming for reliability and preserving the nuances of the detailed and complex data.

Qualitative research attaches great importance on the ethics of *transparency* (Levitt et al., 2018; Levitt, Motulsky, Wertz, Morrow, & Ponterotto, 2017). In this regard, it is important to understand that a researcher's perspective(s) influence the entire process of the research (Morrow, 2005). A researcher's experiences, thoughts and feelings in the research endeavour should therefore be shared to illuminate what Cartwright (2004) calls observer bias. It is important for researchers initially to engage meaningfully in identifying their personal reasons and motivations for studying a phenomenon and the feeling states associated with these. The greater the degree of insight a researcher can gain in this regard, the more accurate the interpretation and analysis of the data will be (Cartwright, 2004). The use of my self is a valued part of this research process. This reflexive process was initiated before the interviews, and continued throughout this project, so as to acknowledge the effects that may be brought into the entire process. Hence, my subjectivity is continually considered in this study to reach a degree of greater understanding of the data. As Renik

(1998) believes, “objectivity” in psychoanalysis can only be achieved to any degree by considering one’s subjectivity. My reflexivity forms the focus of Chapter Five. Outlining how a researcher attempts to remain open to the emerging data increases the *credibility* of the arguments made in a project (Levitt et al., 2018).

Within the ambit of the adapted psychoanalytic research interview method, *neutrality* is always an aim that a researcher should strive for. Such a researcher creates enough psychic space from the participants to think about the interactions during data collection (Hollway & Jefferson, 2000). Thus, it was important to be consciously aware of my role in the process, which was made possible by actively thinking through this and engaging with it in personal psychotherapy – something the next two published articles delineate.

A researcher’s transparency thus enhances the integrity of the research method, resulting in greater trustworthiness of the project (Levitt et al., 2018). Cartwright (2004) suggests following four principles to achieve the most accurate interpretations. The discussion should be as *coherent* as possible, free from contradictions or gaps in understanding. Coherence was achieved in the study by confirming interpretations of the data against any competing data. Such verification also achieves a *comprehensive* account of the participants’ experiences. Evaluating the account of the data by using psychoanalytic theoretical understandings with the intention of ensuring that the project’s outcome is not personally self-fulfilling assists in *external consistency* (Cartwright, 2004). *Validation* of the findings (Cartwright, 2004) was achieved by asking my psychoanalytically trained research supervisors to evaluate my analysis and interpretations of the interviews.

These above four principles were practised in this study, along with Lincoln’s and Guba’s (1986) *trustworthiness* criteria, which although dated, remain a standard of credible qualitative research (Schwandt et al., 2007). Prolonged, in-depth engagement with the

participants in the form of repeated and lengthy interviews went some way toward achieving *credibility* (Guba, 1981; Lincoln & Guba, 1986). Any contradictions within the data could be followed up on in the second interview with a participant. Debriefing (Guba, 1981) after the interviews through note-taking, supervision with my psychoanalytically oriented research supervisors, and in personal psychotherapy helped me to maintain an ethical engagement in this project. Verifying with participants what they recounted, and altering my understanding when necessary, furthered the credibility of this enterprise, and the audio-recordings of the interviews (Guba, 1981) were a useful tool in this regard.

Transferability was achieved by purposively sampling the participants (Guba, 1981). Acknowledging contextual embeddedness (Levitt et al., 2018) was another way in which I attempted to ensure transferability in this study. Providing thick descriptions of the data (Lincoln & Guba, 1986), with many participant quotations and contextualised interpretations (Cartwright, 2004), enhances the transferability and credibility of the discussion sections of this research. Furthermore, relevant, detailed descriptions of the participants are provided.

Cartwright's (2004) fourth principle of validation, discussed above, is similar to Lincoln's and Guba's (1985, 1986) *dependability and confirmability* criteria. They all discuss an audit of the analysis by an external auditor – something achieved in this study with my supervisors.

To achieve an *authentic* research account, a researcher needs to be fair (Lincoln & Guba, 1986) in providing a balanced account of the data. Authenticity can be pursued by receiving informed consent from participants (Lincoln & Guba, 1985), as well as checking the researcher's understanding with participants, as I describe doing, above. Authenticity is also achieved by providing an empowering, as opposed to an impoverishing, account of the data

(Lincoln & Guba, 1986). An empowering discussion is an aspect that I constantly engaged with throughout this study, especially as I am aware that it is considered crucial in the field of disability studies (Shakespeare, 1996; Sinason, 2002). Thus, great care has been taken to ensure that the participants were not deceived in any way.

Ethical Considerations

Chapter Four presents a published article that explores some of the core ethical dilemmas encountered in this research project. Here, the focus is on general ethical issues and the processes I adhered to.

The current research abides by the University of the Witwatersrand's Code of Ethics for Research on Human Subjects. Ethical clearance was obtained from the Human Research Ethics Committee (non-medical) before embarking on the study (the clearance certificate is included as Appendix E). The participants provided their signed consent to participate in the research and to be interviewed, after being informed in detail about the nature of the research and the expected level of involvement. A participant information sheet detailing the purpose, aims and method of the research was given to each participant (see the consent forms and participation information sheet in Appendices A, B and C).

Participants' identities were protected throughout the research process by using pseudonyms and removing identifying information from the data, or disguising such information. Thus, participants' confidentiality and final anonymity in this thesis are assured. The transcribed interviews are stored in password-protected computer files.

A number of issues arose that need to be constantly reflected on, especially around avoiding over-interpreting data (as discussed in the published paper presented in Chapter Four) and other ethical aspects specific to the use of the psychoanalytic research interview approach. Due to the nature of the method of data collection, there was a constant

possibility that some information may arise that participants are not fully conscious of, for example, painful feelings the participants may hold for their children and their disability. Some questions may have elicited information from the participants which they had not adequately dealt with yet. Furthermore, since the focus of the research is on a sector of the population that may at times require extra support, some difficult feelings may have been evoked. It was important to conduct a debriefing session (Kvale & Brinkmann, 2009) with each participant immediately after every interview. The participants were asked the following:

- Are you okay to stop for today?
- How are you feeling?
- Do you have any questions for me?

(See Appendix D for a copy of the psychoanalytic research interview outline.)

Where I found that the interview had evoked difficult, unprocessed emotions, we discussed the possibility of referring the participant for psychotherapy. The details of a free counselling service were provided for participants who felt that they required further debriefing or psychotherapy in this regard (see the participant information sheet for these details in Appendix A). None of the nine participants voiced the need to seek counselling after the interviews.

The ethical responsibility to cause no harm to the participants was constantly borne in mind. This was particularly pertinent, given the potentially sensitive aspects that could arise in the data collection stage. The possible ethical dilemma regarding refraining from offering interpretations to the participants is discussed in detail in the published article in Chapter Four.

Green's (2002) concept of the "stigmatised category" that mothers sometimes find themselves in, as discussed in the article in Chapter Two, is also pertinent to the ethical considerations of this project. I was aware that this study may potentially cause the participants to experience further scrutiny, and this needed to be consciously and sensitively thought about in order to avoid further experiences of stigmatisation and disablism for these women. This sensitivity was hopefully honoured by allowing participants to choose what and how much they wanted to share about their mothering experiences, rather than a fixed set of questions. Furthermore, my psychoanalytic psychotherapist's skills of unconditional acceptance and empathy assisted greatly in this regard.

Chapter Four:

Ethical Emotional Encounters: Contemplating Challenges in Psychoanalytically Informed Research

Introduction

Following on from Chapter Three: Method, this chapter and the next specifically address the second focus of the study, namely what the process of conducting research with mothers of children with physical disabilities entails.

Psychoanalytical concepts and theory were used in the study to guide the data collection regarding maternal subjectivity, and to understand various levels of meaning in the information gathered – "'[p]sychoanalysis' is deliberately employed here as a methodological tool, and not as a particular theory" (Long, 2009, p. 98).

The article "Ethical emotional encounters: Contemplating challenges in psychoanalytically informed research" constitutes the remainder of this chapter. The article details the method of data collection and the accompanying ethical considerations that needed to be carefully navigated during the interview phase of the study. The article appeared in *Psycho-analytic Psychotherapy in South Africa* in 2017.

The article begins to address the second research question; the implications of researching the maternal subjectivity of mothers with disabled children are carefully considered, not least, the intricacies of remaining ethical in respect of both the participants and the research endeavour. I argue that a psychoanalytical interview method can be a very ethical way of being with participants when researchers are also psychoanalytically trained psychotherapists, who work with their own countertransference, as well as participants' transferences. Hence, the intersubjective focus to the study is foregrounded while the paper

addresses the co-creation of material in the emotional encounters between researchers and participants. Arguably, being with participants in this way allows for more nuanced data to emerge – hence, the intimately connected dual focus of the study: the process of researching the experiences of mothers and the material that is shared by the participants.

This chapter should be read as an extension of the chapter on method, particularly the sections on data collection and the relevant ethical considerations.

Article:

Ethical Emotional Encounters: Contemplating Challenges in Psychoanalytically Informed Research

Abstract

Researchers using qualitative methods are required to be ethically mindful not to cause harm to participants. However, when emotional encounters between researchers and participants occur, there are inherent ethical tensions that need to be continuously navigated. In this paper I contemplate the challenges I encountered whilst using a psychoanalytically informed research interview method (adapted from Cartwright, 2004; Kvale, 1999; Strømme et. al, 2010). I interviewed women on the topic of maternal subjectivity when their children have a disability. The ethical quandaries included accessing nuanced data by engaging with participants' unconscious material, as well as the use of the transference-countertransference situation outside of a psychotherapy setting. The literature has previously discussed the ethics of using this psychoanalytic method, particularly around the interpretation of data from a psychoanalytic lens. However, the aim in this paper is focused on the application of psychoanalytic concepts in the process of data collection and how to ethically manage these emotional engagements with participants. It will be argued that when researchers are also mindful, psychoanalytically-trained psychotherapists who engage with their own subjectivity in personal psychoanalytic psychotherapy, this psychoanalytic inquiry method can be a very ethical way of being with participants.

Introduction

This paper is a reflection on the ethical concerns experienced while collecting data using a research interview method that is informed by psychoanalytic ideas and concepts,

specifically the psychoanalytically informed research interview method (adapted from Cartwright, 2004; Kvale, 1999; Strømme et al., 2010). I reflect on how I attempted to ethically manage encounters with participants using examples from my study on maternal subjectivity while raising a child with a disability. Mothers of disabled children were the participants of my study and I interviewed each participant twice.

I felt prepared to conduct these interviews as I had diligently reminded myself of the core ethical principles of informed consent, confidentiality, anonymity and beneficence, aspects that my research training and experience had covered. However, from the very first encounter with a participant it became apparent that this research required a more complex engagement with the discomfort of ethics in research. Although some of the ethical concerns that I consider in this paper are also experienced by researchers conducting other qualitative projects, most of these intricate, less apparent ethical tensions are specific to the data collection phase of this psychoanalytic method.

These particular ethical challenges involve accessing and working with participants' preconscious and unconscious material outside of a psychotherapeutic relationship and the possible promotion of a psychotherapeutic expectancy in participants. Further, I explore aspects of the existing debate around the legitimate and ethical use of transference and countertransference outside of the psychotherapy setting. I reflect on how I navigated some of these issues in the encounters with participants so that other researchers employing this specific method may be assisted. It is my contention that a researcher employing this interview technique should ideally be a trained psychoanalytic psychotherapist. Further, this researcher should be in personal psychoanalytic psychotherapy in order to attain the level of reflexivity and mindfulness that is required in the complex, intricate emotional encounters with participants. Although this contention could be thought of by some as an

elitist position, I argue that unlike training to be a psychoanalyst, training to become a psychoanalytic psychotherapist can be accessed by individuals across different economic groups. This too is the case for a researcher accessing psychoanalytic psychotherapy, as opposed to entering into psychoanalysis. Further, some may argue that all competent qualitative researchers should be mindful, and this I agree with. However, the level of insight that is required when working with the transference-countertransference is deeper than merely being researcher reflexive.

Before I engage with this discussion, let me very briefly outline the method I used.

Introducing the Psychoanalytically Informed Research Interview Method

This technique enables the collection of participant narratives that go beyond more superficial descriptive accounts. Psychoanalytic theoretical concepts and practices are used in an attempt to collect rich and nuanced data, including preconscious and unconscious material. Freud (1923), who initiated the psychoanalytic technique, described the fundamental premise of psychoanalysis as mental life consisting of the conscious and unconscious. Conscious thoughts are those that one is aware of. Unconscious thoughts are differentiated into preconscious and unconscious. Preconscious thoughts are latent and underlying, yet have the capability of becoming conscious, those thoughts that individuals have conscious access to once they are encouraged to reflect upon them (Strømme et al., 2010). Whereas Freud (1923) postulated that true unconscious ideas can only become conscious through psychoanalysis, Strømme et al. (2010) stated that preconscious and unconscious defence processes often colour a participant's subjective account.

This psychoanalytic inquiry method employs an analytically based interview method grounded in the psychoanalytic listening perspective (Strømme et. al, 2010), which is described as "free-floating responsiveness" (Sandler & Sandler, 1978, p. 289). It is further

developed from Hollway and Jefferson's (2000, 2008) free association narrative interview method which involves inviting participants to narrate their experiences by voicing whatever comes to mind around the topic of the interview. Freud (1923, p. 239) depicted this basic premise:

> … the attitude which the analytic physician could most advantageously adopt was to surrender himself to his own unconscious mental activity, in a state of evenly suspended attention, to avoid so far as possible reflection and the construction of conscious expectations, not to try to fix anything that he heard particularly in his memory, and by these means to catch the drift of the patient's unconscious with his own unconscious.

The researcher's role is to create the necessary conditions that will facilitate the participant in constructing his or her narrative. Consequently, this method aims to access conscious, but also preconscious and possibly unconscious meanings, intrapsychic processes, object relations, fantasies and defence mechanisms associated with the focus of the research (Cartwright, 2004).

In order to maximally facilitate the collection of rich data, each participant is interviewed two to four times. The first, and potentially second, interview is unstructured and flexible, asking participants to start where they wish in giving their narratives, loose associations and thoughts related to the topic. The researcher follows the participants' free associations in whatever direction they take. Often participants' spontaneous remarks reveal preconscious and unconscious processes which they possibly would not have shared (Strømme et al., 2010) in other interviews, specifically more structured formats. All subsequent interviews give participants a chance to reflect on what they shared in the initial interviews. Additionally, memories and thoughts often arise between interviews that can

then, hopefully, be shared. Any contradictions, conflicts and psychological defences that have arisen in previous interviews can be explored in later interviews (Cartwright, 2004).

The nature of this emotional engagement with participants suggests potential inherent ethical tensions. Writings have been published on the ethical use of the psychoanalytic research interview (Kvale, 1999; Long & Eagle, 2009) and while these are most helpful, certain ethical matters need further deliberation. Long and Eagle (2009), as well as Swartz (2015), have outlined the potential benefits and pitfalls the two identities of psychotherapist and researcher can have on the research endeavour. Other authors, including Frosh (2006), Frosh and Baraitser (2008), as well as Saville Young (2009), have tackled the discomfort of the ethical application of psychoanalytic concepts in research. However, these papers largely focus on remaining ethical while interpreting data, as opposed to collecting data, which is the focus of the current paper. While these arguments are helpful in that they offer a critique of the way psychoanalysis has been applied as an ungrounded expert theory in research, they do not adequately assist in managing the very real ethical tensions *at the time* of the emotional encounters with participants. I am aware that it is impossible to clearly delineate between the research phases of data collection and analysis using this method. However, my focus is on how to be true when *with* participants. By deliberating on this emotional encounter, I wish to contribute to the ongoing ethical debate regarding psychoanalytic research. As Long and Eagle (2009, p. 49) stated, “ethical debates should be kept alive rather than foreclosed”.

Engaging with Participants’ Unconscious: Participant Over-disclosure?

Although informed consent, as in all research, is obtained from participants before conducting interviews, this can be an area of ethical contention when using the proposed method in this paper. Interestingly, Matebeni (2015), as well as Long and Eagle (2009) have

raised the issue of whether participants know exactly what they are consenting to when the researcher cannot know beforehand what information will be elicited. Participants may find it more difficult than they had anticipated withholding information (Mitchell & Irvine, 2008) as a psychoanalytic way of being with participants inevitably shapes the unconscious material that emerges, causing participants to reveal intense emotional parts of themselves which they barely recognise. Let me share a part of an interview to illuminate this point.

One of the participants in my study who has a daughter with cerebral palsy narrated her traumatic birth experience. She went into premature labour at 29 weeks, although she did not appear to realise that the pain she was experiencing was labour. She recalled her sense of remorse: *"And then there was a whole area of guilt because I felt that while I lay in ICU with my uterus rupturing and the doctor not arriving … I felt very guilty that I hadn't insisted on medical attention"*. This rather laden statement was merely dropped into her narration and when I tried to make sense of what she was saying, she went on:

> *Meaning if someone had come and attended to it a couple of hours earlier, she* [her disabled daughter] *might not have been as oxygen deprived, and she might have been okay. Not only might she have been okay, but I might have had twins* [her other baby died at birth] *who would have been okay. So my role in the, in the implementing of medical care, because the doctor just didn't come and they gave me a … suppository for pain, they thought I might have a bit of gastro [gastroenteritis] because I was vomiting. So there's been, there was that whole side to it*.

I responded in an attempt to contain the rather emotional story I had just heard: *"Okay you thought you might be responsible for …"* This seemed too difficult for this participant to hear and she became psychically defended and avoidant by interrupting me and referring to my birth, in an attempt to distance herself: *"You see now in your case with*

your mother [referring to the researcher's mother]*, she wouldn't have felt in anyway responsible …* [she] *had no impact on the outcome, so there's no guilt"*. The participant then closed the subject: *"Um so there was that … just trying to think what else …"* I tried to stay on this topic as I felt I needed to contain her and process the traumatic story told to me. The sense that the participant was at this moment accessing preconscious material highlights how this interview method requires a particular kind of containment that goes beyond the ordinary skilled interviewer armoury. Her comments were so emotionally laden and her narrative felt that it has not been meaningfully worked through. Thus the participant's defended subjectivity is evident at this instant. I went back to the beginning to try and unpack it: *"So what happened, you felt pain? You weren't well? And you went to the doctor, the hospital …"*. She continued:

> *Yes, just a stabbing pain in the middle of the night, then I went off to the Labour Ward … Ironically it, I've only realised now but if I'd gone to an Emergency Room, like [another hospital] I might have got better care … And the Labour Ward were just treating me as if I had maybe um, what, sort of some, the onset possibly of premature labour or maybe a bit of gastro, or maybe a bit of, there weren't emergency doctors or … you know what I mean? Whereas I would have got a doctor, let's put it that way, I would have got a doctor* [at the Emergency Room]. *Whereas if they'd sent me down to Emergency … now that might … so all these ifs and buts …*

I responded in an attempt to elicit some of her preconscious feelings and fantasies: *"Yes … when you think of that, that decision that you'd gone to Labour Ward instead of …"* Her preconscious response followed: *"I only thought of that now. Had I thought of it then, I would have been absolutely tormented I'm sure …. Yes, but now there's a lot more acceptance of how it's unfolded and I don't dwell on any of it anymore"*. I was aware that

this last statement suggested a defence against her more difficult emotions of guilt and anxiety. This excerpt is but one example of a participant's unconscious material disclosed using this data collection method. I chose to let her uphold her defensive structure by following her change in subject. I was aware of a tension inside of me, as I wished to follow this thread in her narrative, and if she had been a psychotherapeutic patient I would have offered an interpretation. However, I respected her need in that moment to shift focus, and her position as participant.

Working with the unconscious brings to the fore the importance that the researcher is also a trained psychoanalytic psychotherapist. Although this level of disclosure may occur in other qualitative interviews, the very nature and skills of the researcher as a psychotherapist, including recognising and working with psychic defences and unconscious material, may bring about unexpected, deeper divulgences from participants. Strømme et al. (2010) posited that the researcher is required to be competent within a psychoanalytic frame in order to maximise the potential of this method. In agreement with these authors I contend this method can only be used to its full impact if the researcher is a psychoanalytic psychotherapist. Further, the ethical tensions can be somewhat quietened when a researcher depends on his or her psychoanalytic training and experience while interviewing participants. It is necessary to develop an interview relationship that considers the emotional atmosphere between researcher and participant. The reliance on the two central psychoanalytic concepts of transference and countertransference is crucial in understanding, as well as managing, the emotional aspects of this relationship (Strømme et al., 2010).

Working in the Transference-Countertransference with Participants

Long and Eagle (2009) suggested that once an individual has been trained in therapeutic (I argue specifically psychoanalytic) skills, these cannot be dispensed of in order to conduct research interviews from a different position. Indeed, while these particular skills are essentially helpful in eliciting nuanced, meaningful information from participants, a researcher's psychotherapeutic style of engaging and following up responses often can inadvertently elicit highly sensitive conscious, preconscious and unconscious material, as evident in the participant's excerpt above. Thus, the revealing nature of such interviews is arguably unavoidable, and in fact invaluable.

The intimate encounter and co-construction of meaning using this research method brings to the forefront the importance of the inseparable situation of transference-countertransference. Freud understood transference to be the patient re-experiencing early life feelings, thoughts and wishes towards others in relation to the psychoanalyst (Freud, 1910a). Transference is partly an unconscious process (Freud, 1910b). Psychoanalysts in the present era perceive transference to be an intrapsychic occurrence which refers to the patient's entire relationship with the psychoanalyst (Langs, 2004). Transference thus acknowledges the role of a patient's past relationships, and the relationship with the psychotherapist (Ogden, 1994), as well as with other transference objects. For the purposes of the discussion at hand, transference also encompasses a participant's relationship with the researcher.

Freud (1910a) defined countertransference as the psychoanalyst's unconscious responses to the patient's transference. Current psychoanalysts place great focus on the usefulness of countertransference (Carpy, 1989), as it is believed to provide insight into a patient's pivotal relational dynamics (Hayes, 2004). A modern definition of

countertransference includes the psychotherapist's own conscious and unconscious feelings for the patient, which are based on actual characteristics of the patient, as well as on individuals in the psychotherapist's current and past life (Hayes, 2004). Thus psychotherapists are encouraged to be aware of, and responsible for, their own emotional reactions. Kvale (1999, p. 95) described countertransference as the psychotherapist's "reflected subjectivity". For the intents of the present discussion, the most helpful, mutually created and inseparable transference-countertransference situation (Ogden, 1994) involves everything, past and present, which a participant and researcher bring into the encounter. Thus, the researcher's thoughts, feelings and responses towards the participant are included in this situation. Paying attention to the transference-countertransference situation enables the researcher to access some of the participant's unconscious thoughts and feelings.

In the case of the psychoanalytically informed research method, the feeling states in the interview encounter are understood to be intersubjectively created between the researcher and participant. These emotional responses are used to assist the researcher in eliciting some preconscious and unconscious material from the participant. Thus this psychoanalytic technique can be challenging to use as a researcher, especially if one is not also a psychoanalytic psychotherapist who is trained and experienced in working with transference-countertransference.

Furthermore, Marks and Mönnich-Marks (2003) stated that countertransference reactions are unavoidable, and that transference-countertransference is present in all human interactions. These authors warn researchers that being unaware of these emotional reactions may result in the loss of important data, and, I contend, may also result in potentially unethical engagement with participants. Thus there is a substantive difference

between this method of data collection and sensitive, unstructured or semi-structured interviews with no psychoanalytic theory framing them. This psychoanalytic way of engaging with participants requires a specific kind of moment-by-moment awareness, self-analysis, attention to the transference-countertransference situation and containment of the participant by the psychoanalytic researcher.

Accordingly, this interview method requires the researcher to be an active participant in the process. Thus, the researcher needs to consciously consider his or her subjectivity throughout the research endeavour. Further, Holland (2007, p. 195) discussed the centrality of, and the crucial role that emotions play in research, going so far as to say "emotion is necessary for knowledge". Holland (2007) argued it is impossible for a researcher to be detached during the process. In agreement, I believe a researcher needs to recognise and work with countertransference.

Interestingly, researchers, and not only participants, can resist and defend against more difficult feelings during interviews. Holland (2007) raised a crucial point – researchers need to be willing and able to engage in personal unconscious processes if they want to be able to explore participants' conscious, preconscious and potentially unconscious dynamics. Psychoanalytic psychotherapists are expected to display this inward attention with patients. Thus working with countertransference can be more natural for psychoanalytic researchers, compared to non-psychoanalytically trained researchers using this method.

It is imperative that researchers realise how their identity, experiences and emotions shape the ideas with which they enter into interviews. Holland (2007) warned of the shortcomings if this interplay of individuals, as well as the research process, is not considered. Thus, it is immensely beneficial if such a researcher is in personal psychoanalytic psychotherapy. Researchers need to gain insight into their own subjective position and be

mindful and conscious of transference-countertransference as both a source of potential blockage to accessing data, but also as a source of rich data if sufficiently comfortable in this internal milieu. Indeed, Long and Eagle (2009) warned that researchers have an ethical and moral responsibility to constantly be attuned to their own feeling states and the impact they are having on participants, and not to avoid difficult and sensitive material. They argue that it is their psychoanalytically oriented training that often results in researchers' being empathic to the point of eliciting participants' preconscious material. This is unavoidable, and I think need not be feared as unethical if it is dealt with in a sensitive, thoughtful manner. Hence, this way of being with a participant is empowering and dedicated to accessing sincere accounts. However, it is important to remember that participants' intrapsychic functioning can only be partially understood because of the limitations of the research interview setting (Long & Eagle, 2009).

I would like to share some ideas from reflective case notes I made after interviewing a participant, in order to illustrate how the transference-countertransference can be used during the data collection phase (as well as during ongoing data analysis). At the time of the interviews, the participant's daughter, who has cerebral palsy, was three years old. After the first interview, I was aware of how tired I had become during our encounter. The participant had related in intimate detail the birth of her daughter, the undiagnosed stroke that her daughter had suffered and the consequent development of her physical disability. During this initial encounter I found myself thinking about my own children (six and three years of age at the time) and the current, as well as past, maternal challenges I was experiencing. Despite these various difficulties I was facing, I became aware of how grateful I am for my happy, healthy children – something this participant also voiced about her daughter. Towards the end of the interview the participant became tearful, relaying her deep

ambivalence towards her daughter, and I found myself becoming emotional too. I understand my suppressed tears to be a result of her transference, as well as my countertransference.

This participant was prominent in my thoughts throughout the next few days. I was left wondering why she was having such an impact on me. Her story constantly reminded me how precarious life and the human condition are, and how we are all fallible – myself and my children. I understand this to be the participant's transference, as well as my countertransference. This situation was powerful and I found myself believing that it was not necessary to interview this mother again as I felt she would not have anything more to tell me. My psychoanalytic research supervisor encouraged me to set up another interview and after reflection in personal psychotherapy I contacted the participant. I was struck by how much more this woman had to share with me in our second meeting. I became aware that I had been defended against some of my more painful countertransference by avoiding a second interview with her. A psychoanalytic psychotherapist and researcher is trained and experienced in working in this way – using the transference-countertransference situation, which resulted in more nuanced, detailed data for my overall research endeavour. This reflection highlights the need for vigilance and engagement with countertransference during encounters with participants, between these encounters, during supervision, and within the researcher's personal psychotherapy. Further, it highlights that this way of thinking about, and being with participants can be highly ethical, as this participant needed to be heard again and given another chance to complete her story, something I was initially not going to allow her to do.

Research, Not Psychotherapy

It is not the researcher's intention to psychoanalyse participants; this is what a psychoanalyst would do. Indeed, Kvale (1999) cautioned against promoting a psychotherapeutic expectancy in the participant due to the nature of this method. Thus it is important for the researcher to remain in the data collector role and not present as a psychotherapist. The researcher listens to the participant and responds with the research agenda in mind (Swartz, 2015), which is different from how a psychotherapist listens for the unconscious when with a patient. This suggests that the type of responses and interpretations a researcher makes are research-driven, rather than psychoanalytically driven. Accordingly, the tendency for participants to potentially utilise the researcher as someone to talk to about personal struggles and gain insight will hopefully be avoided.

Further, a stark difference between the psychoanalytic research interview and psychoanalytic psychotherapy is that, as in the former case analysis, interpretations of the participant's story are made after the emotional encounter. In the case of psychotherapy, interpretations of a patient's story are made during the encounter, to the patient. A researcher merely uses psychoanalytic concepts and practices as a way of eliciting and understanding the participants' wishes, anxieties, struggles and feelings, those aspects in the participants' intrapsychic functioning that are "unspeakable and unbearable" (Long, 2009, p. 98).

Long and Eagle (2009) argued that a different type of relationship is formed between a researcher and a participant versus that which is established between a psychotherapist and a patient. The crucial difference is that access to a participant's unconscious dynamics is limited, due to the specific relationship between the researcher and participant. A research participant and a psychotherapy patient each has different expectations and investments in

the two different processes. A researcher elicits a different transference to that elicited by a psychotherapist. Furthermore, the transference relationship has far less time to develop due to the temporal constraints of the research interview process. Although these are valid points, transference-countertransference operates in every relationship, not just those of a psychotherapeutic nature, and it is present from the outset of any encounter. Hence, paying primary attention to these dynamics within the research relationship (although they may be represented differently to those in a psychotherapeutic relationship) is ethical and beneficial to both parties, as well as to the overall research endeavour. It may, at times, be unethical to attempt to ignore them.

As with all research, the researcher needs to constantly bear in mind the ethical responsibility to cause no harm to participants. Researchers are responsible for creating a safe environment in which participants feel contained and secure so they are comfortable to share intimate thoughts and difficult emotions about the topic without feeling exposed. A psychoanalytic-researcher's clinical training and experience become extremely helpful, particularly the use of containing comments throughout the interview, yet at the same time being mindful of not taking the role of psychotherapist. Some may argue that this blurring between psychotherapy and research may be more easily crossed by a psychotherapist researcher. However, a psychotherapist is acutely aware of what psychotherapy entails and thus can constantly guard against this. This is an emotionally demanding, conscious and ongoing undertaking in research. Grappling with this in my own psychoanalytic psychotherapy went some way toward achieving this difficult balancing act.

Interestingly, as a researcher, I often found myself deliberately stepping out of a psychotherapist-type role, identifying with participants from my own various levels of identity. This level of sharing is consciously protected against as a psychoanalytic

psychotherapist. At times I volunteered very limited, personal information as part of a conversational, rapport-building technique, including shared pregnancy experiences, general information about my children, as well as day-to-day mothering experiences. This manner is in stark contrast to how I relate to patients as a psychoanalytic psychotherapist: I never disclose personal information to patients. However, participants enter into the relational scenario with different expectations from those of a patient. Participants have not chosen to share their story for psychotherapeutic gains, but rather they have been asked to share information for the gains of the research enterprise.

Kvale (1999) cautioned researchers against making interpretations on the data to participants which are beyond their subjective reports. This is for various reasons: notably this encounter is not psychotherapy and participants may not have the self-understanding, and thus not be psychologically ready, to hear such interpretations, which could cause them distress. However, interpretations made by a researcher can result in participants' sharing more of their story. Researchers are left with the dilemma of refraining from making any such interpretations, while wanting to elicit meaningful material through the interview process. This is an ongoing, sensitive and conscious balance to strike. I was aware of this balancing act inside of me at various points throughout my research study, yet at times it is not a tension as it has positive outcomes for both researcher and participant. As Strømme et al. (2010) found, participants are often interested in contributions from a researcher, provided these are given as genuine, exploratory comments and not as definitive interpretations. Participants can experience these responses as opportunities to reflect on, and further understand, their experiences. Crucially, the number and content of such reflections need to be determined by the established quality of the relationship and the participant's degree of psychological defensiveness (Strømme et al., 2010). I was excited

when I elicited nuanced narratives from mothers and at the same time assisted these women in making meaning for themselves.

Participants have been found to participate in research that is of interest to them as they believe it grants them access to a therapy-type space (De Vries & Henly, 2015). Birch and Miller (2000) discussed the close parallels between this type of research and a psychotherapy setting. In both instances an individual reveals intimate experiences to an empathic listener. Participants often describe the opportunity to reflect on their experiences as therapeutic as they discover new meanings to difficult past events. While this may again be true for other qualitative research methods, I believe this particular psychoanalytic interview method can elicit deeper meaning-making moments for participants. Participants in my research experienced these moments of awareness. One participant reflected on the interview process: *"It helps in terms of getting it* [her experiences and feelings] *out because it all just sits there, it does sit there … sometimes when you say everything out loud you realise … you realise you do feel certain emotions that you just don't want to admit"*. The same woman further reflected on the insight she had gained from her first interview: *"It was after the interview I think I started seeing things that I didn't think about before … like my frustrations, certain things, where I find it difficult, things that might not get mentioned"*. She remarked that she was *"a little bit more aware of that feeling"* after sharing her experiences with me. Another participant positively reflected on her initial interview: *"It was great because I think it was also a learning curve for me"*. She went on to say: *"It helped me a lot to put things in perspective"* and *"it was a great interview and I think also for me it was having to go through all the details is a reflection of where we* [her and her family] *were and how far we've come"*. She further reiterated her point: *"I think it's* [participating in the research] *going to help me as well in my journey"* with

raising her son with a disability. Yet another woman realised after her first interview that she is *"much more stronger than I was before"*.

More, the benefit of repeated interviews is marked for participants as they can have the opportunity to revisit previously shared material for clarification purposes, which can elicit further meaning-making for them. This highlights the agency of the participants. The following excerpt emphasises how even "unconscious" defences can be identified by participants in the interview process when they are given the chance to proceed at their own pace. The excerpt is from my initial clinical-type reflections on a participant, made in my research journal, to illustrate how I used psychoanalytic understandings of a participant's behaviour in a way that respected her process and illustrates unconscious operations at play:

> *It has been quite difficult to set up the first interview, even though I received the participant's details from a physiotherapist who had checked with the participant and at that point she was willing to be interviewed. We haven't always been able to find a time that suits both of us for various reasons. When we did finally settle on a time, when I arrived at her house she was out shopping. She hasn't always answered calls and messages, but finally today she answered her phone and said she was sorry she had been a bit inaccessible lately, but she was still very willing. She sounds happy to meet and I wonder about her psychological defences. We arranged for tomorrow morning at her suggestion and then she asked me how long it would take and when I said maybe one and a half hours she said that she doesn't know if she wants to speak for that long on her mothering experience. I reassured her and explained a bit about my research and she felt much better hearing that it wouldn't be a question-answer session or questionnaire. I explained that she could share whatever she felt*

comfortable to and that we could stop whenever she'd like to and that I could even come back to talk to her.

My reflections and reliance on my knowledge and experience as a psychoanalytic psychotherapist assisted me in understanding this woman's avoidance of me and of the interview. I was acutely aware that she may be psychically defended during the interview and that I would have to tread carefully. I was also aware of her anxiety and thus I utilised my psychotherapeutic skills of reflection and containment to put her at ease.

My reflections continued after meeting her:

1st interview:

Took place at her house, she was on the phone when I arrived and she chatted for about five minutes while I waited, gesticulating that she was sorry.

My reflectivity and subjectivity in the moment included wondering about this possible delaying tactic as a sign of psychic defensiveness against her anxiety and maternal subjectivity. I wanted to respect this, yet also ethically elicit the data I required for the research project.

One of her male colleagues was working inside her house (we met on the patio) *and I was aware of him through the window. She also called her domestic worker to clean the table at one stage and her daughter was in her bedroom studying. I wonder about these other presences and disruptions – perhaps it made it easier, less anxiety-provoking for her. We only met for 45 minutes and her colleague interrupted us after 40 minutes to say 'watch the time'. My fantasy was that she had asked him to do this so that she could stop the interview. I respected this and drew the interview to a close. On my way out she said: 'Don't think me cancelling was by accident'*.

This final comment is interesting as it suggests she had some insight into her level of anxiety. It was telling of this woman's level of psychic defensiveness that she chose to share this at a moment when I could not explore it with her. It was potentially a psychotherapeutic moment in which I could have given an interpretation the next time we met; however, I was aware of my role as researcher and not psychotherapist. Towards the end of our next interview I felt I could address this last moment of our previous encounter. I felt a meaningful level of rapport had been established between us and I had assessed her level of emotional functioning (something a psychoanalytic psychotherapist is trained and experienced to do). I believed she could manage an interpretation in order to elicit further information regarding her subjectivity: *"When I said good-bye to you last time, you said, 'don't think my cancellations are unconscious sort of thing' … you're very aware of …"* She responded:

> *I've been very … like you said to me, will you do Monday, and I think to myself, maybe the next Monday, maybe the next day… The irony is, I thought to myself, at 8 o' clock I'll be there, and then why am I running late, I wonder if that's actually by mistake, on purpose, why am I late? I'm late and I knew I was coming.* [She arrived 30 minutes late for her second interview].
>
> She went on: "*And you wonder, am I late because I don't want to do it* [the interview]*? I don't mind doing it, because I must, but I don't like anticipate it with joy*".

The above insert demonstrates this participant's unconscious defence against aspects of her maternal anxiety and subjectivity. However, it also suggests that she has a certain level of awareness of these deeply uncomfortable feelings and processes. My notes illustrate how I utilised psychoanalytic understandings of defences and participants' needs

for their defences before, during, as well as between, encounters with participants in order to ensure an ethical engagement.

Further, various authors (Karnieli-Miller, Strier, & Pessach, 2009; Kavanaugh & Ayres, 1998) have described different reasons why individuals participate in interviews, including catharsis, self-acknowledgment, sense of purpose, self-awareness, empowerment, healing, providing a voice for the disenfranchised, as a coping strategy, the participants' nature of interest in the research topic, as well as altruism. The women in my research voiced their desire to advocate for disability and their wish that their participation would help other mothers raising a child with a disability. One mother gave her reason for sharing her story: *"[M]aybe a little bit of what I am telling you can maybe help* [other mothers]*"* and *"maybe some little piece of what I say at some point might make you* [other mothers] *go actually, I'm okay …."* Another participant said about her interview experience:

> *It's good for me to be able to share because I hope that somewhere someone down the line maybe reads your paper … that it would be able to shed some light. Because I know the stuff that I read helped me when I was still at that stage* [adjusting to being a mother of a child with a disability] *… makes me feel good that I know that … if one person is touched by this and their life is improved then you know it makes it worthwhile.*

The idea that these women felt they could share what was important to them, as opposed to answering pre-determined research questions, points to an experience of being given a genuine opportunity to be heard. Such an opportunity can be an ethical way of being with a participant. Birch and Miller (2000) advised researchers who aim to explore intimate experiences to be prepared for these interviews to be perceived as opportunities for psychotherapeutic engagement by participants. I argue it is important for a researcher to

acknowledge this may occur and decide as far as possible prior to the interview how this difficult line between role of researcher and psychotherapist will be tread. In addition, the more contact a researcher has with a participant, as in the case of repeated interviews, a strong and intimate relationship is established leading to greater participant disclosure. This extended contact may replicate a psychotherapeutic relationship in the participant's mind (Knox & Burkard, 2009), especially as he or she is asked to share personal, intimate experiences which usually occurs within long-term relationships (Ribbens, 1989). My experiences of psychoanalytic psychotherapy, as a psychotherapist and patient, informs me that the interviews I conducted were not the same as psychotherapy – experiencing an encounter as therapeutic does not necessarily equate to psychotherapy. Thus it is crucial that a researcher engaging in this method needs to be trained and experienced as a psychoanalytic psychotherapist. Further, personal psychoanalytic psychotherapy can assist a researcher to be mindful in successfully navigating these potential ethical tensions. Paying attention to the transference-countertransference situation is helpful in this regard.

Containing the Researcher-Participant Relationship

When participants disclose intimate, unexpected and potentially unconscious material, the psychoanalytic-researcher can use psychotherapeutic skills of containment and empathic listening. If the participant becomes very emotional and distressed, the researcher can offer the option of stopping the interview or taking a break. Accordingly the participant is likely to feel heard and supported, and is given a chance to process his or her emotions in a contained environment. It can be argued that this could be more ethical than research conducted by non-psychotherapist researchers who also unintentionally elicit unconscious narratives from participants. Non-psychotherapist researchers are not clinically trained to notice when this happens and thus may not necessarily be able to contain it at

the time. As K. Kelly (2006, p. 387) warned, “the interviewer needs to ensure at all times that the interviewee is comfortable with the level of exploration and discussion”. This is a balance that constantly needs to be navigated and strived for, and I believe comes more naturally to a psychoanalytic psychotherapist in the role of researcher.

As some information may arise that participants are not fully conscious of, or have not adequately dealt with, I suggest, as do others (Kvale & Brinkmann, 2009), that researchers conduct a debriefing session with each participant immediately after every interview. Such sessions involve establishing whether the participant feels contained to end the interview. If it is found that unprocessed emotions have been evoked, the researcher can discuss the possibility of referring the participant on for psychotherapy. Indeed, given a psychoanalytic researcher’s natural manner of containing and reading the transference-countertransference, the participant is almost always in an emotional place to end the interview. In my research study on maternal subjectivity, despite participants’ sharing previously undisclosed information, I never had an occasion where a participant was too emotionally uncontained to end the research encounter. Thus the process is not only focused on collecting data for purposes of the research enterprise, it is also concerned with the participants’ well-being, which is something from which all participants benefit.

Interestingly, Hollway and Jefferson (2000) pertinently argued that a participant experiencing emotional discomfort during interviews does not necessarily equate to harm. These authors maintained that this discomfort brings meaningful data and thus the researcher-participant relationship needs to be recognised and contained (Hollway, 2008). Further, as Long and Eagle (2009) suggested, containment in psychoanalytic research interviews often involves more than listening and non-judgmental engagement. If the researcher is not psychoanalytically psychotherapeutically trained, he or she may enact

and/or retaliate to the participant's projective material, rather than contain it. How I navigated these most personal emotional encounters in my research study using research reflexivity is worth additional contemplation.

Considering Psychoanalytic Researcher Reflexivity

Cartwright (2004) stated how important it is for a researcher to initially engage with personal motivations for studying a particular phenomenon and the associated feeling states. The greater the degree of insight the researcher can gain in this regard, the more accurate the interpretation and analysis of the data. I also suggest that the greater the researcher's insight regarding the reasons for wanting to research the specific topic, the greater the chances for a more ethical and contained encounter between researcher and participant. This process, initiated before the interviews, and continued throughout the research, further assists in limiting adverse effects that may be brought into the interviewing process. Accordingly, the researcher's subjectivity is taken into account in order to reach greater understanding of the participants' shared stories.

Self-awareness can be strived for by continually grappling with one's own subjectivity as researcher through psychoanalytic-researcher reflexivity (see Harvey, 2017b). Other authors (Bourdieu, 1999; Frosh & Baraitser, 2008; Hollway & Jefferson, 2005; Saville Young, 2009) have begun to write helpfully about developing the role one's self plays in psychoanalytic research, namely reflexivity in research. However, again these discussions, although useful, are positioned in the analysis and interpretation stages of the research. Although this is crucial to this form of research, I wish to develop the discussion on reflexivity further regarding the actual process of collecting the data. Of course, interpreting the data often begins while interviewing; however, my focus is rather on the ethical use of the self with regard to participant comfort.

Reflexivity has developed from “a relatively simple, technical matter, perhaps an issue of confession or self-revelation” (Saville Young, 2011, p. 48) to understanding that “there can be no psychoanalytic theorising of the other without open involvement and discussion of the self” (p. 20). I argue for an interpersonally deep and ongoing engagement with one’s thoughts and feelings.

Prior to embarking on the research endeavour that is the focus of this paper, I had been working in personal psychoanalytic psychotherapy on various matters related to my overall subjectivity, particularly regarding my disability and motherhood. However, my therapy hours again focused on these aspects of my personhood once I began the research, particularly because certain emotional memories and experiences were elicited within me as I read the literature on the topic of motherhood and disability, and more so when I started engaging with this topic in interviews with participants. The above excerpt in which the participant directly refers to my mother’s possible experience when I was born left me feeling a range of emotions including discomfort, guilt and sadness. Having previously processed some of these emotions in therapy went some way in assisting me to remain open in the moment with this participant, to allow her to share her story. Another excerpt shared in this paper, regarding the mother who was initially avoidant of the interview, resulted in intense emotions inside of me, including discomfort and frustration. I engaged with these feelings and my fantasies around why she was avoidant in various formats (including psychotherapy, note writing, and research supervision) so as to keep my research ethical (for more detailed discussion on how I use my reflexivity, please see Harvey, 2017b).

Frosh and Baraitser (2008, p. 350) state: “[T]he priority is reflexivity, understood as an interactively critical practice that is constantly reflecting back on itself and is always suspicious of the productions of its own knowledge”. Reflexivity requires a researcher to

"keep an honest gaze" (Frosh & Baraitser, 2008, p. 359) on what he or she contributes to the entire research process – a psychoanalytic subjectivity and reflexivity, as psychoanalytic concepts, bring sophistication to this process. Consequently, researcher subjectivity is viewed as a potential resource and not as a hindrance (I. Parker, 2005), which I have demonstrated through excerpts from my interviews and case notes, illustrating the utility of psychoanalytic understandings when applied in the research endeavour, as opposed to in clinically therapeutic ways.

A level of accountability to the participant's stories is adhered to by the researcher's creating enough psychic space from the participant in order to think about the interaction (Hollway & Jefferson, 2000). Thus it is important for the researcher to be consciously aware of his or her role in the process, which is possible by actively thinking through this and preferably by engaging with it in personal psychoanalytic psychotherapy. Further, the practice of reflexivity can be channelled purposively through research supervision sessions with another psychoanalytic researcher, which is evident in the excerpt above when my research supervisor encouraged a second interview with a mother whose material had elicited a defensive avoidance in me. As discussed above, the working through of this avoidance allowed for greater ethical engagement with this participant. Marks and Mönnich-Marks (2003, p. 3) suggested "integrated intervision" which is a combination of formal supervision and peer supervision, as another way of working with researcher reflexivity.

Making clinical-type journal notes (Cartwright, 2004; Strømme et al., 2010) immediately after each interview reflecting on the conversation and noting aspects such as personal impressions, thoughts and feeling states that arose during and after the interaction with the participant, as well as non-verbal observations, is invaluable. I found my personal

psychoanalytic psychotherapy, the practice of clinical note journaling, and engaging with difficult reactions with my psychoanalytic research supervisor crucial when using this research method.

Final Thoughts

In this paper I have argued that, in many ways, the very essence of the various ethical tensions that have been raised by others (Frosh, 2006; Frosh & Baraitser, 2008; Kvale, 1999; Long & Eagle, 2009; Saville Young, 2009; Swartz, 2015) when using the psychoanalytically informed research interview methods, concern the overarching ethical concern of causing no harm to participants, and is addressed when participants are treated with thought and sensitivity. In contrast to Frosh and Saville Young (2011, p. 53), who stated that "there is no magical transformation of the researcher required before one can experiment with psychoanalytic ideas and methods, just the need for caution" I have contended that a researcher should not "experiment" with a participant's preconscious and unconscious, and that to do so may become unethical. While it is possible for well-trained researchers to conduct highly effective and ethical interviews (Posel & Ross, 2015), when the psychoanalytic research interview is utilised by a trained, experienced psychoanalytic psychotherapist in the role of researcher, it can allow for the uncovering and exploration of deeper anxieties and associations in ways that can be emotionally containing and meaningful for both participant and researcher.

When the transference-countertransference situation can be accepted and worked with (rather than be regarded as something to be avoided) in the emotional encounters with participants, the participants, researcher and the research endeavour can be protected. Crucially, this psychoanalytically aware way of being with participants is not to be confused with a psychotherapeutic way of being with patients. I have argued that the

transference-countertransference situation is present in every relationship and thus rather than avoiding engagement with it, attending to the transference-countertransference can allow for greater empathy and allow for highly ethical research. In order to successfully and ethically collect data using the transference-countertransference situation I maintain that it is imperative that the researcher is in personal ongoing psychoanalytic psychotherapy, so as to manage his or her own defences to find ways to be more attuned to feeling states and subjectivity in relation to the participants.

The flexible nature of this method allows participants to direct and pace the interviews. However, this can lead to disclosing previously untold, even unknown, experiences. When the researcher is also a psychoanalytic psychotherapist, he or she is trained to discern and contain these moments, if necessary, which can be more ethical than when other researchers elicit the same interactions and do not notice or manage the affect associated with the moment. Further, assisting participants in realising these experiences can be extremely useful for them and does not necessarily equate to psychotherapy. Thus, researchers, particularly those who are trained and experienced in psychoanalytic technique, should not shy away from the psychoanalytically informed research interview method for fear that it is potentially unethical. When this method is engaged with in as continually conscious a manner as possible, by an individual who engages with his or her own subjectivity and particularities in personal psychoanalytic psychotherapy, this technique can be used in an ethical manner.

My intention has been to add to the ongoing debate around the ethical use of psychoanalytic concepts in research. Specifically, my addition has been focused on the ethical tensions experienced within the participant-researcher relationship at the time of data collection.

Chapter Five:

The Intricate Process of Psychoanalytic Research: Encountering the Intersubjective Experience of the Researcher-Participant Relationship

Introduction

Once I began interviewing the participants, my own selfhood with its many layers became central to the study. The notions of researcher reflexivity and intersubjective researcher-participant encounters are integral to the study, so much so that the process of researching maternal subjectivity in the face of disability emerged as an object of study in and of itself, and a core aim of the research. This second focus of the study developed precisely because of the dual topic of study – both motherhood and disability.

The psychoanalytical data collection method used in the study was influenced by the contextual nature of meaning: knowledge is created in relationships and encounters, between researchers and participants (Cartwright, 2004). This happens when the "lived reality of the conversations as well as the human situation portrayed in the subjects' stories" (Kvale, 1999, p. 88) are accessed. The centrality of subjectivity and interpersonally mediated experiences in the context of interactions with others is the essence of the intersubjective and relational psychoanalytic schools: emotional experiences always take shape in intersubjective relating. It is thus essential for psychoanalytically oriented researchers to acknowledge and work with their own subjectivity, particularly when dealing with or using the transference-countertransference situation. Furthermore, truly engaging with reflexivity is crucial when researchers and participants share similar identities, as was the case in this project.

From the outset of the study, I was aware that my own selfhood, with its many layers (including the fact that I have a visible physical disability, and that I am a mother, as well as a mother to a disabled child, a psychoanalytically oriented psychotherapist, and a researcher) would to some extent influence and contribute to the various research phases. My unique and multi-layered selfhood had the potential to enhance and/or impede the study, depending on how I engaged with my own subjectivity. To engage psychoanalytically with one's own reflexivity can be a demanding task – as Layton reminds us, it is "a cornerstone of the ethics of psychoanalysis: to bear painful truths (2009a, p. 2). She adds: "… perhaps it is precisely in bearing painful truths about ourselves that we might find a key to dissolving the false dichotomies of 'us vs them'" (Layton, 2009a, p. 2). Working with my own thoughts, feelings and experiences in relation to the various participants, the topic, and the interview material has enhanced the ethical nature of the study. Constantly engaging with my selfhood in the context of the study allowed me to relate to mothers (and by implication disabled experiences) as subjects in their own rights, thus "dissolving the false dichotomies of 'us vs them'".

I would suggest that approaching the study from a prominent intersubjective angle has created an opportunity to relate to participants in their entirety as complex, whole people. Hence, the experiences of disability and motherhood are portrayed in their totality – arguably important in the field of disability studies (e.g., Charlton, 1998; Lester & Nusbaum, 2017; Shakespeare & Watson, 1996), as well as motherhood studies (e.g., Bassin et al., 1994; Hollway, 2015; Kruger, 2003).

The article presented in this chapter, "The intricate process of psychoanalytic research: Encountering the intersubjective experience of the researcher-participant relationship", highlights the centrality of intersubjective researcher-participant encounters

and researcher reflexivity in general, but also in this particular study, and when interviewing specific groups of people, including those who live in the disability realm. The paper was published in 2017 in the *British Journal of Psychotherapy*. The original article, as published, does not refer to the participants by their pseudonyms; however, to develop the overall discussion in the thesis, the pseudonyms have been included in brackets when the participants are referred to in the article.

The paper introduces the concept of "psychoanalytic researcher thirdness", a process of active engagement with my own reflexivity in order to "allow" the participants to identify with me in different ways because of our shared subjectivities. I argue that practising this thirdness made room for additional interview material to arise. Some of this intersubjectively created data is introduced in the article. Hence, the article addresses the first research question: What are the implications of researching the maternal subjectivity of mothers with disabled children? The article also begins to address the second research question, namely the subjective experiences of mothers of children with a visible physical disability.

Article:

The Intricate Process of Psychoanalytic Research:

Encountering the Intersubjective Experience of the Researcher-Participant Relationship

Abstract

Qualitative research in general, and the psychoanalytically informed research interview method specifically, can be emotionally demanding on researchers as they form relationships with participants. This is especially the case when researchers and participants share particular identities and experiences. In this paper, I reflect on my experience of interviewing mothers raising children with a visible physical disability about their maternal subjectivity. At times, this was an emotionally demanding and ethically challenging process, as participants closely identified with certain aspects of my identity, particularly with my visible physical disability and motherhood peculiarities. Often participants unexpectedly reversed our roles, asking me intimate questions. I will deliberate these dilemmas using interview material. I argue for a mindful blurring with participants when this occurs. Using certain psychoanalytic researcher concepts of intersubjectivity, transference-countertransference and psychoanalytic researcher thirdness helped me successfully navigate these encounters. I will also explore the rich participant psychic functioning that was generated from this intersubjective relationship between myself and the participants.

Introduction

"I was going to ask you, and then I was 'okay maybe I am just being too inquisitive, I will ask eventually' … You came to research me, not me you; but I eventually said something" is what one participant remarked to me, a visibly physically disabled researcher, in her first interview in my study on maternal subjectivity. My particular and multi-layered identity includes the fact that I am a female with a visible physical disability, achondroplasia. I am

also the mother of two children, one of whom, my daughter, has the same physical disability as I do. Further, I am a psychoanalytic psychotherapist and researcher. Although Sigmund Freud, the father of psychoanalysis, used the term “analyst”, I choose to use the term “psychoanalytic psychotherapist”. These two terms are not to be conflated. I choose such a term as I am not a psychoanalyst, but rather a psychotherapist who is psychoanalytically oriented in my approach to my work with my patients. Throughout the paper I use the term “psychotherapist” to refer to “psychoanalytic psychotherapist”.

The data collection method I used for the research project referred to above was an adapted version of the psychoanalytically informed research interview (from Cartwright, 2004; Kvale, 1999; Strømme et al., 2010). Non-disabled mothers of visibly physically disabled children were the participants. Each mother was interviewed twice on the subject of her maternal meaning-making and identity as a mother to a child with a visible physical disability. Ethical approval was granted for this study from the University of the Witwatersrand’s Human Research Ethics Committee (Non-Medical). Further, all participants gave me their consent to use their narratives and direct quotations in this paper.

My preconceptions about how the data collection process in my research would unfold included that participants may respond to me in a more open and less defended manner due to our shared similarities. However, I also anticipated that perhaps my disability might cause participants to withhold certain thoughts and feelings for fear of offending me. I decided to conduct repeated interviews with each participant, hoping this would facilitate a relationship of trust and openness and ameliorate the possible silencing effect of my disability. I also informally addressed my disability with participants at the beginning of our first encounter, discussing my interest in motherhood and disability stemming from personal lived experiences. Given the visible nature of my disability I felt it was helpful to

address it from the very beginning to try to avoid an organisation of the participants' psychological defence mechanisms which could have curtailed the amount and depth of information they shared. This is likely to also extend to researchers with particular physical characteristics such as gender and race, depending on the nature of the research project.

My two identities of disabled and mother to a disabled child, in particular, played a significant role in the data collection process. The unexpected interaction between myself and the participant above is one example of many that occurred quite regularly during the interviews with participants in my study. Unexpectedly I found participants turning the interview relationship around, asking me questions about both my disability and my own mothering experience with my daughter. These interfaces seemed to invert the researcher-participant relationship. I had the sense of a blurring, even a reversal, of roles. Because there were so many of these interactions in the interviews, I faced a series of unforeseen, challenging ethical conundrums. These interactions left me with a sense of uncertainty as to whether I should/could answer these questions? If I did divulge personal experiences, what would this mean for the participants and the research? How would it impact on the researcher-participant relationship? In this paper I will deliberate these dilemmas using interview material to highlight some of the ethical situations that arise in qualitative, and specifically psychoanalytic, research. I will also discuss some practical guidelines that assisted my navigation of these ethical dilemmas. I decided to share, within limitations, and answer participants' questions. These responses were well received. I believe a deeper rapport and sense of safety was established between myself and the participants at the time, and for subsequent interviews. My willingness to answer participants' questions seemed to leave them feeling less emotionally exposed as they shared more and made ongoing contact with me after the interviews. I was also struck by how I felt better at having

perhaps helped the participants, having given them something, as they had gifted me so openly and generously with their personal accounts. This intersubjective relationship between researcher and participant has a great generative potential, as it brings a different angle to the data; this will be explored in the second part of this paper using data from my study. Let me now turn to the intricacies of this relationship.

The Qualitative Research Relationship

Qualitative research in general, and the psychoanalytically informed research interview in particular, recognises the central and dynamic role the person of the researcher plays, not only in accessing and understanding the personal experiences of participants (the notion of researcher as "instrument"), but also as contributing to the data collection process itself. The researcher-participant relationship is a human relationship in which data are collected. Although researchers are trained to take care to be as neutral and facilitative as possible to guard against overly influencing participants' responses, participants nonetheless apprehend multiple aspects of the researcher's personhood from his or her manner, physical appearance and manifest personality characteristics. Thus the researcher-participant relationships, and indeed all human relationships, operates on, and have ongoing resonance within and between, the conscious, preconscious and unconscious levels of both participant and researcher (Hollway & Jefferson, 2000; Strømme et al., 2010). A distinctive feature of the researcher–participant relationship is that it is a working alliance. The goal of this working relationship is for one person (the researcher) to collect another person's (the participant's) story of a particular phenomenon. The outcome is a version of the participant's experiences comprising a structured interpretation of the collated responses. As it is a working relationship, there are predetermined official roles for each individual to play. Defining and maintaining a research relationship is complex, and presents

an ongoing challenge that needs to be renegotiated throughout the research (Mitchell & Irvine, 2008). A balance needs to be continuously strived for between the dangers and benefits of being too close or too distant from participants (Dickson-Swift, James, Kippen, & Liamputtong, 2006). The notion of intersubjectivity is particularly central to this form of research. As with most human interactions, the researcher-participant relationship is an interpenetrative, intersubjective one; each individual affects the other on multiple levels throughout their interactions. This in turn has a direct impact on the interview process and nature of data that are collected. Let me discuss the intersubjective nature of this relationship further, before exploring what was generated from it in my research.

The Intersubjective Nature of Shared Identities

The intersubjective nature of the research encounter shares similarities with the psychotherapist-patient relationship (Strømme et al., 2010). Sigmund Freud, who originally developed the psychoanalytic technique, first introduced the concept of transference as the patient re-experiencing aspects of his or her early emotional life, including wishes and feelings, toward persons from his or her past, in relation to the psychoanalyst (Freud, 1910a). This is at least partly an unconscious process (Freud, 1910b). Modern psychotherapists also acknowledge the role, not only of a person's past relationships, but also their real and current relationship with the psychotherapist (Ogden, 1994), and other transference objects[10]; in the case of the discussion at hand, myself, the researcher.

The concept of countertransference was first introduced by Freud (1910a) as the psychoanalyst's unconscious reactions to the patient's transference. More recently, the

[10] The term 'objects' is taken from the psychoanalytic school of object relations theory and refers to that which an individual relates to. External objects are people or parts of people that individuals emotionally relate to; the mother is usually one's first object. Internal objects are an individual's representation and reflection of another person in his or her life (Klein, 1957, 1958). In the case of my research I became one of the participants' objects that they externally and internally related to.

potential importance and usefulness of countertransference has been increasingly recognised (Carpy, 1989). A psychotherapist's emotional reactions to their patients are believed to hold clues to a patient's important relational dynamics (Hayes, 2004). More recent psychotherapists, initially led by Heimann (1950), have broadened this definition of countertransference to include all of the psychotherapist's (or in the case of the topic at hand, researcher's) own feelings, conscious and unconscious, towards the patient (or participant) which are based on characteristics of the patient and of people in the psychotherapist's current and past life (Hayes, 2004). Countertransference encompasses everything, past and present, which the patient brings into the relationship with their psychotherapist, as well as the psychotherapist's thoughts, feelings and responses towards the patient (Heimann, 1950; Joseph, 1985). This developed definition encourages psychotherapists, and researchers, to take responsibility for their own emotional reactions. Subsequent developments in the field of psychoanalysis have led to the recognition of the way in which the two are interwoven and inseparable, referred to as the transference-countertransference situation (Ogden, 1994).

The multiply layered interactive process of the transference-countertransference situation has more recently been acknowledged to be a ubiquitous and essential aspect of the therapeutic process, referred to by some as the intersubjective therapeutic relationship (Joseph, 1985; Strachey, 1934). This has led to a shift in the ways that all of the psychoanalytic schools understand the therapeutic relationship which in turn affects technique. However, intersubjectivity is not to be conflated with transference-countertransference. Transference-countertransference takes form within the ongoing intersubjective backdrop of the psychotherapist's and patient's interacting worlds of experience (Atwood & Stolorow, 1996).

According to Stolorow and Atwood (1979) Freud discusses subjectivity as a psychoanalytic construct in the context of a one-person psychology. Atwood and Stolorow (1996) called for a theory of subjectivity in 1992 and later developed their theory of intersubjectivity. It is a theory of interacting subjectivities, as well as reciprocal mutual influences to describe the continual, changing intersubjective nature of intrapsychic experience. Intersubjectivity as a process is thought to be the fundamental happening in all human relating. According to L. J. Brown (2009), there is a central intersubjective nature to psychic life as both individuals in an interaction operate on one another's unconscious. The intrapsychic and the interpersonal are intricately intertwined. In this way, meaning is co-created.

Intersubjective psychoanalytic psychotherapists are constantly in tune to the ever-changing intermediate space between their patient and themselves (L. J. Brown, 2009). I believe this to be a helpful concept for the discussion at hand and for the method that I employed with my research participants. Intersubjective psychoanalytic psychotherapists have adopted intersubjectivity as a relational model of psychotherapy. This was originally taken up by Atwood and Stolorow (1984, p. 64), who argue that psychological phenomena "cannot be understood apart from the intersubjective contexts in which they take form". Other theorists have begun working with this focus, including Thomas Ogden.

As a psychoanalytic psychotherapist I am always attuned to transference-countertransference manifestations and intersubjectivity, and I have been trained to work with them with my patients. In this particular study a very personal and intimate relational process unfolded in each encounter with a participant but as I was in a researcher role I felt unsure about how to manage it. I was clear that I was not in a psychotherapist role and thus could not manage these interactions solely according to my psychotherapist training. These

dyadic interactions raised various ethical concerns for me and in turn required very careful responses. The careful attentive thought that was required of me suggests that various psychoanalytic researcher skills were crucial throughout my research encounters. Specifically, I found the concept of analytic thirdness helpful. The concept of "thirdness" was originally developed by Britton (1989) and later taken up by Ogden (1997), amongst others. The "third" is used by various theorists to portray different elements. In this discussion I use "thirdness" to refer to a psychic capacity, to an intersubjective relatedness (Benjamin, 2007).

In order to be attuned to intersubjectivity, a psychotherapist needs to be receptive to the co-creation process of meaning through ongoing introspective engagement and reflection. In my research I too constantly engaged with what was happening between myself and my participants. I needed to rely on my unconscious and conscious responses as an instrument (Freud, 1910b) of data collection and engagement, something I like to call psychoanalytic-researcher thirdness, to adjust Ogden's (1994) psychoanalytic therapeutic concept. I constantly engaged with the nuanced, ever-changing interplay of my subjective experience, the participant's subjective experience, and the intersubjectively created experience of both of us (the experience of the psychoanalytic research third). The position of thirdness is a demanding one to engage from as one is simultaneously within and outside of the intersubjectivity of the researcher-participant relationship. However, I argue that when this type of psychoanalytic-intersubjectivity reading of the research method is used, a different lens is provided of the data. I will turn to this in the next section of this paper. Pertinently, I found an ongoing emphasis on my self-awareness (the notion of *researcher depth reflexivity*) acted as a restraint on any of my omnipotent tendencies to intrude knowledge

into the research encounter. Researchers need to remain conscious that the research process is firstly about the participant.

Researchers are trained to be mindful of the ethical use of qualitative interviews with regard to participants' physical and psychological well-being, notions of beneficence and non-maleficence (Connolly & Reid, 2007). However, there is limited focus on the psychological and emotional experiences of researchers (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Collecting data can be emotionally intense for, and demanding on, researchers, especially when the topic of research is of a sensitive nature. This was certainly the case in my particular study. Ely and colleagues (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991, p. 49) state in this regard: "[I]f we undertake to study human lives, we have to be ready to face human feelings". If researchers are ill prepared to manage their own emotional responses, they may be left feeling vulnerable, even distressed, and, according to Dickson-Swift et al. (2007), at risk of physical and emotional exhaustion.

All researchers are of course participants in social life and thus can be thought of as socially similar to their participants in certain general ways. When the participant and the researcher share/have shared experiences of certain kinds, it can result in the participant identifying with the researcher. This may be particularly the case amongst participants in marginalised and vulnerable populations, including women and the disabled, as well as participants belonging to various minority groups, including different sexualities and substance abusers. However, shared identities do not necessarily equate to participant trust due to idiosyncrasies of personalities (Few, Stephens, & Rouse-Arnett, 2003). Such participants, because of how they have been treated by majority groups, often need reassurance that their participation will not be disempowering and one of the ways to achieve this is by forming an "equal" relationship through mindful, conscious researcher

self-disclosure (Dickson-Swift et al., 2007; Few et al., 2003). I was unaware of how inherently this would occur between myself and the participants due to our shared identities and experiences.

Particular Intersubjective Identifications Generating Rich Data

Part of the complexity of research encounters involves participants entering into the research encounter with their own perceptions and expectations regarding the process and the role the researcher will play (Mitchell & Irvine, 2008). Often it is not an apparent or even conscious role that a researcher takes as participants have been described as inducing "mistakes" in a researcher, causing them to slip out of role (Holmes, 2014). Strømme et al. (2010) describe a "role-reversing interaction" as participants "seduce" researchers into certain roles. Gabbard and Hobday (2012) describe patients as unconsciously recreating their internal object relations in the transference-countertransference relationship with their psychotherapist. I suggest that the same occurs in the nature of the research relationship using the psychoanalytic method I employed and thus researchers need to be very mindful of this blurring in order to manage it successfully.

My experience of the research process was one of being cast in unexpected roles; the unanticipated blurring of identities felt initially disquieting. The feeling of being in uncharted territory without a map was palpable with each participant. I was aware of the strong transference push to answer participants' questions and it would have been easy to automatically respond. However, I soon realised the necessity of remaining conscious of my more difficult feelings in order to reflect on the other person's internal experiences and

respond meaningfully[11], lest my emotions contaminate the research (Fonagy & Target, 1997).

I perceived three different roles the participants positioned me in, depending on their identifications or dis-identifications with me at the given moment of interaction. This affected what participants shared at particular times. These included identifying with me as a disabled individual, and thus like their child. At times this identification moved towards identifying me as an advocate for disability. There were also moments when they dis-identified with me: othering me as a disabled person. At other times participants identified with me as similar to themselves; we are both mothers of a disabled child. Lastly, I was identified as a mental health professional and researcher. In turn, the various roles I was ascribed informed my countertransferential responses as I was pulled in different directions in my position as psychoanalytic researcher. The intersubjective processes in the relationships I shared with the participants in my research, coupled with my ethical and mindful use of the transference-countertransference situation within these relationships, provided me with rich and valuable information regarding the participants' psychic functioning, including their defence mechanisms, fantasies and other internal structures with regard to their maternal roles. Let me expand on this further.

Identifying and Dis-identifying with Me as a Disabled Individual

Many participants identified with me as a disabled individual, and thus similar to their disabled child. This seemed to be a positive, facilitative experience for them in the interview process. One participant (Jessica) voiced this directly and repeatedly: *"*[The

[11] This is akin to the process of mentalisation, or reflective functioning, which is the ability to understand the mind of another so to meaningfully make sense of another person's behaviour. This involves the concept of self-reflection to enable an individual to distinguish between internal and external reality (Fonagy & Target, 1997). It is the ability to reflect on another person's internal experiences and respond meaningfully.

interview] *is absolutely welcoming because I don't have that interaction with any other dwarfs"* and *"I've never been able to speak to an actual person that has dwarfism in an adult state"*.

"I don't get to speak to a lot of people with the same condition as my daughter … it's so nice to actually get to speak to somebody because I know you would probably relate to me ten times better than anybody else can" is another participant's (Sandra) particular identification with me as similar to her child due to our disability. These types of engagements were especially emotionally demanding for me as I was forced to engage with my specific disabled particularity, something I was not entirely prepared for as I entered the encounter as a researcher. The participants' identifications with my disability aspects did not afford me the role of "pure" researcher and I was left feeling perplexed and frustrated. I was acutely aware of my overriding thought: was this going to be yet another encounter centred on my disability at the expense of my other particularities, most notably, me the researcher?

These encounters also ignited the helper in me due to my countertransferential responses to the participants' needs for engagement over our foregrounded shared experiences. I could relate to their desire to identify and connect with someone similar to their child, an experience that is hard to come by on a frequent basis. I was also left feeling worried that I may not access the data I had hoped; however, it soon became apparent that this intersubjective nature of my research provided me with rich, albeit unpredicted, information.

Further, when participants identified with some of my specific personal characteristics they seemed to feel comfortable to share intimate stories as they felt I particularly understood them. One participant (Chloe) stated: *"Well I'm sure … you get it all*

the time" when referring to how non-disabled individuals stare at her disabled child in public. Another woman (Sandra) remarked: *"I feel that maybe you can relate better to me than anybody else can because you have probably been there, in those situations* [the same as those her daughter has been in]*"* and *"I think you know exactly how I feel … you've been there, through all of what I'm still busy going through"*. Yet another participant (Joan) described relating her personal mothering experiences to me: *"I can sort of relate better because I know you've got some frame of reference* [of disability] *… so talking to you is probably easier than me just talking to someone who looks completely baffled"*. These identifications with me as disabled, although surprising, were manageable as I constantly engage in how I feel about being disabled in my own psychotherapy and I am used to individuals relating to me as disabled. However, that is not to say that I did not feel ambivalent. A part of me wished that I could be solely afforded a researcher role, to hear participants' stories without at times bringing my disability aspects to the foreground of the encounter.

One particular participant (Joan) referred to me and my life as a disabled person throughout her interviews. Interestingly she presumed that my mother does not have a disability, and thus she was identifying with her, and with me as being like her daughter: *"[Y]ou see with your disability … your parents knew"*; *"You see now in your case with your mother, she wouldn't have felt in any way responsible"*; *"I don't know if your Mom ever did this, but this is something I have done"* and *"If you think of any of the issues you've gone through over the years … probably similar to her* [her disabled daughter]*"*. This particular woman repeatedly referred to, and focused on, my disability, at the expense of relating to me as a whole person. I was left feeling ambivalent, annoyed with being othered and dis-identified with. I felt that she presumed how I felt and experienced things. This reminded

me of the many times I have been seen as disabled, nothing else. However, I was also empathic towards her need to address her daughter's disability and thus focus on my disability. Although difficult for me, I could understand this as a defensive process, as a projective identification. Her dis-identification was also painful and possibly guilt-inducing for her as a mother of a disabled child. This is but one example of how personal and demanding the emotional engagement can be for a researcher in such an encounter.

I argue that this identification with my disability helped these women feel that they could disclose, at times, previously untold stories, as they felt genuinely understood, and that their experiences were validated. This was extremely exciting and I felt privileged; however it required a constant demanding engagement on my behalf of maintaining the boundary between encouraging participant participation and keeping the emotional encounter contained.

Kleist and Gompertz (1997) discuss how participants can confuse the role of a researcher with that of "expert helper". At times I experienced participants as furnishing me with a superior, "expert" status as a disabled person, creating the relational scenario of wanting me to provide guidance on certain aspects of life. Some questions that participants asked me included: *"So what was she* [my Mom] *like to you?"*; *"Did your parents offer it* [limb lengthening] *to you?"*; *"Have you found that it's a common response* [from my other participants] *… or if it's my specifics?"*; *"I wonder if she* [my Mom] *felt the same way* [as she does]*?"* and *"I'm hoping for the opportunity where I get to meet, through your research, other parents that can share their experiences with me"*. I consciously chose to empower participants when they asked for information by answering their questions. I have mulled over this self-disclosure: was I unconsciously relating from a position of rescuer or as an authoritarian parent? I was left feeling less guilty about the often one-sided research

relationship after responding to direct questions from participants. Indeed, researchers often feel highly privileged by the willingness of participants to share their most intimate thoughts and experiences. This can leave them feeling ambivalent, simultaneously excited by the quality of the data, yet guilty and responsible for the level a participant has shared (Dickson-Swift et al., 2007). As a result many researchers feel the need to self-disclose to give their participants the experience of being truly appreciated and validated (Dickson-Swift et al., 2006), as well as wanting to give something back to them (Mitchell & Irvine, 2008). I was also aware of my wish not to deny my self-interest in the research topic, perhaps a sense of my own advocacy for disabilities, and thus wished to provide some assistance to participants through sharing my knowledge and experiences.

We are both mothers. The women in my study asked me parenting advice that was specifically disability-related and regarding their particular struggles at the time. One woman (Sandra), who at the time was experiencing one of her non-disabled children as feeling that her disabled child takes up much of her attention, asked me: *"Are you an only child? If you don't mind my asking"*. And after I had answered: *"And how was your brother and sister with you?"* Two of the participants asked me specific child disability-related questions: *"I want to pick your brain about something"* ranged from asking questions about grommets, bicycle choices, to car seats. These types of questions felt fairly manageable for me to address due to their limited personal and emotional requirements and my countertransference of the participants' genuine need for practical guidance. I could also respond without moving the interview to become about me.

One mother (Chloe) asked me: *"How do you deal with* [it] *when people point 'n laugh?"* This was also a concern for another participant (Janet): *"What's it like when you go out as a family?"* as she reported how members of the public stare at her disabled child and

ask questions about why she cannot walk. These types of questions were more personally demanding for me to engage with as they required that I connect with a sensitive topic related to the visibleness of my disability, something which is not always positively experienced by others. The responses I could give to participants were not necessarily straightforward or particularly encouraging, which left me feeling ambivalent about how to respond.

One woman (Janet) asked me about how my mother managed raising me as she remarked: *"I'm worried that when she* [her daughter] *grows up, what would she think? Because you want them to think positively of you* [as her mother]*"*. This was a difficult and direct question to approach as I was aware that we were both left experiencing strong feelings. The participant seemed to desperately need me to reassure her that she would have a good relationship with her daughter. I was aware that her fantasy and hope seemed to be that I have a good relationship with my mother, despite my disability. I was left with strong countertransferential responses regarding my, at times, own difficulties with my mother around my disability, as well as my ongoing grappling with mine and my daughter's relationship and our disabilities. I chose to respond using psychoanalytic-researcher skills of reflection and containment to communicate to her that I heard her very real concerns that she is doing the best she could as a mother. This had the effect of her sharing more of her experience.

Although the questions were unexpected, my therapeutic default of always thinking before answering was vital: my psychoanalytic researcher thirdness. My responses were always given after internal deliberation based on the ethical principle of beneficence, the protection of the research project, as well as my own level of comfort. I believe the participants experienced me as retaining appropriate boundaries as far as possible, as one

participant (Janet) expressed: *"I was going to ask you and then I was 'okay maybe I am just being too inquisitive, I will ask eventually'"*. And: *"You came to research me, not me you; but I eventually said something"*. I think this indicates that I was able to manage the encounters in a predominantly facilitative manner, enabling me to build relationships with participants that were boundaried but also flexible enough to allow for a two-way sharing of information.

Given that motherhood is often part of many women's core, overarching identities it can enhance the relational connection between mother participants and mother researchers (Ribbens, 1989), as was the case in my research. One participant (Jessica) asked me: *"[H]ow do you deal with it now, especially with having a dwarf* [same disability as her child] *baby?"* She later remarked: *"I don't get to speak to many people that have children with achondroplasia* [our children and I have this disability]*"*. These types of questions made me aware of how easy it would have been for me to fall into an acquaintance type role, casually discussing the highs and lows of mothering our children. It could have also been quite natural to fall into parent guidance type roles with participants as I wanted to share some aspects that I thought may be useful for these mothers as I identified with their feelings of loneliness and confusion. However, I was always aware that these sorts of encounters were about their experiences, not mine.

Relating to me as a mental health professional and researcher. Participants at other times identified with me as a successful professional, and this seemed to elicit hope in them for their disabled child's future. One participant (Becky) reflected in her second interview that having met me she had realised: *"When he's* [her disabled son] *an adult … there is a way forward; that you're studying at Wits* [University]*"*. It seems that her identifying with my perceived success, despite my disability, gave her hope that her child would be able to

achieve the same. I was left feeling that I had instilled some hope in this participant and that this was helpful for her as an individual and as a mother. This pleased me. However, I was also acutely aware of her future fears and anxieties about her child's future.

Another woman (Joan) appeared to identify with me as a psychotherapist, remarking: *"you'll know more about why"* when talking about not wanting to initially bond with her disabled daughter. I was struck by how honest a disclosure this was and how perhaps this mother would not have shared such personal thoughts with a researcher who was not a mental health professional. I was also aware that this statement of hers felt so guilt-laden and how relieved she may have felt sharing it with someone who she perceived would not be judgemental. I was mindful of my deep empathy for her and her internal struggle as she navigated her journey as mother of a disabled child.

The careful, ethical management and engagement with these various identifications seemed to help build a researcher-participant relationship that encouraged the sharing of meaningful and nuanced information.

Such a paper would be incomplete if I did not pay specific, albeit limited, attention to practical steps researchers can take in managing these kinds of emotionally intense research encounters so as to ensure that the intersubjectivity of shared identities remains as ethical as possible. Let me turn to this before concluding.

Benefits and Safeguards: A Researcher's Psychoanalytic Reflexive Practice

It is important to acknowledge that it is impossible for a researcher to remain completely neutral when conducting qualitative research due to the researcher's own subjectivity being evoked during the process (Hollway & Jefferson, 2000). Thus a researcher's self-reflexivity is essential to consider. Reflexivity involves a researcher's self-examination and consciousness of his or her own emotional responses, behaviours and

thoughts; it is not a method, but rather “a mode of consciousness” (Doanne, 2003, p. 99). Reflexivity is an “immediate, continuing, dynamic and subjective self-awareness” (Finlay, 2003, p. 108) and Frosh and Baraitser (2008) argue it is incumbent on researchers to keep this “honest gaze” on what they bring to the entire process. This is particularly pertinent when aspects of the researcher’s identity may be similar to that of the participant. Researchers need to be fully conscious of their subjectivity and how this impacts on and transforms the research (J. Brown, 2006), so to safeguard the entire research process. This practice requires the researcher to engage in extensive professional reflections (Strømme et al., 2010) in an attempt to understand the nature of their interactions with participants.

In this way, using subjectivity objectively (Elliott, Ryan, & Hollway, 2012) was an ongoing approach that I took in my research. Another way I think about this is as depth reflexivity: a psychoanalytic approach to reflexivity. Ongoing self-reflection is a continual, established practice of mine, facilitated by ongoing personal psychoanalytic psychotherapy. Indeed Holmes (2014) suggests that entering into psychoanalytic psychotherapy is a potential means of fostering reflexivity in a researcher. Further, Waddell (1988, 1998) usefully captures reflexive practice as a process of learning from one’s experience of living in the world. This ongoing process throughout my research assisted me in managing the ethical dilemmas I faced. Making use of a psychoanalytic researcher’s clinical-type journal for my self-reflexivity, including my experiences and countertransferences, was also most beneficial. Thus when managed in this way, a researcher’s subjectivity is not considered as a weakness, but rather as a resource for bringing the researcher closer to an in-depth account of the data (I. Parker, 2005).

I believe that researchers need to uphold researcher-participant boundaries, but boundaries that are not rigid and that allow for self-disclosure where appropriate, a mindful

blurring of boundaries and intersubjectivity. Retaining this boundary in practice is not always easy, especially when the research focus is of a sensitive nature (Mitchell & Irvine, 2008). These boundaries need to constantly be reflected on and negotiated throughout the process. The decision to answer participants' questions and share personal information should be taken with participants' well-being as paramount but without forgetting that the researcher's well-being is also very important. I found it helpful to take my cue from the participant as well as what felt appropriate to the specific encounter. There is not one set of standard practices that can be followed and researchers need to be sensitive, responsive and flexible to the needs of each participant (Mitchell & Irvine, 2008). In this regard I argue that a psychoanalytic researcher needs to practise thirdness, as well as work in the transference-countertransference, within the research encounter.

Formal research supervision with a psychoanalytic researcher as well as debriefing supervisory and peer researcher sessions also assist in guarding against the potential ethical concerns addressed in this paper. It is vital for researchers and supervisors to acknowledge the effects of emotion when it arises in the research process (Holland, 2007; Mitchell & Irvine, 2008). Pacing interviews so that there was enough time between to process my emotions (Dickson-Swift et al., 2007) was another useful strategy I employed. Ideally researchers should take the time and space to meaningfully think through their emotional investment in the research and the possible impact of the process prior to beginning the research. In this preparatory phase researchers should consider their thoughts and feelings about forming a research relationship, developing emotional connections with participants, listening to often untold participant stories, and coping with emotional vulnerability in participants and themselves (Dickson-Swift et al., 2007). I argue that this is something that

may be more natural to a psychoanalytic researcher, an individual who has undergone psychoanalytic training as a psychotherapist.

In conjunction with the challenging aspects I have mentioned, I also experienced unexpected personal benefits through the conducting of data collection for the study.

At times during the interviews stepping out of a researcher role was not just because the participants had necessarily provoked me towards this, but because I felt I needed, and wanted, to and thus consciously chose to share. I volunteered information related to the topic of the participants' stories. I understand this to be linked to feelings of guilt related to the often one-sided research relationship and wishing to give something back to participants. This relational position appeared to be well received by the women and this left me feeling good. Other participants requested if they could stay in contact with me, with some sending messages and one sending a disability-related video after our interviews. Further, I feel that I may have given each participant an experience that went beyond psycho-education about their children during the interview process. Their interactions with me seemed to give the participants a unique opportunity which they used to quieten some of their various anxieties in relation to their disabled children and their mothering role. The lived experience of our encounters possibly provided them with a precious, comforting snapshot of their child's, and their own, future self which can sustain them through difficult maternal times. I believe that this is not always the experience for qualitative researchers and I argue it is because of our shared aspects of identities and experiences that this occurred, as well as my conscious use of psychoanalytic-researcher thirdness.

Concluding Remarks

In this paper I have argued for a mindful use of intersubjective identifications between researcher and participant in order to conduct ethical qualitative research,

particularly using the psychoanalytically informed research interview. I have reflected on my experiences and challenges in the process of conducting the data collection for my research project on maternal subjectivity when raising a physically disabled child. The research process was permeated with surprises as participants turned the interviews around, demanding personal and emotional engagements from me. I argued this is because we share particular identities and life experiences, including motherhood and disability identities. These unexpected ethical dilemmas were something I felt ill-prepared for from my research training. However, my training and experience as a psychotherapist, as well as my personal psychoanalytic psychotherapy, became crucial as I was able to continually engage and reflect on this process so as to protect the participants, myself and the research endeavour. These complex social encounters at times caused me to consciously share personal experiences with participants and these were well received. This steady flow between carefully navigated identifications and distancing between myself and my participants ultimately benefited both parties, as well as the overall research process. I argue that I successfully navigated this process because I consciously worked with transference-countertransference in these encounters, as well as psychoanalytic researcher thirdness. The end product was a rich and unanticipated type of data: very particular participant psychic functioning was generated through the intersubjective psychoanalytic relationships the participants and I created.

Chapter Six:

The Uncanny Effect of Disability:

Uncomfortable Maternal Love for a Disabled Child

Introduction

The discussion shifts in this chapter and the next toward an emphasis on the subjective experiences of mothers of children with a visible physical disability. The motherhood experience of the participants is explored through moments of maternal ambivalence which emerged in different threads in the data, particularly in the mothers' narratives of their perceptions of unfamiliarity and disavowal of their children because of the children's disability. Several authors, including Hollway (2001), Kraemer (1996), R. Parker (1996) and Winnicott (1949), have written about maternal ambivalence, but such contradictory emotional experiences have not been addressed consistently in the field of disability studies.

The article comprising the body of the current chapter focuses on the often dislocating, foreign impression that encountering disability in another can create for non-disabled people. Applying Freud's (1919) concept of the uncanny to the experience of disability, in general, and to disabled children more specifically, the article argues that disabled people may be experienced simultaneously as familiar and as yet strange by non-disabled others. Since disability in these mothers' children is forever visibly present and produces particular responses from other people, the mothers are constantly challenged by their own conflicting feelings and perceptions of their children as unfamiliar too. Consequently, mothers of disabled children are often confronted with great maternal ambivalence.

The article “The uncanny effect of disability: Uncomfortable maternal love when her child is disabled” has been accepted for publication in *Contemporary Psychoanalysis*. The article addresses the public, social and interpsychic aspects of mothering, which in turn have a strong impact on maternal intrapsychic aspects. Ambivalent feelings for one’s child can create great anxiety (Fairbrother & Woody, 2008), particularly because of society’s prescriptive, often unattainable, expectations around motherhood. Arguably, the mothers who participated in this study are faced not only with society’s expectations, but also with the “unremitting, pathologising violence of the non-disabled gaze” (Hughes, 2009, p. 406), creating an experience of psychoemotional disablism (Reeve, 2008; C. Thomas, 2007). In the article, I argue that the mother-disabled child dyad is constantly disrupted, never allowing maternal ambivalence to settle fully. Thus, these particular women’s subjectivities are constantly threatened because of other people’s responses to their disabled children (Baraitser & Noack, 2007).

The paper explores what it means for women to love and care for their physically disabled children, who also evoke strong, often horrified and horrific feelings from others, and from the mothers themselves, because of the children’s disabled selves. Different maternal attempts at tolerating such pain are discussed, including falling back on various defence mechanisms. According to R. Parker (1996), tolerating ambivalence implies a woman’s ability to know herself so that psychic integration can be upheld. She believes that managing ambivalence is the foundation of maternal subjectivity. Indeed, it seemed from the findings presented in the article that when the participants could manage their ambivalence, their love and care for their children continued to grow. This article therefore primarily addresses the first research question: What are the subjective experiences of mothers of children with a visible physical disability?

The bi-focal angle of this study is maintained in this paper, because the paper also explores how the participants responded to me as a disabled person. I record how, at times, they also related to me as inducing an uncanny experience, which may be understood as maternal attempts to cope with their discomfort about disability. Managing these interactions brings into sharp focus once again the second research question: What are the implications of researching the maternal subjectivity of mothers with disabled children? Hence, the intersubjective research situation continues.

Article:

The Uncanny Effect of Disability: Uncomfortable Maternal Love for a Disabled Child

Abstract

Disability can produce an experience of the uncanny for non-disabled people. The paper explores the phenomenon of the uncanny for mothers of children who are visibly physically disabled. Arguably the gaze of others provokes a particular maternal response, since others experience disabled children as unfamiliar, resulting in mothers seeing their own children through the eyes of the other. Accordingly maternal ambivalence is amplified. Maternal attempts to manage these various feelings and complex experiences so as to maintain love for their children are explored. A continual fluctuating process of projection, introjection and expulsion is apparent. The mothers' continuing processes of psychic development vacillate between integration and being unravelled as they sit on the boundary of their own sense of the uncanny. The paper includes a discussion on how the women used the disabled author, at times also perceived as uncanny by the mothers, in an attempt to cope with their discomfort.

Introduction

The paper explores how disability can evoke a sense of the uncanny (Freud, 1919). Drawing on a study exploring the subjectivity of mothers whose children are visibly physically disabled, the paper will argue that mothers' sense of selves, and their own feelings of unfamiliarity within themselves, never quite settle because their subjectivity is constantly disrupted by others' responses to their children. Subsequently, women's ambivalence for themselves and for their children is amplified because of the presence of disability in their children. The implications of the immense maternal ambivalence this evokes is explored. Mothers describe powerful feelings towards their children. Although

their maternal love is more explicitly described than maternal hate, the discomfort of their feelings indicates at least an unconscious presence of powerful and complex ambivalence. Mothers' processes – often uneasy and uncomfortable – of making sense of having a child with a disability are considered. I too have a visible physical disability – achondroplasia, the most common form of dwarfism in humans. The disability results in disproportional short stature because of shortening in legs and arms and a prominently large head (Ornitz & Legeai-Mallet, 2017). The paper will explore how my presence disrupted the mothers I interviewed. My disability seemed to accentuate a sense of the uncanny for these women, as well as heighten their maternal ambivalence, prompting them to "use" me in particular ways. The paper concludes with some reflections on implications for maternal subjectivity.

Before considering Freud's (1919) concept of the uncanny, the context of the study needs to be provided. Non-disabled mothers raising visibly physically disabled children were interviewed several times about their maternal experiences and their experiences of themselves as mothers. An adaptation of the psychoanalytic research interview technique (see Cartwright, 2004; Harvey, 2017a) was used. The children's disabilities are congenital; specifically, the mothers referred to in this paper have children with achondroplasia and cerebral palsy (CP). The children ranged in ages from three to sixteen years. The mothers were accessed through various support groups for people with physical disabilities, as well as physiotherapists working with disabled patients.

Arguably the gaze of the other produces a particular experience for mothers of disabled children. In certain moments, others perceive their children to be uncanny, which leaves mothers also experiencing their children, and themselves, as strange. Aspects of Freud's (1919) elusive theory of the uncanny are briefly discussed to explicate this complex

maternal experience. Certain concepts from Lacan (1953, 1988, 2001) and Sullivan (2013) are also considered.

The German psychiatrist Ernst Jentsch (1906/1995) originally explored the uncanny as a psychological concept to describe an experience that is difficult to decipher. A person experiencing something/someone as uncanny is left feeling uneasy, even disorientated, owing to the foreign feel of the occurrence. Haughton (2003, p. xii) deemed the uncanny as "a particularly intense experience of strangeness" and Freud (1919, p. 220) described it as "something one does not know one's way about in". The onlooker is left feeling uncertain as to what category this person/thing falls into (Freud, 1919; Norden, 2007; Royle, 2003; Wilton, 2003) – human or mechanical, human or evil, alive or dead, adult or child?

Freud (1919) traced the origins of uncanniness to the time of the infantile, primitive ego. During these early mental stages the developing ego has an urge to project outward that which is foreign inside itself. Consequently strangeness perceived in another becomes terrifying, since occasionally that which was originally repressed to unconsciousness, and should have remained hidden, becomes known again; hence the familiar feel to the uncanny. Sullivan (2013) described how particular circumstances can reawaken primitive, severe anxiety resulting in various "uncanny emotions" of awe, dread, horror and/or loathing. Sullivan's (2013) sense of the uncanny arises from a rudimentary interpersonal personification of "not-me", formed from difficult-to-comprehend interactions which are experienced as dreadful and cannot be consciously articulated.

Freud (1919) used the German word *heimlich* and its opposite *unheimlich* to describe the uncanny. *Heimlich* means homely, known, belonging to the family, and the opposite of what is unfamiliar. Everything that ought to remain hidden is *unheimlich*. Usefully for the present discussion, among the many definitions Freud (1919, p. 223) gave for *heimlich*, the

term comes to means its opposite: “what is heimlich thus comes to be unheimlich”. *Heimlich* develops in the direction of ambivalence, for *unheimlich* begins to mean both familiar and unfamiliar. A quote by Freud (1919, p. 223) may ambiguously develop further understanding: “[*Heimlich*] belongs to two sets of ideas, which, without being contradictory, are yet very different: on the one hand it means what is familiar and agreeable, and on the other, what is concealed and kept out of sight”.

Since Freud is most ambiguous and ambivalent in discussing the concept, his theory of the uncanny lends itself to be used as a conceptual pivot for the purposes of this paper. His vagueness allows for the extension of the application of the theory of the uncanny to the particular experiences felt by mothers of children with physical disabilities. Freud linked the uncanny to disability, albeit not explicitly. His examples involve blindness, dismembered limbs and epilepsy (see Wilton, 2003). Goodley and Lawthorn (2013, p. 164) have argued that disabled children in particular evoke the uncanny for the non-disabled, inducing “often contradictory processes of fear/fascination; attraction/repulsion; recognition/extermination”. The notions of homeliness and unhomeliness assist in making sense of the mothers’ accounts and their specific ambiguities towards their children. Particularly, the notion of the uncanny develops an understanding of how these mothers maintain a level of maternal care and love alongside their intense unease in relation to their disabled children.

Uncomfortable Encounters: The Uncanny Evoked by the Other

Some of the mothers’ children appear to evoke a sense of the uncanny in others, particularly those children who have achondroplasia because of the prominent bodily disproportion of the disability. This disability specifically causes particular contradictory responses in others since they are left wondering if this an adult or a child; is this a doll or a

person? “Dwarfism is a dramatic, physically distinctive, and immediately identifiable condition” (Ablon, 1990, p. 880), and it powerfully resists person classification. Further, this noticeable difference has strong associations to folklore and humour. “The rarity and novelty value of restricted growth [or dwarfism] meant that it was impossible to escape the curiosity, and occasionally the hostility, of non-disabled people” (Shakespeare, Thompson, & Wright, 2010, p. 26). People with dwarfism (and by implication parents of people with dwarfism) report significant disabling factors in managing the attitudes of others, cultural prejudice and stigma (Ablon, 1984). Chloe, whose son is six-years-old with achondroplasia, stated: *“[O]ften when I’m in shopping centres … people will point* [at her child] *… often they will say ‘Oh, he’s got a big head’ and I will say ‘That’s because he’s a dwarf. He’s a little person’”*. Consequently, from others’ reactions to her child, Chloe also experiences her child as different, even strange, in these fleeting moments.

Encountering ambivalence and the uncanny. Moments in which mothers sense that their children are experienced as uncanny by others, and in turn by themselves, potentially heightens the ambivalence they feel towards their children. Feelings of both love *and* hate for their children, which are felt alongside one another, are experienced by all mothers. This is maternal ambivalence (Raphael-Leff, 2010). In Rich’s (1977, p. 21) words, “my children cause me the most exquisite suffering … the suffering of ambivalence: the murderous alternation between bitter resentment and raw-edged nerves, and blissful gratification and tenderness”. The word “suffering” evokes the strength of the contradictory feelings women experience for their children. Such emotions are difficult to endure, since children are sometimes felt to be a burden and prevent the fulfilment of other aspects of women’s lives, leading to feelings of “resentment” for their children. Mothers’ conflicting feelings have been described as “the unacceptable face of maternal ambivalence” (R. Parker, 1996, p. 49)

because it is difficult to accept that women can feel hate for their own children. Further, literature has often taken a pathological view of ambivalence resulting in a "demonization" of mothers (Raphael-Leff, 2010). However, contemporary motherhood scholars accept that mothers' ambivalence is to be expected, and is productive. Kraemer (1996) described *ordinary* hate that mothers feel, and Winnicott (1949) named eighteen different reasons why women may hate their babies. Winnicott (1949, p. 355) said, "the mother hates the baby before the baby hates the mother", going so far as to have said that mothers hate their babies from the very start. Yet, the subject of maternal ambivalence is under-researched and under-conceptualised within disability and motherhood studies, perhaps understandably, given the difficulty in accepting maternal hatred.

Each woman demonstrates a different capacity to tolerate ambivalence, ranging from mildly disturbing to incapacitating (Raphael-Leff, 2000). For some women "the negative arm of ambivalence prevails" (Raphael-Leff, 2010, p. 9). *Unmanageable ambivalence* (R. Parker, 2001) arises when mothers find it too anxiety provoking and guilt inducing to hold mixed feelings simultaneously for their children. Raphael-Leff (2010, p. 9) coined the phrase "primary maternal persecution" to describe such an experience. This mother is vulnerable to a reawakening of painful and dangerous feelings, including rage and even thoughts of harming her baby (Raphael-Leff, 2010; Welldon, 1988).

Usually, women reconcile their ambivalence by adapting to the idiosyncrasies of their children (R. Parker, 1996). *Manageable ambivalence* (R. Parker, 2001) is the term given when women can bear the painful contradictory feelings through a reparative process of integration of their contradictory feelings within themselves, and for their children (Klein, 1940). Managing ambivalence is an ongoing process in which women need to develop ways of mothering that are congruent with their own ideals and abilities. Part of such a process

involves resisting societal pressures to measure themselves against maternal mythologies (R. Parker, 2001) of the “perfect” mother; and further, to not compare their children against child-perfect ideals – a process particularly difficult when their children, because of disability, bring unwanted responses.

The ambivalent feelings of the mothers in this study, particularly those of hate, are latent and inferred as being predominantly unconscious from certain aspects of the mothers’ narratives during the interviews. It will be suggested that mothers’ contradictory feelings towards their disabled children are often amplified. Since the hate may appear to be solidly anchored in the disability, the love must be also amplified to be at the measure of the hate, at least at the measure of the hate of the disability. Crucially, it seems that such women’s hate for their children is stretched because of their ambivalence about their children’s disability, and not necessarily for their children. Yet, the disability is part of their children, causing great dissonance. Further, this discord never completely settles because they can never fully process their feelings for their children. Owing to society’s responses to disability, and to their children (which often ignite an uncanny sensation), mothers are constantly confronted with their own feelings of guilt, responsibility and shame. Consequently, their subjectivity is always challenged. Chloe’s above recollection of the numerous times others enquire why her child looks different because of his large head may not only cause her to experience her disabled child as uncanny; these encounters also never allow her dissonance to fully settle.

The hostility of the social gaze may cause mothers to feel protective of their children. Sometimes Chloe becomes overwhelmed with anger, aggression and hatred because her ambivalence is felt to be unmanageable in particular encounters when her child is experienced as odd:

> *"We were down at the … Coast and there were this Afrikaans* [a South African cultural group] *family. Fat and ginormous, like freaks in my mind* [laughs] *and then* [this family said to Chloe and her son]: *'Look at the pikkie!* [derogatory Afrikaans term for small child] *Look at the pikkie!'"* Chloe responded: "*'He is not a pikkie … Go and look in the mirror!' Like I was so irritated and angry ... I don't know why I got more angry with them, because like 'You are the freaks!'"*.

Chloe feels great resentment because these others, whom she perceives as imperfect (grotesquely different because they are very overweight), were mocking her son. Further, she is forced to engage with the fact that in this encounter her son is perceived by others as strange because of his disability. Her son is incorrectly perceived as a younger child, and thus uncanny, because they cannot determine what category he belongs in – is he a boy or a baby? This hostile interpersonal experience is reminiscent of Sullivan's (2013, p. 316) description of the uncanny as "sudden attacks of all-paralysing anxiety", and as revulsion – for all involved. Chloe is also confronted with her own perception that her son looks like something he is not, leaving her with intense feelings of anger, hate and shame. Her painful ambivalence is aggressively projected onto this family as she identifies them as *"freaks"*, repeating this word, suggesting her anguish that her own child is perceived by others as an anomaly. Further, Chloe's response suggests unacknowledged ambivalence (Raphael-Leff, 2000) since her feelings of anger and aggression have been denied. She is surprised how angry she became in the moment, indicating that she discovered that her anger was greater than she had known it to be suggesting her preconscious emotions rising to consciousness. Chloe was also responding to the intrusive and disabling attitudes of non-disabled normative society.

Chloe's narrative introduces a further, foundational dimension to the concept of the uncanny. Not only do mothers experience the uncanny in relation to their disabled children because of various social responses but, crucially, also because mothers' sense of the uncanny is already present within themselves. Hence, others' reactions to their children activate their sense of a pre-existent, but unconscious, experience of the uncanny. According to Freud (1919, p. 291), the experience of the uncanny is found at the very core of the sense of self – "that class of the frightening which leads back to what is known of old and long familiar". Freud recalled an unpleasant experience when he unexpectedly caught a glimpse of his reflection in the mirror, yet did not recognise who he thought was an elderly gentleman intruder (Dolar, 1991; Freud, 1919). The uncanny is a foundational experience of the other/stranger within the self: "An uncanny experience occurs either when infantile complexes which have been repressed are once more revived by some impression, or when primitive beliefs which have been surmounted seem once more to be confirmed" (Freud, 1919, p. 248). In Chloe's encounter, her initial observation of the family as *"fat and ginormous, like freaks in my mind"* was made before she connected the experience to her disabled child. Hence, freakishness, as a dimension of the uncanny, is an experience within her self that need not be mediated through external reactions to her child. Chloe experienced an uncanny response before she felt a sense of unfamiliarity applied to her child, and indirectly to her, from this external source. In such an instance, "the personality is partly torn from its moorings" and is threatened with collapse (Sullivan, 2013, p. 325). Chloe responded by mobilising her counterprojective anger: *"You are the freaks!"*

One's double and the uncanny. Freud's (1919) "encounter" with his unfamiliar self in the mirror elicits the uncanny effect of one's strange double. Lacan's (1953, 2001) concept of the mirror stage – the jubilant "recognition" of a baby catching sight of itself in a

mirror – may help explicate mothers' experiences of the uncanny, within their selves and in relation to their disabled children. Lacan (1953, p. 14) postulated the mirror stage as "a decisive turning-point in the mental development of the child" because it marks the beginning of the developing body-image (self as object), and thus early ego formation. Crucially, the image a baby sees is a discrepant one – between the perceived coherent image in the mirror and its actual, physical experience, which is still experienced as fragmented (Lacan, 1988). Hence, Lacan's (2001) ego is a product of misunderstanding whereby the self is experienced as alienated from itself because the distorted (integrated) mirror image is of the actual fragmented state of the subject. The self-alienating image of the self produces ambivalence – while it is "jubilantly" desired, it also creates a haunting and unbridgeable gap (Lacan, 2001). In turn, one's narcissistic phantasies are born.

Lacan (1988) later understood the mirror stage as representing "permanent" subjectivity because understanding of the relationship to the self and to others develops (Felluga, 2011a) through endless misrecognitions of the real (a primitive materiality of existence) because of the need to construct a sense of perceived "reality". Importantly, for the present discussion, others can create this fantasy image of the self (Felluga, 2011a), which introduces Lacan's (1988) notion of the gaze. The development of the self through social interactions in which the image of the self is reflected back to the person emphasises an intersubjective lens (see also Sullivan's (2013) intersubjective understanding of the uncanny). The concept of the gaze is linked to Freud's (1919) sense of the uncanny: there is a sense that the other is looking back, igniting a feeling of lack of control because one's familiarity, and thus narcissism, becomes threatened. In turn, the person is left feeling anxious because of the disruptive effect of the eruption of the real within familiar reality (Dolar, 1991; Felluga, 2011a), something Chloe reported above.

Chloe continued: *"I think there's always that perception … 'Oh, you're a dwarf. You must be in the circus'. Those sort of preconceived, sort of put someone in a box … to look at … that are more difficult than others* [encounters]*"*. Her words further suggest that in moments she experiences others as perceiving her child as uncanny, as someone/something unclearly human, perhaps even as mechanical – a clown that belongs in a "*circus"*, or on show "*in a box"*. Consequently, on some level, Chloe is made aware of the unfamiliar effect her child creates, which seems to amplify her ambivalence because she is reminded of the strangeness of her son. Further, the gaze in relation to her son, and in turn her, causes great discomfort since she is pushed into contact with her own sense of otherness. Lacan's (1988) mirror stage not only includes the way a person perceives the self; importantly it includes how one understands others. Hence, the mothers in the study, as with all people, "recognise" themselves in the other's gaze, and at times receive a haunting, unwelcome reflection because of the presence of disability in their children. The Lacanian Gaze brings a reminder of what these women are not – their own lack – "the materiality of the Real staring back at us" (Felluga, 2011b, n.p).

Jessica, whose five-year-old son also has achondroplasia, discussed her sense of feeling overwhelmed by the many questions from her family when he was born:

> *He had ten fingers and ten toes. I mean completely, little beautiful little boy, and then when they* [her family] *found out, I think the lack of knowledge started to … have their mind-set change, and it was: 'Is he going to die? Does he have to go to a special school? Can he even read and write? Is he going to be in a wheelchair? How do we treat him? Is the only job he is ever going to have as that of a clown in a circus?'*

These questions led Jessica to realise that her son is perceived as an anomaly, which ignited her fears. Her family's reaction to her son appears to be to "other" him since they do not know how to *"treat him"*. Further, the question *"is the only job"* he is going to have is *"that of a clown in a circus?"* brings her into contact with how others perceive her child as *unheimlich* and that others' reactions to him are hostile. However, Jessica tries to focus on the love she has for her son by focusing on his beauty, which is possibly an unconscious attempt to compensate for the discomfort brought about by others' perceptions of him, or even an unconscious denial of his disability: she sees only his fingers and toes. Jessica explained how she coped with these painful familial questions and responses: *"instinctively as a mother I needed to push forward … this is just seriously a bump in the road; it can't be all that bad. I realise there are going to be variations of how I am going to do this … So that was really initially hard and then I found people started feeling sorry"*. A level of avoidance as a healthy psychic defence against the pain (*"hard"*) is apparent in her need *"to push forward"* and to minimise the hurtful effects of these questions, by referring to them as just *"a bump in the road"*. She appeared to find a helpful, greater perspective to focus on. It is apparent that her son's disability makes it difficult for Jessica to settle her relationship to her own sense of her uncanny because his presence and others' responses to him constantly disturb her. Jessica's increasing sense of disquiet with how those close to her began to pity her and her son is also apparent. Mothers' experiences of the pity of others may potentially push them into contact with their personal contradictory feelings that they are attempting to tolerate. The mothers' attempts to settle their uncanny experiences by making the stranger within tolerable will always remain somewhat precarious because they are left with a constant and undeniable reminder, through their children and through the eyes of others, of their own strangeness.

> Jessica also recalled *"one very, very bad incident in the family"* at a dinner party: *They* [her in-laws] *kept saying 'like a clown, like a clown', and I am like okay this is it, 'let's be respectful here, he doesn't know you are calling him a clown but is this the only reference points we can have for a person that is short? Really let's be realistic. So do we call tall people giants, do we do that? Do we call, you know, mentally handicapped children, you know do you, is that respectful?' I said 'Let's be fair to this, we need to start speaking the language that we would need to use when he is older and he understands. Start now. Then I am going to suggest that until you can find a place in your life where you can start respecting him for who he is, then we* [her and her husband] *are going to only associate ourselves with people that can accept him for who is, and accept us as his parents for who we are and respect us by how we are going to raise him*'.

It appears so incredibly difficult and painful (*"very, very bad incident"*) for Jessica that her son is perceived as an uncanny figure by those close to her. She was made uncomfortably aware that her child is seen as a human aberration – a *"clown"*. The sense of the uncanny potentially causes mothers to question how they then care for, and love, their children, igniting a particular ambiguity. Further, the fact that in this moment Jessica's son is related to purely through his disability, which others perceive as a defect, brings her into contact with her intense feelings of ambivalence because she feels disrespected. She responded angrily, choosing to isolate herself from her in-laws since it was too painful for Jessica to associate with others who perceive her child as unacceptable. In turn, following Lacan's (1988) notion of the gaze, perhaps she too is reminded of her own unacceptable parts. Jessica protected herself and her son by avoiding the gaze of her in-laws (*"we are*

going to only associate ourselves with people that can accept him") and by asserting a value independent of others' judgement (*"for who we are"*).

Another mother, Sandra, who has a five-year-old daughter with achondroplasia, described her painful sense of loneliness as a mother to her child: *"they* [Her family] *will never know the feeling of walking somewhere and somebody points at your child and laughs … It hurts you know"*. Sandra is repeatedly confronted by the unfamiliarity of her child. This confrontation does not diminish her capacity to identify with her daughter, but she feels the ostracism. Through this identification, it also leads her to the painful reminder that she too experiences her child as strange. Sandra is left feeling extremely hurt and alone since this 'laughable' child has come from her, causing her to re-encounter her own sense of uncanniness. Another incident that Sandra recalled further illustrates her intense, ongoing ambivalence because of others experiencing her disabled child as peculiar: *"[A] lady pulled out her cellphone and said to her* [her daughter] *'I need to take photos of you, because I need to show people what baby midgets* [derogatory term for a person with dwarfism] *look like'"*. Sandra became understandably angry and aggressive, and she then seemed to project her feelings of hatred (for her child? for disability? for herself for producing this child?) onto this woman and child by retaliating: *"I see your one little girl has … many freckles, it looks ridiculous"*. Sandra's own sense of the uncanny is reawakened in this interaction and her response suggests an attempt to keep this intolerable aspect in the "not-me" domain of the self (Sullivan, 2013) by placing it in the other – not-her. Thus the other (the lady and her *"ridiculous" "little girl"*) holds the blame for the horror which Sandra had previously maintained by dissociation and Sandra can continue to "uphold" her psychic integration. Sandra reflected on the encounter: *"It is not as if I never get angry, I do get angry. I want to punch people in the face"*. Her sense of vulnerability – for herself and her daughter – which

is reminiscent of how the gaze of the other robs one of control (Lacan, 1988), caused her to attack. Her raging response further suggests Sandra's intense love and feelings of protectiveness that seem to mitigate whatever feelings of hate she has for her child: she described ending this encounter by picking up her daughter.

Feeling *for* Their Children in an Attempt to Cope with Their Dissonance

Having explored uncanny maternal encounters with their children through the gaze of the other, attention now shifts to how mothers find ways to tolerate, and manage with, the depth and intensity of emotions that they feel. Some mothers in the study tolerated their ambivalent emotions by positively identifying with how it must feel for their children to be disabled, as suggested by Sandra's sense above that her daughter needed physical protection. R. Parker (1996, p. l7) conceptualises ambivalence as an achievement when the "awareness of her coexisting love and hate for her baby … can promote a sense of concern and responsibility towards, and differentiation from, the baby". Winnicott's (1953) notion of the "good-enough mother" helps us understand how mothers negotiate ambivalence towards their children, and how in turn their children can develop a good-enough sense of self. "A mother has to be able to tolerate hating her baby without doing anything about it" (Winnicott, 1949, p. 355). Patsy, mother to a three-year-old daughter with CP resulting in a physical tightness in the right side of her body, positively identified with her child and her disability which *"has made her* [daughter] *who she is"*:

> *With everything that's happened to her … I think part of it* [her disability] *has made her who she is, quite honestly … and I think it will continue to shape her and I think she will, I think she's going to go out to do greater things because of it and because of how we treat her now, I think she will go on to make a difference somewhere along the line, that's my hopes for her* [began to cry].

The excerpt suggests a sense of hope that her daughter's future will be great because of her disability. Further, Patsy uses the defence of idealisation (Spruiell, 1979) to manage her struggle with her child and her disability. According to Klein (1940), when hatred is mitigated by love, psychic integration can then develop. Thus ambivalence can be experienced as positive when it is a safeguard against feelings of hate (Klein, 1935). Patsy seems to be using her ambivalence to protect against her more painful feelings by dwelling on the positives of her daughter's subjectivity and disability.

It was apparent that the mothers have undergone, and continue to go through, a transitional process. Many recounted initially experiencing shocked and fragmented feelings when their children's disability became known. A distant sense of their own uncanniness, as well as ambivalence, appeared to be particularly prevalent at this stage. Yet at other times many of the women display a very loving, and mostly healthy depressive experience (Klein, 1946), in which their contradictory feelings are more manageable. They have found a way to process their maternal experiences so that their love mostly predominates over their difficult feelings for their children. Through this emotional moderation (which is always distorted because of the constant reminder, through their children, of their own sense of the uncanny) mothers are able to mostly integrate their different psychic aspects. R. Parker (1996) argues that manageable ambivalence promotes the capacity to think meaningfully about one's child, as illustrated by Patsy above. Mothers display a desire to know their children, and to understand their own feelings and experiences, because of the intense pain and conflict of the co-existence of love and hate (R. Parker, 1996) and the constant gaze on their own sense of the uncanny. A mitigation of hate by love is a creative form of care for their children (Klein, 1940) and it seems particularly important that hope is identified and held onto in this process. Patsy demonstrated how she fosters her love for her daughter,

something Ruddick (1989) termed "preservative love": *"I'll be honest, like she is, she's the best thing that ever happened to us* [her and her husband] *… she's just got the cutest personality, she just … she literally is just a treat"*. Patsy focuses on the positive attributes she identifies in her child and what her daughter brings to her own life. She continued:

> *There's never a day goes by that I don't look at her and realise how much of a miracle she is … and we never let her forget that. Because she has come through so much … when I say we get on with it, that's for her benefit, more essentially than ours, is that she's not led to feel any different. But definitely every single day I look at her and I think she's beautiful, she's a miracle. Because she is. Because what happened, the stroke could have killed her… she has come through every single adversity. And she's done it with grace. So there's definitely a lot of emotion there*.

Patsy's repetition that her daughter is *"a miracle"*, describing her as *"beautiful"* and that she has managed her disability *"with grace"* suggests a positive identification with the disability, and with her daughter. Consequently, Patsy's intense pride and love for her child predominates, albeit not without *"a lot of emotion"*, and the sense of the uncanny is tamed.

Sandra expressed pain for her daughter with achondroplasia and seems to identify with how difficult it feels for her to be disabled: *"[W]e had to be honest with her* [daughter] *from the beginning, when those questions were asked. She does ask me sometimes 'Am I going to grow taller?' 'No, this is what's going to happen. This is how you are probably going to end up looking'"*. It seems that by telling her daughter a piece of the truth, Sandra is inoculating her daughter against the full brunt of the truth, and thus from experiencing painful feelings. Sandra is also re-confronted with her own dissonance in these interactions, and further she is reminded of the uncanny effect of her child. When I asked Sandra how she manages with these questions from her daughter, her response was:

> *It breaks my heart … because … even though I know she is very happy and she is strong, there are times when I can see she does, you know, things get to me* [referring to her daughter (and perhaps herself)]. *I know the simple thing that gets to me* [referring to herself as her mother] *is like shoes. She loves beautiful shoes and shoes with* [her] *feet has just been, that's like my biggest challenge in life, just finding shoes that fit her. So when we go to shopping centres and places and there are pretty little shoes, she tries her best, she is a little girl … so she tries her best to put on the prettiest little shoes and they just don't fit. That simple little thing breaks my heart, because that's, you know, that's all she wants. And to me, it's like, I can see there's; when it comes to that sort of thing, then I think she wishes things could be slightly different*.

Sandra describes the pain she feels that she cannot provide "typical" accessories in the form of shoes to allow her daughter to feel like a little girl – perhaps also her own wish of sharing this experience with her daughter, and for herself as a mother. Indeed, she repeated that it *"breaks my heart"* that she cannot fulfil her daughter's wish, leaving her with immense sadness and guilt. Sandra seems to project onto her child her own feelings of guilt and her wish to eradicate the disability because these emotions are painful to hold. Instead of being able to enjoy the shared experience of how things are, she has to resign herself to sharing with her daughter that she *"wishes things could be slightly different"* – these are Sandra's wishes too. The use of the word *"slightly"* seems to suggest Sandra's discomfort with her unconscious hate and accompanying guilt: she implies that she wishes for only a slight change in her daughter's disability. She also manages her painful emotions by identifying with her daughter's experience and fantasising how it is to be in her body. Additionally, Sandra may wish society was different in catering more adequately to

differences – in producing a wider choice of shoes. The social world is disabling for her daughter (see M. Oliver (1990) on the social model of disability). Thus, Sandra's hate may also be directed at an ableist society. Again it is apparent that the mother-disabled child dyad is constantly disrupted by external aspects making it difficult for mothers to ignore (which is never truly possible because of their distorted subjectivity) their own sense of strangeness, and resolve their ambivalence.

Sandra offers a way in which she and her daughter cope with this ambivalence: *"[B]ut she gets over it quite quickly. I think she has a lot of my personality that way. We tend to maybe, at that moment, it affects you, but … we can brush it off quite quickly"*. Perhaps Sandra is trying to find a resolution between the loss of the wish to identify with her daughter around *"pretty little shoes"* and the confrontation with the harsh reality of *"wishing things could be slightly different"* in order to cope with the intense emotions she sometimes experiences in relation to her child and her disability. She is also describing her and her daughter's resilience in the face of disability – an effective survival strategy. Resilient mothers can tolerate themselves as mothers and simultaneously bear the accompanying guilt arising from their ambivalent feelings (Baraitser & Noack, 2007), and thus integrate their own sense of the uncanny, as well as unfamiliar aspects they perceive in their children.

Discomfort amidst loss. Feelings of maternal hate are often deeply rooted within the unconscious (R. Parker, 2001). The mothers in the study never directly voiced hate for their children; however, their difficult feelings for their children and disability became apparent in certain things they said and did in their encounters with me. One form ambivalence takes is in mothers' great sense of responsibility and accompanying considerable guilt and immense shame for producing a disability in their children. The guilt is accentuated within a society

that does not tolerate maternal hate (R. Parker, 2001). Mothers' psychological functioning is largely coloured by their preconceived ideals of mothering, and whether these are fulfilled (Pines, 1997; Raphael-Leff, 2010). With childbirth and the arrival of the real baby comes the loss of the phantasy baby (Birksted-Breen, 2000). Loss can intensify the conflict between love and hate (Klein, 1940). Ambivalence in mothers of children with disabilities holds particular poignancy, since the loss of the idealised, longed for (non-disabled) baby is intense (Harvey, 2015a). Women need to adapt their expectations of their children (I. Parker, 1997) and tolerate comparisons with cultural expectations. Further, such mothers hold some awareness that their children will struggle because societal messages prescribe able-bodiedness, causing great tension and guilt within them. Thus, mothers' sense of selves are constantly interrupted by external communications.

Accompanying the loss of the culturally acceptable baby is the loss of the "phantasy self-as-mother" (Birksted-Breen, 2000). Such loss can elicit enormous feelings of guilt and anxiety, as well as disappointment and sadness. Maternal hate is unconsciously internalised so as to protect one's child against one's hostility. However, maternal persecutory guilt (R. Parker, 1996) is the price mothers pay. On some level Patsy is conscious of experiencing feelings of anxiety and guilt which she tries to conceal from her daughter:

> *The emotion we* [Patsy and her husband] *give her* [daughter] *is love rather than anxiety. At least that's what we try to … you don't want them* [children] *to see you … I don't want her to see my crying, because she has seen me crying, and I think it shocks them … it almost scares them a little bit so that's why I try not to cry*.

This excerpt suggests Patsy's fear that her own emotions have the potential to (further) damage her child. Moreover, it hints at the sense of responsibility she feels for her child who she knows will suffer because of disability.

With the loss of the idealised baby, and unexpectedly being faced with disability in their children, mothers may reflect on possible reasons for the occurrence of the disability in order to manage their ambivalence (R. Parker, 2001) and the uncanny affect that is evoked. According to R. Parker (1996), if mothers have a sense that their children bring a purpose to life, their ambivalence is somewhat tolerated. Patsy tries to make sense of why her daughter was born with CP by focusing on her daughter's strengths and how she enriches her life:

> *We* [Patsy and her husband] *were just looking at her* [daughter] *… you've realised that the Universe doesn't give you more than you can handle, and* [her husband] *and I are educated, we're in a financial situation that we can deal with it* [daughter's disability]*, and I do believe that somebody had to get this little angel, and it was us. There was a lesson in it you know, for us, because … you know life is not always easy sailing, and I think you sometimes take a lot for granted … I just think she's lucky that she came to us, and we're lucky to have her because she's taught us courage, she's taught us strength, she's taught us tenacity, she's taught us … I mean I don't think hers are conscious choices, but she's done it all. She's an inspiration, in my view she's an inspiration*.

The formulation that her daughter is a gift because *"she came to us"* and has "*taught*" them so much seems to help Patsy cope with her contradictory feelings. Perhaps relating to her daughter as a positive part of her life and as *"an inspiration"* alleviates some of Patsy's guilt that this disabled child came from her, and thus her own sense of the uncanny can be endured. Further, positively perceiving her daughter as a *"little angel"* may help Patsy defend against, and thus alleviate, some of her own disappointment and anger that this is not her fantasised baby. Such a positive manoeuvre also suggests idealisation

(Spruiell, 1979) as a way mothers find meaning and adapt to having a child with a disability. Further, Patsy transforms her child's disability from the demonic into the angelic, suggesting an attempt to counter the dreaded feeling of her child as heinous and thus persecutory (see Norden (2007) on the link between disability and evil). This attempt speaks to the different aspects of the uncanny that lie beyond consciousness and how disturbing the various aspects and contrasting feelings of subjectivity may be. The feelings evoked by a disabled child make it difficult for mothers to settle into their selves.

Chloe also appears to have made some sense of why her son was born with achondroplasia, *"because that's the way God made him"*. Chloe chooses to externalise the responsibility of her son's disability by using religious reasoning. Thus she partly frees herself of her own feelings of guilt and responsibility for producing the unanticipated baby. Chloe's way of dealing with her ambivalence and of preventing psychic disintegration suggests the use of projection (R. Parker, 1996). Klein (1937, p. 341) points out "we so much dread hatred in ourselves that we are driven to employ one of our strongest measures of defence by putting it on to other people – to project it". Chloe seems to be projecting onto God and religion in order to understand being human and cope with her ambivalence. Thus, she has found a helpful narrative for something that is difficult, inexplicable and culturally devalued. Thus, these mothers' children, while experienced as alien, are also positively experienced as familiar, which allows some toleration of the mothers' own sense of their uncanny and allows possibilities for maternal love.

(Dis)-identification with Disabled Others

An idiosyncratic development in response to the uncanny effect of disability and accompanying ambivalence for mothers of disabled children concerns patterns of identification and dis-identification with the disabled other. Some of the mothers in the

study identify and dis-identify with other people with disabilities as an attempt to diminish their intense feelings for their children and maintain psychic integration. Specifically, at certain times during the research some of the mothers perceived me as something uncanny which re-articulated their sense of their children as *heimlich/unheimlich*, as well as their own sense of unfamiliarity. Some mothers made efforts to connect with me as another disabled person, and thus as similar to their children. I was someone for them to positively identify with because I seemed to provide hope and reassurance that their children would be fine. Using me in this way seemed to be an attempt to help strengthen their children's identity, and their own. I was left experiencing a range of emotions. Interpretation of these maternal efforts with the help of concepts of transference and countertransference aided me in understanding mothers' encounters with the disabled other, and also in understanding my own powerful responses to the interviews. While the concepts of transference and countertransference are usually reserved for the analytic situation, a number of scholars (e.g., Cartwright, 2004; Holland, 2007; Holmes, 2014; Long & Eagle, 2009) have applied the concepts to the interview situation. The powerful interactions arising in this research necessitated ethical engagement with the possibility of transference-countertransference phenomena (see Harvey (2017a) for an in-depth discussion of this engagement in the current study).

Moments in which the mothers experienced me as peculiar seemed to serve to disconnect them from their painful experiences in relation to their children's disability since they appeared to project the disavowed aspects they recognise in their children onto me. These mothers are understood to have been attempting to tolerate their own sense of the uncanny by projecting their repressed, "not-me" (Sullivan, 2013) aspect into me. This was a two-dimensional process since my feelings in relation to my repressed aspects were elicited

in response, and I too re-experienced myself as strange. These experiences have a particular unhomely, discomforting feel to them, both for myself and for the participants. Although difficult to capture, three such experiences are described below.

Janet has a seven-year-old child with physical manifestations of CP. She closely identified me with her daughter when recalling how others respond to her child: *"It's not that I'm* [referring to me, the researcher] *a dwarf because I choose to be. It's not that I* [referring to her daughter] *can't walk because I choose to"*. This is emotionally difficult for me to engage with, primarily because of the casual way Janet uses the term *"dwarf"*; I was struck by how she was predominantly seeing me as disabled. Indeed, she remarked later in our first interview: *"[T]he first thing when you* [me] *came was … is the word 'dwarf' the right word? … So is 'dwarf' the right word?"* In this moment, Janet is perhaps attempting to contain the urge to say the wrong thing, and to identify with me positively instead. However, in both disquieting moments, I am struck by how I feel Janet is seeing me as a member of the "outgroup" of society. Potentially this is projective identification (Klein, 1946) since Janet places her disavowed feelings onto me and in turn I feel the horror (Sullivan, 2013) of Janet's projections and they touch upon my own impressions of unfamiliarity.

This difficult encounter with Janet continued: at the end of the interview she took me to where her two non-disabled children were playing so that she could *show* me to them and they could *see* me. She voiced that she wanted to see their reaction to me. I was extremely unnerved by this idea and yet felt I needed to play along since she had given so generously of her time and thoughts for my research. I revisited this experience with her in the following interview. Her response did not make me feel any better because my disability was foregrounded, at the expense of my entirety: *"[M]aybe they* [her children] *just thought*

you were like a kid [child] *or something. I was trying to explain to them 'no, you're not, you're a mother'"*. Further, her children's momentary perception of me as something that I am not – a child – left me feeling vulnerable and upset due to the uncanny feel of the encounter. It was almost as if, like Freud, I had caught a reflection of myself in the mirror and could not recognise myself in the image. The "mirror", however, was the gaze of the other and a distorted image of myself was reflected back to me (Lacan, 1988). Janet further explained how she had told her disabled child about me and my dwarfism, and her daughter's response was: *"[F]or real? When's she coming? I want to see her"*. This left me feeling exposed and uncomfortable with the idea that her child wanted to *see* me, rather than perhaps *meet* me. I was the peculiarity, pushed into facing my frightening, repressed aspects as I am made into an object on display. Further, I seem to be the uncanny object for Janet, which potentially heightens her ambivalence and brings her into contact with her own sense of uncanniness.

A similar encounter occurred with Joan, mother to her sixteen-year-old daughter who also has CP: *"[Y]ou're* [me, the researcher] *just not okay in every sense of the word, but you're okay. You've become a psychologist, you've got a husband, you've got children, you've got a future …"* Again this was a difficult moment to manage. *"You're just not ok"*, in every sense, is difficult to hear. While I do not deny my disability, I am forced to confront the disavowed aspects within me and the fact that another is seeing these aspects too. I also wondered whether I had received Joan's own projected repelled aspects, and those parts she hates most in her child, as if they belonged to me. Free of these parts, Joan can cope with her difficult maternal feelings and continue to uphold her previous psychic structure, and to love her daughter. However, Joan sees me as a role model who can, by implication, give value to her daughter's life: I also represent hope for her daughter's future.

She is trying to manage her unbearable ambivalence. Yet, even in this process of hope I am confronted with something that ought to have remained hidden in me; it is familiar, yet terrifying – *unheimlich*.

Chloe too seemed to project the disquieting aspects of her son's dwarfism onto me in an attempt to maintain her sense of self. When describing how people stare and point at her son in public, she identified with me: *"[W]ell I'm sure* [laughs] *you* [referring to me] *get it all the time"*. This was yet another unnerving experience for me since I was likened to an anomaly that others stare and laugh at. I was unwillingly pushed into contact with my peculiarity. This was a painful reminder of the horror (Sullivan, 2013) that "we", the dwarfs, are on show for the public, because we are intriguing frightening freaks. Indeed, I do often get laughed at in public. Further, Chloe's laughter suggests the defence of humour as a way to mitigate her potential sense of shame and guilt.

I was uncomfortable hearing these remarks at the time of the encounters; however I also feel disturbed revisiting these narratives since I am again made acutely aware of the weirdness within me. I am reminded of the many times I was, and still am, made to feel like an outcast in society – that my body is the other. Just as the boundary between self and the distasteful within me is a tenuous one (see Harvey, submitted), so too is the border between what the mothers identified as peculiar in me, and what they identify as uncanny in themselves, and in their children. This is a continual fluctuating process of projection, introjection and expulsion, which directly affects a person's overall self-definition, and the maternal sense of self. The women's ongoing processes of subjectivity vacillate between integration and being unravelled as they sit on the boundary of their own sense of the uncanny.

To Conclude

The foundational sense of one's own unfamiliarity to oneself brings immense discomfort. Arguably the unease evoked by the uncanny more generally is particularly amplified when applying the concept of the uncanny to the experiences of mothers of disabled children. Freud's (1919) theory of the uncanny is valuable in making sense of non-disabled people's responses to disability in others. The paper has argued that mothers of disabled children are repeatedly confronted with the gaze of the other, reflecting back to them something profoundly unfamiliar about themselves and their child, but also something disturbingly familiar. In turn, the uncanny as a foundational experience of the self elicits great ambivalence in mothers. Their own sense of peculiarity is constantly open to disruption by others' responses to disability and to their children, never allowing their dissonance to reconcile. Their love for their children is burdened with intense conflict, challenging and stretching their sense of selves. The mothers creatively manage these interruptions in various ways so as to continue to develop their maternal subjectivity. They use various defences, including idealisation, avoidance and projective identification. Some mothers search for reasons for disability in their children – conceptualised here along the lines of a divine/demonic identification. Additionally, the mothers were re-confronted with their own sense of uncanniness because of my disability, causing them to project these unwanted aspects into me. In turn, I am forced to re-bear my disavowed disability-related aspects. Such a manoeuvre allows the mothers to continue to love and care for their disabled children, and thus their psychic integration is maintained. While mothers were actively re-confronted with the uncanny, they also resist its summoning by repositioning their children outside of the realm of the uncanny. This resistance to conformity has transformative potential:

> … those locales in which disabled bodies are able to resist conformity with dominant representations may help to foster uncanny moments in which the distinction between self and devalued other is less certain. [This] can help us to theorise the origins of anxieties toward physical disability in the complex interrelationship between self and social environment. (Wilton, 2003, p. 385)

Such anxieties are not insubstantial. As painful as it was for me to hear and bear the mothers' complex emotions for their children, I am acutely aware that it may be painful for the reader of this paper to bear. The experience of maternal ambivalence for mothers of disabled children is as unique as it is ubiquitous to motherhood: it offers both the exceptionality of disability and a lens (albeit a sharpened one) into the ordinariness of everyday maternal subjectivity. Furthermore, we all have disabled parts of ourselves that are all too familiar in their unfamiliarity. This painful, complicated ambivalence is what the mothers live with, and shared in the study. Hence, it is imperative to hear this dark underbelly of their mothering experiences and not shy away from it because it is difficult to endure. The intention of this paper is to do justice to the ongoing, complex emotional experiences for mothers who are raising their disabled children and for the daily complexities disabled children and adults endure, particularly when encountering the discomfort of others.

Chapter Seven:

Subjectivity and the Return of the Abject in Mothers of Physically Disabled Children

Introduction

The final article of the thesis develops the picture of maternal ambivalence in the face of disability, a notion introduced in the previous article of Chapter Six. Specifically, the paper explores how maternal ambivalence is experienced in moments of disavowal or abjection, as Kristeva (1982) calls it, in relation to the mothers' disabled children. The paper, "Subjectivity and the return of the abject in mothers of physically disabled children", was co-authored with Carol Long and has been submitted to *Studies in Gender and Sexuality*.

Schmied and Lupton (2001, p. 245) point out that "[t]hat which is marginal or different is always located as a source of danger and vulnerability to the self". This disruption to the order of things was termed the *abject* by Kristeva (1982). She explains: "Abjection is above all ambiguity. Because, while releasing a hold, it does not radically cut off the subject from what threatens it – on the contrary, abjection acknowledges it to be in perpetual danger" (Kristeva, 1982, p. 9). Kristeva (1982) applies the notion of the abject to the female body and subjectivity; in the article in this chapter, the concept is additionally applied to the disabled body. This connection is made on the basis of Goodley's (2011a, p. 80) argument that disabled people are "assigned the position of monstrous other" because they do not subscribe to that which is ideal.

This thesis pushes the reader to confront the unspoken – that disability greatly threatens that which is proper, an idea that goes against the politically correct view of disability, led by the social model of disability (e.g., Barnes, 2012; M. Oliver, 1990). I have

argued in the thesis that the experience of disability often transcends these politically correct ideals because of the raw affects that disability produces – something the mothers of the study live constantly in relation to their children.

The abject "gnaws at the coherence and stability of identity" (Hughes, 2009, p. 405). This final article of the thesis therefore details the experiences of two mothers whose subjectivities were initially greatly challenged by the birth of their disabled children as their primal abject returned because of physical disability in their children. Yet, the paper also addresses how these two mothers negotiate their abjectionable experiences with their children and disability so that their maternal love can continue to be reached. The two mothers are also confronted with society's grave limitations regarding disability. Attempts at "purifying" the abject are discussed, including through the mothers' "use" of me and my disabled status to make the abject feel less threatening, and to allow them to continue to love their disabled children. Thus, the intersubjective nature of the study is also highlighted, as are the implications of the process of researching maternal subjectivity in the face of disability. Hence, the paper again addresses both research questions, although the paper primarily attends to the first question: What are the subjective experiences of mothers of children with a visible physical disability?

Article:

Subjectivity and the Return of the Abject in Mothers of Physically Disabled Children

Abstract

The paper explores some of the complex ways in which mothers of visibly physically disabled children manage moments of abjection in their relationships with their children. The stories of two women are told in order to illustrate the power of their disturbing experiences, as well as the ways in which these mothers strive to share the unsharable, and thereby empathically connect with themselves and their children. We argue that understanding of maternal experiences is important in and of itself, and that such experiences also offer a model for how others may find ways to embrace disability rather than reject, avoid or hate it. A model of maternal ambivalence that can show how mothers negotiate the abject may go some way towards thinking about the unthinkable. This makes a deeper acceptance of disability becomes more attainable.

Introduction

> There looms, within abjection, one of those violent, dark revolts of being, directed against a threat that seems to emanate from an exorbitant outside or inside, ejected beyond the scope of the possible, the tolerable, the thinkable. It lies there, quite close, but it cannot be assimilated. It beseeches, worries, and fascinates desire, which, nevertheless, does not let itself be seduced. Apprehensive, desire turns aside; sickened, it rejects (Kristeva, 1982, p. 1).
>
> Disabilities … confront us with incomparable exclusion, different from the others: the disabled person opens a *narcissistic identity wound* in the person who is not disabled; he inflicts a threat of *physical or psychical death*, fear of collapse, and, beyond that, the anxiety of seeing the very *borders of the human species* explode.

> And so *the disabled person is inevitably exposed to a discrimination that cannot be shared* (Kristeva, 2010, p. 251; Kristeva's emphases).

Thus began two essays written by Julia Kristeva, exploring respectively the abject and disability. Although she did not herself link these two concepts, in both essays, she is interested in approaching the intolerable and unthinkable – in *not* turning aside. Her argument in her paper about disability is both that "the disabled person is inevitably exposed to a discrimination that cannot be shared" (Kristeva, 2010, p. 251) and that there is immense political value in taking the stance that the vulnerability of disability can indeed be shared. It is these contradictions – that the unsharable can be shared, that the unassimilable can be assimilated, and that the unthinkable can be thought about – that stands at the heart of our paper.

For Kristeva, her investigation of disability and call to share its vulnerability is not just an intellectual pursuit. She is a mother to a son with neurological difficulties: she is both non-disabled[12] and intimately connected to disability. She observes the threat she writes about and also reaches towards it. This uniquely personal position of being a non-disabled mother to a disabled child forces her to be in touch with both the intolerable and the tolerable at the same time.

Winnicott (1949) argues that all mothers occupy the contradictory position of both hating and loving their child simultaneously. Authors such as R. Parker (1996) and Welldon (1988) have extended the theme that maternal ambivalence is not only unavoidable, but that, more importantly, it is potentially generative. In the case of mothers whose children are disabled, we argue that, potentially these contradictions are heightened. These mothers

[12] This term has been chosen to counter the implication in "disabled" that ableism is normatively more acceptable (Shakespeare, 1996; The language of respect, n.d.). While our stance is to reject ableist language, the terms available to us remain inadequate.

are negotiating the very dilemma posed by Kristeva: they are not able to share and yet are overcome by the abject, but they are also compelled to turn towards, rather than to turn aside.

For us too, this is not just an intellectual pursuit. The paper, based on a broader interview-based study of the maternal subjectivity of non-disabled mothers of visibly physically disabled children, tells the story of two women, actively, and sometimes viscerally, recalling their entry into motherhood when their children were born. The voices of these women, the abjection that they encounter in their responses to their babies, and the love and hate they express, offer a lens into their processes of becoming mothers. Furthermore, we are personally positioned: Clare (the first author) is a disabled mother to two children, one disabled and one non-disabled. Clare, also a clinician and an academic, conducted the interviews that form the core of this paper, which meant that the interviews themselves were deeply, and sometimes uncomfortably, infused with the encounter between disability and non-disability – see Harvey (2017b) for a reflection on this interplay. Carol (the second author) is a non-disabled mother to a non-disabled child. She tries to confront, but does not fully confront, her own "abjectionable" responses to motherhood and her own ability to share the vulnerability of disability.

The multiplicity of the relationship between disability and non-disability is important for this paper. The paper's intention is not to contribute to the exclusion of disabled people and their experiences, something which studies in the past have often been criticised for (Shakespeare, 2005b; Vehmas, 2008). Kristeva (2010) stresses that each disabled person is a singular person with unique experiences. Such particularity is true for non-disabled mothers of disabled children too. Kristeva (2010, p. 257) also warns against the problematic tendency to merge "all disabled people together without taking into consideration the

specificity of their sufferings and exclusions". Thus, this paper hopes, amongst other things, to develop Kristeva's (2013, p. 219) aim for a "fuller appreciation of the incommensurable singularity of each [disabled and non-disabled] person".

Mothers of disabled children continue to be kept on the margins of both the disability and psychoanalytic literature. A deeper understanding of their subjective experiences is important in its own right. Because these mothers stand in a unique relationship to disability – so close and yet so far – an understanding of their experiences also promises some insight into the implications for children with a disability who routinely face the hatred, fear and rejection of people much less loving than their mothers.

In the larger study exploring the subjectivity of these mothers from a psychoanalytic perspective (see Harvey, 2019), it is apparent that mothers experience a wide range of emotions and that their relationships with their children are multifaceted. By focusing on the abject, this paper hones in on only one part of this multiplicity. The paper offers an in-depth case study of two of the mothers, focusing particularly on moments in interviews when the abject arose. In line with Kristeva's (1982) formulation of the abject as bodily, these moments often referenced the bodily experience of mother and baby. Inevitably, much of their story is excluded by this focus. Although these mothers are unique in their singularity, their stories of their experiences shortly after the birth of their children hold the possibility of understanding how they negotiated abject responses within themselves. We argue that it is important to understand all aspects of these mothers' experiences, including those that are shocking or linked to horror, and away from which we may wish to turn.

Choosing to focus on the abject poses a risk of negatively stereotyping disabled individuals – of implying that they are abject – and of negatively stereotyping mothers as unloving. Indeed, some of the descriptions offered by the mothers are difficult to hear.

Despite these risks, we believe it is important to hear these experiences. It is necessary to face and comprehend their hate, but it is equally necessary to explore their negotiation of their encounters with their own abject responses. The way these mothers negotiated their abject responses holds the potential to offer a model for clinicians and for non-disabled people alike. This model may go some way towards attaining Kristeva's (2010, p. 252) utopian vision "to revitalize … the battle for the dignity of the disabled by constructing what is still sorely lacking: respect for a vulnerability that cannot be shared" and also, as Kristeva (2010, p. 252) contradictorily stresses, that "can be *shared"* (Kristeva's emphasis).

Confronting the Abject: The "Me That is Not Me"

Kristeva (1980) perceived people as fluid *subjects*: as thinking, speaking, doing agents. Her notion of *subject-in-process* is particularly relevant to understanding maternal subjectivity. Everything in, and around, the subject-in-process contributes to the formation of the self. The initial process of subjectivity includes Kristeva's (1982) concept of abjection, which she introduced in *Powers of horror*. She built upon Freud's (1914b) concept of repression as the central process in ego formation, in that thoughts and memories of instincts, forbidden wishes and traumas are inhibited and relegated to the unconscious. The preconscious thus acts as a gatekeeper between repressed fantasies and awareness of them.

The process of abjection begins at the initial sense of a border to the body (Kristeva, 1982) and involves denying and moving beyond primary narcissism (love only for that which is part of one's self), and thus away from a primitive identification with the mother (McAfee, 2004). Since the infant has no concept of subject and object yet, there is only an uncertain demarcation of an "I" and "not I" with nothing to hold it in place, and no way to name it. This primary psychological force of rejection is an important developmental process,

because a person becomes his or her own subject (Kristeva, 1982). An example of the abject is the mother's body, which, while providing fulfilment, simultaneously threatens to engulf the infant (K. Oliver, 1993). Consequently, the two key features of abjection, "fascination and repulsion" (Kristeva, 2002, p. 448), describe the relation between the subject and object. Various examples of what an infant will abject include a mother's sour milk and her engulfing embrace, as well as its own faeces (Kristeva, 1982). These examples suggest a primitive, physical process; indeed, abjection occurs at the developmental stage when the body and its functions are not yet controlled by the ego or led by societal expectations. The abject thus confronts us "with those fragile states where man strays on the territories of *animal*" (Kristeva, 1982, p. 12; Kristeva's emphasis).

The horror of the abject is felt both in the physical and psychic realms, since the deeply disturbing aspects of the self are expelled to the periphery of the psychic structure so that a sense of identity can develop. Kristeva (in Guberman, 1996, p. 118) describes abjection as "something that disgusts you … it is an extremely strong feeling that is at once somatic and symbolic, which is above all a revolt against an external menace from which one wants to distance oneself, but of which one has the impression that it may menace us from the inside". In the process, a part of the self is aggressively banished: "I expel *myself*, I spit *myself out*, I abject *myself* within the same motion through which 'I' claim to establish *myself*" (Kristeva, 1982, p. 3; Kristeva's emphases). These excruciating parts remain permanently unassimilated on the periphery of the self, thereby playing the essential role of upholding borders of identity (Fletcher & Benjamin, 2012; McAfee, 2004). The abject is "not me … But not nothing, either. A 'something' that I do not recognise as a thing … On the edge of non-existence … of a reality, that if I acknowledge it, annihilates me" (Kristeva, 1982, p. 2). Hence, the abject is slightly different to Freud's concept of the repressed, since,

structurally, the abject remains on the periphery of the conscious, promising to undo subjectivity.

Various, almost daily, encounters serve as reminders of what was originally repelled, pushing the self into contact with its own and with others' abjected parts. During these moments, feelings of disgust are re-evoked and the borders of the self feel menaced, since the expelled aspects threaten to return (Kristeva, 1982). The abject can take many forms – we argue that two such forms are the maternal body and the disabled body.

Significantly, Kristeva describes the maternal body as the original abject. For women becoming mothers, abjection returns into their own bodies. Given that babies themselves are full of "waste … vomiting … and muck" (Kristeva, 1982, p. 2), it is possible that becoming a mother summons the return of the abject in two ways: through the transformation of one's own body into a maternal body and through the intimate, and sometimes repugnant, contact one has with one's baby's body.

If one's baby is also disabled, another potential layer of abjection is evoked. Kristeva (1982, p. 4) stresses that waste, vomiting and muck are not themselves abject, but symbolise something frightening, something of one's own that returns unbidden to confront one: "It is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite." Having a baby with a disability confronts one with the myriad social associations of abjection that capture – and distort – the public imagination. Disability studies powerfully challenge the prejudiced and often repugnant and hateful social fantasies about disability (e.g., Davis, 1995; Goodley, 2011b; Hughes, 2009). Interestingly, however, according to Hughes (2009, p. 406), "the concept of the abject has had little impact on disability studies. It has been used at the margins of disability

discourse". Wendell (1997), who has engaged with the abject and disability, argues that the "usual" process people engage in of evacuating the effects of the abject is comparable to how non-disabled people disavow the disabled, and furthermore, to the psychological threat that disabled people pose to non-disabled people's psyches: "[D]isabled people are constant reminders to the able-bodied of the negative body – of what the able-bodied are trying to avoid, forget and ignore" (Wendell, 1997, p. 268).

While Kristeva did not significantly link abjection and disability, she advocates an integration of disabled and non-disabled people, calling for an end to marginalisation of the disabled (Kristeva, 2006, 2010, 2013). However, as Grue (2013) points out, while Kristeva highlights the divide between disabled and non-disabled people, she misrecognises that some disabled people are indeed incorporated in society.

The limited psychoanalytic literature on disability (e.g., Sinason, 2010b; Watermeyer, 2013; Wendell, 1997) does not specifically speak to the experiences of non-disabled mothers in the face of their physically disabled children. Hence, one goal of this paper is to further theoretical understanding of the experiences of the non-disabled, specifically mothers, in their encounters with the disabled. Kristeva (2010) said that a disabled person is confronted with the "irremediable"; those in contact with the disabled, including clinicians, who do not confront their own irremediable aspects cannot fully help another. It is anticipated this paper will encourage clinicians, mothers and others to engage in such self-reflection so as to be of further assistance to disabled and non-disabled people, including mothers and children.

The Horror of, and for, the Non-disabled

When non-disabled people are faced with disability in others, their emotional experiences can be complex (Watermeyer, 2006, 2013). Specifically, the terrifying

awareness of one's own bodily fallibility may be evoked. In this regard, Kristeva (2006, p. 223) suggests that facing disability in another can push people into confronting their "own anxiety of castration, the horror of narcissistic wounding and … the unbearableness of psychical or physical death". We are concerned by disability "not necessarily because 'it could happen to anyone', but because it is already in me/us: in our dreams, our anxieties, our romantic and existential crises, in this lack of being that invades us when our resistances crumble and our 'interior castle' cracks" (Kristeva, 2010, p. 266).

As with our knowledge that we will die, we all live with fear that potentially we could have been, could be, or could yet become, disabled. Non-disabled people may split off and project into a disabled person parts of the self that arouse internal turmoil as one way of maintaining psychic equilibrium (Harvey, 2015a, b). Shakespeare (1994, p. 287) aptly describes the disabled in this process as "dustbins for disavowal". Layton (2009b, p. 106) discusses a "neoliberal trend" to disavow vulnerability and interdependence in an attempt to distinguish the self from those more vulnerable. Although Layton (2009b) views this trend in light of "gender, class, racial, sexual, and national collective identities" (p. 106), her ideas can be applied to the distance that non-disabled people unconsciously and consciously create between themselves and the disabled. Indeed, Emanuel (2016) wrote about "implicit ableism" as entailing a failure in empathy because common vulnerabilities are denied and the capacity to feel responsible for "the suffering of others" (Layton, 2009b, p. 105) is diminished, resulting in a "safe" distance from another's vulnerability. However, Kristeva's concept of abjection implies that this distance is never safe, since that which we repudiate always threatens to return. Through a re-confrontation with one's own abjected aspects, identified as existing within the disabled other, the non-disabled person's sense of self can feel threatened. The disabled body becomes the disavowed abject.

The Returning Abject: Finding Maternal Love in the Face of Disability

Accordingly, the process of subjectivity becomes particularly complicated for non-disabled mothers raising a disabled child. Generally, the topic of disability arouses painfully ambivalent feeling states (Harvey, 2015b). Everybody has had experiences that have shaped their thoughts and feelings about disability which build on the abject-repression within themselves. Such experiences can be re-evoked when a woman confronts the more difficult aspects of her baby. Consequently, a woman might feel shame and guilt when she has a disabled baby, as she is confronted with the loss of the idealised (non-disabled) baby of her imagination (Harvey, 2015a; Sinason, 2001). Importantly, all mothers, regardless of their children's constitution, experience difficult, ambivalent maternal feelings (Winnicott, 1949). However, primary narcissism (Freud, 1914a) becomes additionally complex for a woman whose narcissistic object is a disabled baby. Her narcissism and sense of self are further affected by the responses of non-disabled others to her child, since she must tolerate people's projections of the disavowed aspects of disability onto her baby (Harvey, 2015a). Hence, a mother's tenuous psychic structure momentarily face the threat of collapse when her child is born with a disability.

The concept of abjection applies to that which inherently disturbs social order and conventional identity (Childers & Hentzi, 1995). Abjection occurs both at a micro level, in the realm of subjectivities, and at a macro level, through society's language and laws (Gelder, 2000). People fall back on various mechanisms to manage abject impressions, including staring and abjectifying to try to recover a sense of self, and expressing such disturbing states to try to manage the emotion (Frances, 2014), including through religion, as well as creative acts such as art and writing. Emotional interconnectedness can also bring about a management of the abject. By naming, and talking about, one's abject experiences

in an emotionally connected manner, “abjectionable” responses lose their power and become less objectionable. As Kristeva (1982, p. 190) claims that, “by naming it [the abject], both have it exist and go beyond it”, since the abject originates in the pre-language state. If what is felt to be horrific is named, the terror dissipates as one gains control by making it conscious (Kristeva, 1982). When one considers how mothers navigate the abject, this process of naming, and thereby humanizing, the abject (Pentony, 1996) may go some way towards settling their abject responses, connecting with their maternal love, and upholding their psychic selves. Such a process is akin to Winnicott’s (1955) maternal holding environment, in which a mother’s emotionally engaged way of being with her baby enables her baby to continue to develop a sense of self in the face of abjection.

The interview material from the two mothers is considered separately below to uphold the integrity of each woman’s unique experience. The mothers are quoted verbatim to reflect their experiences first-hand, as far as possible. Readers should note that at times the language the mothers used to describe their children’s disability is controversial and suggests an ableist undertone. While we do unpack these stories, it is not our intention to collude with their, largely unconscious, or society’s, ableist language.

Lara and Kim

Lara has a six-year-old daughter, Kim, who has Pierre Robin sequence, which manifests in a series of marked features in her head and face. The most noticeable of these are that the baby is born with a small lower jaw (with the result that the tongue is positioned far back), and a cleft palate. These features can lead to breathing and feeding difficulties (Yang et al., 2017). Kim was born prematurely via an emergency Caesarean section and was consequently incubated, which was difficult for Lara, particularly because she could not bathe her. Lara recalled that *“she eventually looked like a clean child* [after

repeatedly wiping her]. *And she looked more lovable"*. Her recollection is of a process of encountering the physicality of her baby and actively struggling to find a way to reach her lovable baby. For Hughes (2009, p. 405) the abject refers "to a realm that is impure, unclean and disorderly to a murky, disavowed world that threatens propriety and identity". The act of being able to wash her baby erased Lara's initial experience of her baby as repulsive, allowing her maternal love to continue to develop.

Lara also remembered her difficulty in beginning to breastfeed her baby, because she had no milk. She described how she *"didn't want to see his* [doctor's] *horror because I had nothing* [no milk] *to give her* [her baby]*"*. Lara appeared to perceive herself as the bad, ill-providing object – as the bad breast (Klein, 1946). She continued, describing the pressure she felt: *"[A]nd they* [hospital staff] *tell you to squeeze, and I'm squeezing, and they're telling me I'm doing it wrong, that's why there's no milk coming … I hated it … it was so horrible."* She recalled saying to a nurse: *"'I can't look at my baby.' And I start crying. She's like 'Why not?' And I said 'Because I have no milk to give her'."* Lara's anxiety-riddled experience of confronting her baby, as well as her own sense of disappointment and horror, was apparent. So too was her experience of simultaneously feeling observed by others, leaving her feeling judged and ashamed. This emotional experience felt unbearable – *"so horrible"* – for Lara, who felt bombarded by her inadequacies from inside and outside herself, at the already precarious transitional time of becoming a mother. The powers of horror that Kristeva (1982) referred to returned for Lara as much from her own visceral experience as from the gaze of the other.

A further feeding difficulty arose because Kim needing to be fed via a tube. Lara recounted how stressful, utterly foreign and mechanical this was: *"[B]ut now, she's crying, and she's hungry, and the tube's out. There's no other way to feed her, because she's going*

to choke if you feed her on a bottle. Now, how do I put that tube in a crying child?" This plastic, alien piece of equipment formed part of Lara's experience of horror and seeming de-realisation. Her anguish was palpable because she felt she could not provide for her baby. Her feeling of being the bad breast was compounded by the deeply painful and repulsive physical process of feeding, presenting her with an insoluble dilemma. Such a foreign feeding process at an already alien time, that of becoming a mother (Speier, 2001), must have been difficult to tolerate.

One of the most prominent experiences of horror for Lara was when her baby had to have an operation for a tracheostomy – a surgical incision is made in the windpipe and a tube is inserted to allow the person to breathe (Farlex, 2016). Lara described her *"shock"*: *"[N]obody told us that we're not going to hear her voice again"* and *"now, now why would she cry with no sound?"* Lara expressed her confusion and inability, at the time, to digest fully why her baby was crying with no sound. Confronted with the intolerable and the unthinkable, she struggled to assimilate the experience. Lara's experience of trauma from that time is also palpable.

She recalled the medical routine of caring for Kim, involving cleaning and changing the breathing apparatus daily and suctioning her daughter's throat when it became saturated with liquid. Kim would make a guttural sound which Lara described as *"loud; it can get irritating, it can get a lot of attention"*. Lara's description is jarring and evocative, suggesting the intrusiveness of this disturbing, *"irritating"* sound for her. Lara remembered the stressful times of changing tracheostomy tubes. She recounted how the doctor had warned her not to push the apparatus in too far, as this would cause her daughter to bleed. She also recalled how Kim scarred from the ribbon that fastened the tracheostomy to her neck. Moreover, Lara continued to feel like the object of the other's gaze: feeling watched

and judged by those around her. Hence, she did not always feel she was affirmed in her role as Kim's mother (by those around her, by her daughter, and subsequently by herself). Kristeva's (1982, p. 140) words seem particularly descriptive of Lara's experience at that time, "abjection, whose intimate side is suffering and horror its public feature".

Kim had her tracheostomy for three years. Telling Clare about this experience was distressing for Lara and suggests chronic trauma dating back to this stage of her mothering experience. In the interview, Lara brought out her bag of tracheostomy pieces to show Clare. She recounted in intimate detail how each piece needed to be cared for, and then said that it would *"be heartache to lose this"*. It is striking that an object that caused so much pain and revulsion has been lovingly kept and would be *"heartache"* to lose. Perhaps the bag serves as a reminder of her struggle with her own abject responses to a disturbing and painful time. The bag appears to symbolise how far she and her daughter have come together, and what loving memories she has formed. Furthermore, Lara's wishing to show Clare the bag felt like an expression of empathic concern for what she and her daughter have endured together, allowing her love for Kim to expand. It was also a cathartic moment for Lara. She spoke openly and at length about this experience, seemingly needing Clare to hear it. Perhaps this too was a process of continuing to reconcile the abject by naming it – what Pentony (1996, n.p.) understood as ascribing "meaning to the place where it collapses".

Lara related in intimate detail another operation in which Kim's jaw was extended when she was three years old, describing the operation as *"cringeful"* and *"scary"*. She detailed surgeons cutting bone away and using equipment *"behind the ears so that they can twist, they put the pins inside her jaw"*. Lara expressed this as *"so sad for me"* and *"now imagine this. I can't even …"*. Her unfinished sentence suggests how immensely difficult it

was for her to recall this foreign impression of her baby. The reference to the operation being *"sad"* evokes an image of Lara feeling helpless, yet also very loving towards, and extremely concerned for, Kim. The experience appears to have been exceedingly traumatic for Lara. In her interview, her narrative alternated between intense and painful descriptions and moments of retreat. Shortly after her unfinished sentence (above), she said: *"It's like let me just take a moment of silence"*.

A few moments later, after another graphic description, she changed track again: *"But we made the most out of everything we've been through."* It seems that Lara broke the pain of her narrative with brief moments of avoidance to try to cope with it. Avoidance is an understandable defence when re-confronted with the abject. Creed (1993, p. 65) describes the abject as something that elicits repulsion which "must be excluded from the place of the living subject". Hughes (2009) understands the abject as causing a person to want to create distance from this other by fleeing. However, the mothers of disabled children cannot simply flee – their disabled children remain and their confrontation with abjection coexists with fiercely held love towards their children (see Harvey, submitted). Lara avoided remarkably little as she relates her memory of horror, which suggests a reconciling of the abject and deep compassion for her child.

The cost, perhaps, of not avoiding the abject is that it threatens to haunt. For example, Lara described how her daughter *"had no expression on her face after that operation because she was in such pain, she couldn't smile at you"*. Kim's inability to smile – to connect with her mother in a way that Lara had perhaps expected and yearned for – meant Lara was denied the "usual" mothering experience of "mutual gaze" (Stern, 2002) with her baby. Her attempts at maternal attunement (Stern, 2002) with Kim passed

unrewarded by anything in her baby's face or voice. Notwithstanding, she cared for her daughter, despite being denied these rewards.

This haunting is not only from painful and disturbing memories. Lara, as with other women interviewed, was also haunted by the return of her own abject. The ghosts *from* the nursery, to reframe Fraiberg and colleagues' (1975) concept, were often only momentarily visible in interviews, but they were frightening and horrific. For example, Lara graphically described Kim's disability: *"[T]his thin slithering little tongue is in the way of the palate coming together."* Her description, with its inhuman, snake-like connotations, felt like a disruption in the interview: a disquieting moment when the abject ghosts returned. Similarly, Lara remembered an x-ray of her daughter's skull with the jaw extension implements and tracheostomy. Lara described it as *"freak mad"* and *"crazy"*, adding that *"it's hard to believe"*. Her choice of language in this moment raised connotations of freakiness, madness and craziness. However, as Kristeva (1982, p. 28) contends, "one does not get rid of the impure; one can, however, bring it into being a second time, and differently from the original impurity". Lara illustrates the complexity of identifying with the distasteful aspects in her daughter, as well as integrating these into her own meaning-making. Her difficulty in believing the x-ray was of her daughter suggests an attempt to cope with this horror by almost denying it, so as to continue to love and care for her child. The impure was revisited and situated as a moment in a retelling of Lara's love and concern for Kim.

Towards the end of her interview, after having shared so much raw description, Lara became tearful, thinking back to that time in her and Kim's life, saying: *"[S]orry, sorry you* [her daughter] *had to go through that. Sorry you had to get so sore, sorry I couldn't stop it because you had to have that done to you so that you can be the way you are today."* In this

moment she attempted to embrace the horror in a loving way. She voiced sincere compassion for her child, as well as self-compassion. Lara communicated reparative empathy; she identifies with her child as her own, and as part of herself. She expressed an emotionally difficult identification with how it must feel to be in her daughter's body, communicating mixed feelings of love, sadness and protection. Her retelling was resolved, at least to an extent, in the coexistence of the abject with maternal love and tenderness.

Joan and Sarah

Joan is mother to sixteen-year-old Sarah, who has cerebral palsy resulting in a distinctive gait. Joan experienced fertility difficulties, and Sarah is the result of in vitro fertilization. Sarah was born very prematurely, at 29 weeks.

Joan was remarkably forthright in her interview about her initial struggle with coming to terms with Sarah's disability and the sense of the unknown in relation to how Sarah's disability would manifest. No professional could confirm the prospective severity of the disability. Accordingly, Joan described how she attempted to evade bonding with Sarah:

> *You don't bond because you might be just bonding with a zombie, you don't know what the outcome is. So you're scared to bond because I think part of bonding has got to do with all your hopes and dreams and expectations and of a beautiful baby that will …, that's been waited for and been longed for*.

Joan expressed her fear of bonding and her sense of loss of her idealised imagined baby. Her use of the word *"zombie"* is jarring. It is a shocking thought that a mother can see monstrosity in her baby; indeed, monstrosity has been likened to the misrecognition of disabled people. Hughes (2009, p. 399) argues against the use of this kind of language, advocating that understanding the experience of disabled people "requires a more embodied language rather than one that has been generated from … imaginary that is

strongly influenced by a non-disabled subject position in which repulsion for the other … is never fully resolved". Hughes deplores that a more embodied language is not more freely available. In trying to express her loss and fear, Joan conjured the abject in a way that vividly described her struggle to connect with her baby. Joan also compared her child to the *"beautiful baby"* that she had imagined. She appeared so shocked by the birth of her child that she psychically functioned in a world of binaries – perfect and monster, dream and nightmare – suggesting that her baby's disability was a trauma for her, and that she experienced a loss of the wished-for, idealised (non-disabled) baby (Harvey, 2015a).

Joan continued: *"… what happens if it turns out to be that the baby's a deaf, blind, retarded blob and now you're, now you're emotionally invested, this becomes an even more traumatic sort of scenario."* Joan's graphic language, referring to a *"retarded blob"*, put her into direct contact with the powers of horror. As with Lara above, in these moments, Joan was haunted by the return of the abject, specifically in recalling her early motherhood experiences of imagining what her child would be like and being fearful of falling in love with her child.

Joan recalled a moment when she first received a "diagnosis" for Sarah. The occupational therapist said: *"Look her legs are spastic."* Joan described how she *"was mortified … I just envisaged her in a wheelchair almost incapacitated completely … I envisaged a really grim scenario"*. Joan imagined the worst. Her word *"mortified"* suggests an internal experience of profound shame. Furthermore, her choice of words, *"incapacitated"* and *"grim"*, speak of an unbearable, intolerable experience. Indeed, she also used the term *"horrific"*: *"I think the first few years were, to put it mildly, horrific."* She said at another point that *"these sort of scenarios can be very, very sinister; the outcomes can be very sinister"*. Her repeated use of painful-to-digest expressions to describe her baby

and her experience may offer Joan more than an expression of the trauma that she felt. Her hyperbolic language described the worst of her fantasies. It was noteworthy that such descriptions were confined to the past tense: she did not use this language to describe Sarah or her feelings in the present. Paradoxically, her repetition may suggest not an abjectification of her baby, but rather an attempt to "purify" (Kristeva, 1982) the abject by repeatedly naming and controlling it.

At another point in her narrative, she recounted *"how unbearable her* [daughter's] *baby years were"*. Her reflections held a different tone to those described above: one that held not her own fears, but immense empathy for the horror of Sarah's experience. Sarah had surgery numerous times and Joan recalled one risky operation to lengthen Sarah's tendon: *"*[It was] *literally taking a chunk out of the bone of her femur, no, no it was mind blowing. Like she had to spend six weeks in an A-frame plaster cast with a pole between her legs, on bedpans. No, it's…, it was, it was like a horror movie truly."* The likening of this experience to a *"horror movie"* was evocative of Joan's sense of Sarah's trauma. Her identification with Sarah meant that Sarah's horror was hers too. Indeed, she described the many operations Sarah has had to endure as horrific: *"I've been through absolute hell over the past fifteen years* […] *the surgery was excruciatingly traumatic for me."* Joan was deeply disturbed by the pain her baby endured, and it appeared that a part of this trauma was ongoing. Yet, it was marked how she continued to grapple with these excruciating experiences at different times throughout the interviews by sharing the unsharable so candidly, suggesting her deep compassion for her child and herself.

Joan spoke of her experience of post-natal depression: *"I didn't really think I was helpable, I kept thinking, and I kept saying if you can fix my baby … that will help me, I'll be fine."* Furthermore, Joan recalled what one of Sarah's peers said recently: *"[F]ix your legs;*

you'd better fix your legs." The idea of fixing Sarah implies that something is broken. Through "abjectifying we strive urgently, helplessly, to recover our sense of conscious self and restore our symbolic capacities as human subjects" (Frances, 2014, p. 200). On the one hand, Joan is abjectifying: helplessly longing that Sarah can be fixed, and thereby implying that Sarah is broken, along with the ableist prejudice that goes with this assumption. On the other hand, Joan is expressing her own sense of being broken by the pain and depression of her and Sarah's experience. In this sense, Joan can only be fixed through her identification with Sarah. Only Sarah's wellbeing will resolve Joan's depression. A useful argument in this context is offered by Winnicott (1964, p. 88), who posits that "there is no such thing as a baby" – "If you set out to describe a baby, you will find that you are describing a *baby and someone*. A baby cannot exist alone, but is essentially part of a relationship" (Winnicott's emphasis). One could equally posit that there is no such thing as a mother. This formulation may go some way in understanding Joan's abjectifying identifications. Sarah's horror *is* Joan's horror and Joan's salvation from the trauma they share is in Sarah's hands.

To remain in touch with this is, at times at least, intolerable. Joan reflected in her interview on her early tendency to *"delegate"* Sarah's care to various care workers: *"I felt very inadequate at, like feeding her. Just normal things that moms would do."* Joan needed to continue to reject that which she found deeply disquieting (Kristeva, 1982): instead of sharing, Joan took flight. Kristeva (2010, pp. 257-258) reflects that "disability confronts the able-bodied person with the limits of life, with the fear of deficiency and physical or psychical death: disability therefore awakens a catastrophic anxiety that in turn leads to defensive reactions of rejection, indifference, or arrogance". Joan's delegation can be understood as a defensive evasion of her catastrophic anxiety. In contrast to the anxiety Kristeva describes, however, this was a maternal anxiety – rooted in a fear that she would

not be able to keep Sarah alive and that she could not care for her. This anxiety was not only about the limits of life per se, but about the limits of life in relation to a precious other. It is perhaps precisely this maternal relatedness that suggests the possibility of some resolution of the abject.

This anxiety is not, however, disconnected from broader social anxiety about disability. When Sarah was given a "diagnosis", Joan recollected her previous contact with disability:

> *… it brought back to me the specific memory I had as a child, of a spastic man in a chair on the back of a bakkie* [open van] *… Maybe it was a wheelchair, I don't have a clear memory, but he was strapped into the wheelchair with ropes, or perhaps string, but they had strapped him in, onto the back of the wheelchair, I mean the man must have been in his twenties, or at least an adult, not a child. And I have since discovered that he had athetoid spasticity. So the spasticity that he had was movements. He had movements like this uncontrollably … but that sight, that sight of that man in the chair on the back of a bakkie, as a child, was so upsetting and disturbing to me that it was a memory that never went. I was terrified, but terribly, terribly upset by that … when the therapist said to me …* [Sarah is] *spastic, spastic for me meant that. That's what it meant, I was terrified, and I thought that's what she was diagnosed as. So I was almost ill with anxiety, and trauma and fear and all those things*.

As a child Joan was overwhelmed with horror at the sight of a physically disabled adult, as she described it as *"horror stories from my past"* and then she gave birth to a disabled baby. Hence, that which she had pushed to the periphery of her being – her recognition of her own bodily fallibility – forcefully returned to her when Sarah was born, all

the more so since her child had once been a physical part of her. Thus, for a woman, having a disabled child "threatens one's *own and clean self"* (Kristeva, 1982, p. 65; Kristeva's emphasis). As above, however, Joan's anxiety as an observing child was transformed by her maternal subjectivity. Recalling her initial association to this memory, she implicitly distinguished between her formless terror *then* and her object-related anxiety in relation to her child. Joan's anxiety, trauma and fear were as much for Sarah as for herself. Furthermore, Joan shared this memory in her interview. She did not respond with "rejection, indifference, or arrogance" (Kristeva, 2010, p. 258). She wanted to share the unsharable in the hopes of taming some of the terrible anxiety she lived so close to. Perhaps maternal subjectivity offers a particular position from which to share the unsharable.

Joan's family members also seemed to connect with social anxieties about disability when Sarah was born. Joan described how unsupportive her family was at the time: *"[M]aybe they* [her family] *were so mortified, like horrified, they can't respond … they were too shocked and … maybe that was so bad that it's almost, they don't even know how to say shame, because it's more shame than shame, it's unspeakable, it's naturally unspeakable, unspeakably bad."* Asked for an explanation of their absence, Joan immediately imagined unspeakable horror and shame – something that could not be tolerated by her family and so had to be avoided. Whether or not this was the reason for her family's avoidance, her reading of their response suggested her pain of identifying with the horror of the other as well as her immense fear of how others may see her child, and the shame that she herself must face.

Joan's attempts at making sense of why Sarah was born with a disability suggested her acute sense of guilt. She blamed herself, since she felt she had "forced" conception through in vitro fertilization:

> *I wasn't supposed to have children, and I had pushed the envelope too far, and this* [her child's disability] *was the result … I obviously was not supposed to have children, my body was not up to it, and I was not … it was just not all meant to be, and it was my fault, because I had insisted on stretching the boundaries of human nature, and what human nature can do. I had created this aberration*.

Joan's fantasy that she had created an *"aberration"* – that she was responsible for abjection and that her body was to blame – poignantly highlighted her guilt and shame. Her feeling of "stretching the boundaries of human nature" represented a moment in the interview when she felt overpowered by her own abjection. Speaking of the guilt and shame mothers can feel, Kristeva (2010, p. 255) refers to the "culture of the 'perfect child', who is able to repair parental malaise". Perhaps it is this moment in the interview that Joan's pain and shame could be most clearly seen. In sharing the unsharable, she also had to share her own intolerable and unspeakable parts if there was to be any hope of understanding.

This section has considered Joan's narrative largely from the position of her maternal fantasies of herself and her daughter. In concluding the section, it is helpful to consider one of her fantasies that appeared to suggest something of how she has managed the abject:

> *I've had almost fantasy thoughts of* [Sarah] *being one hundred percent, so I've had a vision of her running, which she can't do efficiently. I've had a vision of how she would look if she just sort of moved in a more fluid way, it's almost, it's quite strange … this little fleeting, fantasy vision of the person that they're not*.

Her compassionate endeavour to identify with how difficult it can be to live in her daughter's body and how she wished it could be different was an attempt at furthering her selfhood. Joan also made an empathic connection with Sarah's body, moving through her

fantasy to come to terms with who Sarah is and giving up on her fantasy – now acknowledged as *"quite strange"* – of who she is not.

Continuing to Reach for Maternal Love: The Interview Encounter

Reflexivity is always an important part of qualitative research. Given the multiplicity of the relationship between disability and non-disability discussed in the introduction to this paper and the fact that Clare (referred to as "I" in this section) was a disabled mother interviewing non-disabled mothers of disabled children, the dynamics of disability came alive, sometimes painfully so, in the interview encounter. These dynamics have been extensively reflected on elsewhere (see Harvey, 2017a, 2017b, 2019), so only brief reflections are offered here, because they shed light on the dynamic of sharing the unsharable that is at the heart of this paper.

Neither Lara nor Joan knew of my disability until they met me in person. When I first met Lara, she did not seem outwardly surprised; indeed, she gave me a hug and warmly welcomed me into her home, even asking me to stay for lunch. I asked her at the end of our first interview how she had experienced talking to me, given that I am, like her daughter, physically different. She replied: *"[I]t is no different as I see your face and that is who you are."* Lara's comment could be heard as a denial of disability; conversely it may suggest, given her intimate experience with disability, that she could relate to me in my entirety. The feel of the interview suggested the latter. Lara was also very open in sharing her experiences. She remarked that she had felt comfortable talking to me, and I had a sense, as with other participants, that it was a relief to offload experiences seldom shared or understood by another.

I had a different experience with Joan, who constantly made reference to my disability, as well as to my mother's experience, throughout our interactions: *"[Y]ou see with*

your disability you probably, your parents knew, or could even just research whatever issues might lie ahead … but with me we didn't know […] *you see now in your case with your mother, she wouldn't have felt in any way responsible."* At times I felt uncomfortable with these types of comments; however, I also realised that Joan was trying to make her story relevant to me so as to ensure I understood her experience. Furthermore, Joan appeared to be looking to me for affirmation of, and empathy for, her experiences. Indeed, at various points in our engagement she asked how other mothers in my study had responded to having a disabled child.

Joan commented that telling me her story was *"perhaps easier because I know you've got some frame of reference to it"* and *"it is easier* [talking to me] *because, because you've gone through a lot of what I might be describing"*. Perhaps this perceived sense of shared experience is why Lara and Joan shared so generously and openly with me, because they felt understood.

At times, however, I found these experiences emotionally difficult to engage with (see also Harvey, 2017b). This paper has focused on moments in interviews when Lara and Joan faced the return of the abject – when they recalled themselves facing horror. Perhaps part of the process of writing this paper is about processing the impact of these moments on me, just as Lara and Joan seemed to use their interviews to "purify" the abject (Kristeva, 1982). Lara and Joan offered gut-wrenching descriptions of what their children had to endure, conveying a sense of the pain of their experience that was hard to stay in touch with. It was clear listening to the interviews and writing this paper that tolerating this intolerability is crucial to understanding maternal subjectivity. Moreover, Lara and (to a greater extent) Joan used powerfully evocative language to describe their children. Words like *"aberration"*, *"slithering"*, *"zombie"* and *"retarded blob"* articulate abjection in

disturbing ways. These moments raise discomfort in me too, that a mother can feel this abhorrence towards her baby. In these moments I am also painfully pushed into confronting my own rejected, deeply excruciating parts. I am left thinking of how my mother's own disgust was potentially re-evoked by me. Furthermore, I am reminded of my own challenging subjectivity-in-process as mother to my disabled child. Alongside these painful thoughts, I am struck by how extremely honest both Lara and Joan were with me, suggesting a helpful re-configuration of the abject in relation to their children and their selves. These disturbing words punctuated their narratives, but did not ultimately dominate them: instead, both Lara and Joan rubbed shoulders with the abject whilst dominantly maintaining their love for their children. They may not fully escape the abject, but their love survives.

Conclusion

This paper has explored the experiences of non-disabled mothers to disabled children and their encounters with abjection and beyond. We argue that an understanding of the different parts of maternal subjectivity, including those parts haunted by the abject, allows the possibility of a deeper understanding not only of maternal subjectivity, but also of disability. The paper has also aimed to value the voices of mothers grappling with their children's disability and with their own responses. Making space for these voices, so seldom heard, is enough in itself. But the abject is challenging to face. "Essentially different from 'uncanniness', more violent, too, abjection is elaborated through a failure to recognize its kin; nothing is familiar, not even the shadow of a memory" (Kristeva, 1982, p. 5). It is precisely the propensity for violence that justifies the importance of examining the abject.

While this paper has explored moments where mothers were haunted by abjection, it has also explored how mothers resisted the failure to recognise that comes with abjection

and how they leaned towards the familiarity of their children and towards their maternal empathy. We have suggested that mothers attempt to purify the abject by naming it, rejecting their avoidance by facing the reality of their children's lives and demonstrating the power of their empathic concern to confront the powers of horror. In this sense, mothers tolerate the intolerable, face the unthinkable and endeavour to share the unsharable. Furthermore, they name their limits in relation to their children. They demonstrate the power of finding our limits:

> Finding our limits gives us the ability to share those of the disabled subject, failings and flashes of brilliance alike, in the full sense of the word 'share', which is not fusion, osmosis, or identification. To share: to take part in a distinctiveness beyond the separation imposed on us by our fates; to participate, without erasing the fact that each is 'apart' and recognizing the part that cannot be shared, that is irremediable. (Kristeva, 2010, p. 265)

The mothers' process of tolerating the abjectionable and to share the unsharable is important to trace, as Kristeva suggests, precisely because sharing the unsharable offers a political position beyond the discrimination of the present.

We suggest that mothers did not only share, however. The focus of our paper has not only been on the abject, but also on its coexistence with maternal love. Mothers offer a model based on lived experience for the confrontation of the abject, of a grappling that can lead to a deep appreciation of the singularity and the entirety of both mother and child. In the face of enduring prejudice towards and even hatred of disability, this model may be of service not only to mothers, but also to others (including clinicians). It offers a model of how to share the unsharable, of how to confront repulsion, of resistance to avoidance, rejection, indifference or arrogance. It also offers a model of an empathic encounter with abjection:

able to confront hate but not enact it, indeed to transform hate. In a hate-filled world, this undertaking is precious indeed. If there is no such thing as a mother (just as “there is no such thing as a baby” (Winnicott, 1964, p. 88), then a mother is in a unique position to understand – and simultaneously never understand – disability in her child, and therefore disability in general. Mothers in this study actively digested their experiences, both good and difficult, palatable and distinctly unpalatable, and actively drew upon maternal empathy to connect with their children through all of the disconnectedness. It is hoped this paper will assist us all to resist the strong pull to collude with society’s tendencies to disavow vulnerability and disability, and to thereby dissolve the unnecessary dichotomies between disabled and non-disabled people. If we can do that, disability will be registered as a subject position.

Chapter Eight:

Discussion and Conclusion

Introduction

This study's initial aim was to explore in-depth the subjective experiences of mothers of children with a visible physical disability, including the internal meaning they make of having a child with a disability; what their intrapsychic resonances of this mothering experience entail, as well as how they make sense of their self as a person and as a mother. The study was thus mainly designed to contribute to the limited psychoanalytic research on mothering a visibly physically disabled child. Mothers were invited to engage in interviews about their experiences, thoughts, and feelings. The intention was to centre disabled people in the research by accessing perspectives from mothers themselves – those closest to their disabled children. Thus, another aim was to add to psychologically focused disability literature on disabled people's experiences.

A second focus soon became apparent, and this arose from the manner in which the mothers engaged with me. The actual *process* of answering the questions around maternal subjectivity in the face of mothering a child with a visible physical disability then became the second aim of the study: what are the implications of researching the maternal subjectivity of mothers raising disabled children?

This chapter is comprised of two intimately related sections: a discussion of my conclusions on the findings on the maternal subjectivity of mothers whose children are disabled, and reflections on the process and experience of researching maternal subjectivity in the face of disability, from a psychoanalytic and intersubjective angle. The politics of representation is important to this study. I approached mothers as subjects in their own

rights, and not as background objects to their children's development in line with the recommendations by Baraitser (2009a) and A. Stone (2014). I implemented an ethical approach to disability studies by giving a voice and autonomy to those in the realm of disability, in the case of this study, mothers, those closest to their disabled children, as Fernandes and Robertson (2019) suggest. Hence, although this chapter is not intended to provide a comprehensive description of the data discovered in the study, some of the participants' comments are again purposefully included verbatim to resist and overcome the traditional domination of the disabled by (usually non-disabled) researchers (Shakespeare, 1996).

The study has explored the everyday experiences of motherhood in the area of disability, as well as some of the complex, usually more inhibited, deeply painful emotional aspects of this experience. The lived reality for the mothers in the study involves great maternal ambivalence, in many forms, including their experiences of the uncanny and the abject. The implications of these experiences for maternal subjectivity when mothers' children are disabled are considered below.

Maternal Subjectivity in the Face of Disability

Maternal subjectivity is one self-position experienced by women who are also mothers. Subjectivity is a sense of self that continues to develop throughout life, something Kristeva (1980) termed subjectivity-in-process. Various relational positions contribute to subjectivity, and certain occurrences and social interactions can cause this sense of self to feel disturbed to various degrees – giving birth can be one such event for women. Before, during and after this event, women are often defined in relation to their babies, both by themselves and others, reminding them of their own processes of separation from, and dependence upon their original maternal object. Thus, the birth of a baby is a time of a

great psychic shift as women work towards re-creating who they are. Baraitser (2006, p. 22) goes so far as to describe maternity as "an experience … that unravels, as it proceeds". Maternity includes attempts at reconciling the fantasy-mother with the actual mother, a process that occurs to different degrees for each woman.

This reconciliation is particularly complex for mothers whose babies do not match social ideals. Kruger (2014, p. 473) describes the "loss of a longed-for positive maternal identity" in relation to a mother with an "acting-out child", a scenario that could also be ascribed to mothers with children with unexpected features, including a visible physical disability. As Sinason (2001, p. 2) points out, "there is no country in the world where parents long for a handicapped[13] baby". Mothers can be left feeling disappointed because their children do not allow them to be the mothers they had expected to be and hoped to be (Kruger, 2014; Raphael-Leff, 2010). Children with a disability challenge women's omnipotent views of reproduction (Sinason, 2001). In addition, other people's responses to their children in particular and to disability in general may leave such mothers feeling overwhelmed.

Importantly, the focus in this study on these difficult aspects of motherhood is not intended to ascribe blame to the mother, baby, mother-baby dyad, or disability. Instead, the discussion intends to explore what the mothers in the study related, while acknowledging that the language they used to describe this maternal experience was at times graphic and uninhibited, and sometimes contradicts the more politically correct language of the social model of disability (M. Oliver, 1990).

[13] Sinason uses the term "handicapped" here to denote "disability". Scholars in disability studies consider the term outdated because of its negative connotations. The term is often experienced as discriminatory because it "derives from 'cap in hand', implying that disabled people are expected to beg favours of the able" (Jones, 2001, p. 378). The most recent WHO (2001) classification has replaced "handicapped" with the concept of environmental factors, including societal attitudes that create barriers for disabled people to integrate fully in society (Jones, 2001).

Encountering disability in another can disturb subjectivity. When non-disabled people meet a disabled person, they often respond ambivalently (Watermeyer, 2013). Disability has been described as posing a threat to the psyche, since disabled people prominently act as prominent mirrors to the most painful aspects of what it means to be human – dependence, vulnerability, interdependence and fallibility (Kristeva, 2010; Marks, 1999b; Michalko, 2002). Given this anxiety-provoking scenario, encountering disability is often managed by falling back on psychic defence mechanisms (Harvey, 2015b; Marks, 1999b).

Consequently, when women are met with both of these situations – becoming a mother and encountering disability so intimately in their babies – their sense of self can feel greatly challenged. Maternal management of conscious and unconscious emotional discomfort in response to disability, specifically their children's disability, forms a central thread to this thesis. Such discomfort is felt both in the participants' own personal responses to their children and because of other people's reactions to their disabled children.

The mothers in this study shared graphic accounts of their dark, murky experiences of motherhood and disability, something which is difficult to digest – yet this is what the mothers brought. These aspects are intellectually and emotionally challenging to think and write about. The mothers also brought their lighter, loving experiences of motherhood. Articulating this balance so that an accurate portrayal of this motherhood can be communicated is a central aim of the thesis. These portrayals have highlighted the stark opposition between politically correct views of disability and the affective experience of disability.

The dominant contemporary understanding of disability that is currently politically correct is derived from the social model of disability, which argues for disability to be perceived as external to the person who has the impairment (Barnes & Mercer, 2005). The person is only disabled because of the ableist ways of society: most notably in exclusion, inaccessibility, inequity and discrimination (Flynn, 2016; Shakespeare, 1994). Essentially, society's ableist responses to the mothers and their children would be argued to "make" the mothers' children disabled, not the children's bodily impairment itself. Such a definition helps those to defend against the more difficult emotional experiences related to disability. By contrast, an embodied outlook on disability situates disability primarily in the body and acknowledges that a disabled person experiences complex disability-related emotions because of this embodiment, as well as because of how others respond to them (Garland-Thomson, 2005; Sherry 2006). Thus, an embodied perspective on disability includes a disabled person's personal distress at being disabled.

It is somewhere between these two contraries that the true maternal experience seems to occur. Notably, the mothers in this study illustrated various, creative ways of managing these deep psychical challenges. Accordingly, they revealed that a relationship with their children has developed that is often constituted with dark love. At the same time, these women continue to develop their subjectivities.

The paradox of the disability field – negotiating the space between the social, politically correct model and the complex, often uninhibited, affective responses to disability – is mimicked in the mothers' ambivalent accounts of mothering in the face of disability in their children. The complexity of maternal affect finds expression in experiences of the uncanny and the abject – notions that are separate, yet overlap. The abject is a deeply internal response to the horror mothers see in their children's disability, and at the

same time in the return of their own early rejected repulsive parts, when they encounter disability in their babies. Shame and guilt accompany this experience, since aspects mothers had once disavowed return in the form of their children, leaving mothers greatly disturbed and ambivalent. Moreover, a sense of the uncanny is elicited through the eyes of the other, causing the external to become internal. Such an experience causes mothers to perceive something deeply familiar to them (their children) as unfamiliar because of the other's strange response to them. The process of the uncanny also involves a return of the sense of the self in the unfamiliar. Both the abject and the uncanny relate to that which provokes horror and fascination, threatening to undermine subjectivity. The overlaps between the uncanny and the abject which the mothers experience in relation to their disabled children are nuanced in the expression of their maternal ambivalence. Such contradiction and ambivalence are apparent through this discussion too. It is difficult to reconcile the mothers' need to face the unpalatableness of disability and express this, as well as their need to hold onto the positives of this experience and their love for their children; and yet, these two aspects co-exist.

Maternal Discomfort When Babies are Disabled

Motherhood in a non-disabled realm has been researched from various angles using the psychoanalytic paradigm, and it is generally known how women initially become greatly preoccupied with their infants (e.g., R. Parker, 1996, 2001; Raphael-Leff, 1986, 2000, 2010; Winnicott, 1953, 1956/2012, 1960). This primary maternal preoccupation gradually wanes over time, so that both the baby and the mother can continue to develop their own subjectivities (Winnicott, 1956/2012). However, the literature has not yet extensively covered how, to varying degrees, all new mothers are re-confronted with denied aspects of their selves in parts of their babies.

This confrontation implies that women have to reincorporate awareness of these aspects into their subjectivities. This psychic work is particularly taxing, since what needs to be incorporated is aspects of the abject: that which is generally disavowed about humanness (Kristeva, 1982). Layton (2009a, p. 2) describes the formation of the self as including the "repudiation of otherness", and Sullivan (2013) refers to these abjected states as "not-me". Taking care of all types of babies requires encountering bodily parts and primitive forms of life expression, but in physically disabled children that which is experienced as abject is often much more strikingly evident and present for longer. Arguably, mothers re-encounter a heightened sense of their own abject because of the presence of that which is generally disavowed in their babies. Consequently, the mothers in this study have been found to be almost unravelling in moments of mothering their children, when the disgust and horror they had once repelled so as to integrate their subjectivities came flooding back in the form of their disabled babies – their abject objects (Kristeva, 1982). Birksted-Breen's (2000, p. 22) claim regarding (non-disabled) maternal fears about giving birth to a "monster" was indeed found to be the perceived reality for some of these mothers. However, I have also reported on how these mothers do not have the "luxury" of escaping their abject by keeping it at the periphery of their self, because their "abject" babies remain very much part of their lives. I recorded maternal displays of immense warmth, love and compassion for their disabled children, since I argue that these mothers can be understood to continue to process and "purify" the abject in some form, allowing room to hold the various psychic aspects of their children and of themselves. Hence, a visibly physically disabled child causes mothers once again to face their frightening, vulnerable parts. Thus, their children are experienced as alien (suggesting a link to the uncanny), but, also positively, as familiar, allowing for possibilities for maternal love.

When the mothers in the study gave birth to their children, they were confronted by their own already-developed reactions to disability, as well as other people's responses to their disabled children. Cultural responses to disability can momentarily further unravel mothers' subjectivities. I have used the concept of the uncanny (Freud, 1919) to understand maternal reactions to other people's responses to their disabled children. The sense of the unfamiliar that a disability in their children can evoke, for the mothers and for those around them, was described most explicitly by the participating mothers whose children have achondroplasia. According to Ablon (1990), achondroplasia defies categorisation because of the marked disproportional presentation of this disability. Other people's responses to their children as that which feels uncanny initiates a process in which mothers also identify with this sense of unfamiliarity within their own children. Subsequently, their own sense of self begins to feel threatened.

According to Sinason (2001), trauma is initially felt from outside of the self, suggesting a process of projective identification when others feel traumatised when encountering a disabled person. Arguably, this initial, externally based sense of trauma can also be applied to mothers of disabled children. Yet, this sense of trauma is simultaneously felt internally, in the form of the return of the abject. Hence, Sinason (2010a, pp. 78-79) describes disability as incorporating "external traumatic facts of life with enormous internal and external repercussions".

Mothers can experience feeling that their children are different to them because of disability as alienating, leaving the mothers feeling immensely sad. Green (2002), as a non-disabled mother, expresses such sadness and exclusion, because she feels she is on the outside looking in on her disabled daughter's life, sensing that her daughter's experiences are foreign to what Green knows, because of the disability. Thus, mothers of disabled

children are in a peculiarly marginalised position, because they function as non-disabled people within a disability realm (Ryan & Runswick-Cole, 2008). The common process of maternal identification and dis-identification with their babies (Raphael-Leff, 2010) is thus complicated when women's children are born disabled, since the process is heightened with loss, specifically of the idealised object (the non-disabled baby) (Harvey, 2015a). Thus, a process of mourning ensues; however, this is a complicated bereavement because the object of loss remains present – in their children (Bruce & Schulz, 2002; Green, 2002). Additionally, mothers can feel disappointed and angry because of this unexpected child/disability (P. S. Miller, 2006).

Nevertheless, the mothers in the study manage these emotionally traumatic social interactions, in which their children are experienced as uncanny. They protect themselves, their children, and their maternal love, allowing their subjectivities to continue to develop. A display of loving identifications with their children was apparent. Joan illustrated a gentle moment of empathic identification with what it might feel like to be in her child's body: *"I've had a vision of how she would look if she just sort of moved in a more fluid way, it's almost, it's quite strange … this little fleeting, fantasy vision of the person that they're not."* Prior studies have not highlighted such displays of deep identification. Some of the literature reports on the everyday aspects of raising a child with a disability and what emotional and practical impact this has on a mother, without addressing the in-depth feelings mothers hold for their children and the disability (e.g., Sadat Nurullah, 2013). Other studies have shared maternal experiences and feelings about raising disabled children, but have argued that these experiences are predominantly negative (e.g., Green, 2002).

Thus, when women give birth to disabled children they endure multifaceted threats to their psyches, primarily because they are re-confronted with the abject, as well as an

impression of the uncanny. Consequently, mothers are left with a myriad of emotions that make up their distinct subjectivities.

The Affective Complexity of Subjectivity in Mothers of Disabled Children

In the thesis, I argue that with the birth of their disabled children, mothers are forced to re-confront their preconceived uncomfortable feelings about disability, something they have introjected from society's deficit view of disability (Susman, 1994). In this regard, Layton (2009b) claims that all people have "dutifully shaped their subjectivities in accord with dominant norms" (p. 107).

Cultural perceptions of disability are strongly linked to the notion of the abject because disability is kept at the periphery of society: disabled people are treated as the "unwanted minority" (Sinason, 2010, p. 76). Garland-Thomson (2005) describes one of the dominant narratives of disability as that of abjection: disability must be avoided at all costs. Pre-formed negative and shameful perceptions of disability have a strong impact on how women relate to their disabled children. In this regard, Janet shared a memory from her past: *"[I]f you don't have a* [disabled] *kid in your family you didn't really interact with anyone else* [other families with disability] *as people really … they hid their* [disabled] *children away, especially children with a mental disability."* Becky also recalled how she *"used to be very afraid* [of disabled people] *… I'll feel sorry for them and … when you see either a special needs child or an adult then you're like ag shame"*. Evidently, mothers introject a common experience of pity for disabled people, a sentimental narrative which dominates society's understanding of difference (Garland-Thomson, 2005; Goodley, 2011a). Joan's childhood memory of an adult man strapped to the back of an open vehicle (also see Chapter Seven) is a poignant example of how women's perceptions of disability affect their mothering experience, eliciting great emotional distress in relation to having disabled children:

> *… that sight of that man in the chair on the back of a bakkie* [open van]*, as a child, was so upsetting and disturbing to me that it was a memory that never went. I was terrified, but terribly, terribly upset by that … when the therapist said to me …* [her daughter is] *spastic, spastic for me meant that. That's what it meant, I was terrified, and I thought that's what she was diagnosed as. So I was almost ill with anxiety, and trauma and fear and all those things*.

Arguably such prior introjections cause mothers to experience a sense of shame and guilt that they had once thought of disability (and now their children) in such a horrifying light.

The women's prior traumatic memories of disability contributed to a sense of trauma when their children were diagnosed with a disability. Green (2002) described a diagnosis of disability in a child as igniting a unique sense of loss of the mother's imagined child, and arguably of herself as a mother too. However, much of the literature denies this traumatic experience, suggesting that a disability diagnosis can be a positive experience for mothers (e.g., Ryan & Runswick-Cole, 2008). In some of the literature, parents seeking a diagnosis for their children have been criticised as pathologising their children, as well as disability, because "diagnosing" intimates at a medical model approach to disability (Ryan & Runswick-Cole, 2008). However, the quest for a diagnosis can be understood in the context of medical practices in which mothers find some acceptance in their role while they try move away from society's tendency to blame them for their children's physicality (Read, 2000). Even so, mothers who have sought a diagnosis have been accused of serving their own interests over their children's (Avdi, Griffin, & Brough 2000). This debate in the literature speaks to the double-bind in which these mothers find themselves (Watermeyer & McKenzie, 2014). The predicaments of this form of motherhood need to be

acknowledged, without disempowering or pathologising mothers and disability, as the opposite of denying genuine maternal feelings and experiences would be harmful. From a political stance, embracing a disability diagnosis can be understood as a form of parent advocacy (Ryan & Runswick-Cole, 2008), a vastly different viewpoint to the mothers in the current study who shared traumatic affective responses to receiving a diagnosis for their children. Thus, mothers are constantly negotiating the complexities of an ableist society's response to disability in their children, as well as what such a diagnosis means for their own sense of self.

Once women have children who belong to a disavowed group in society, they must tolerate society's ongoing projections of the denied aspects of disability. They need to manage other people's discomfort at the sight of their disabled children, in turn leaving them with feelings of shame and guilt about having produced these "other" children. Maternal experiences of disablism and rejection emanating from the stigmatisation of their disabled children has previously been discussed in the literature (Ryan & Runswick-Cole, 2008; Sadat Nurullah, 2013). The discussion of how the mothers in this study cope with such marginalisation enhances an understanding of these disabling experiences. Mothers need to negotiate their sense of self in the realm of disability into which they are suddenly thrust. Evidently, mothers work hard to integrate the difficult emotional aspects, as well as those parts they are confronted with in their children because of these social encounters.

Focusing on other aspects of their children facilitates maternal love and pride. Jessica's story about how her family-in-laws responded to the news that her baby has a disability illustrates how mothers fall back on the defences of avoidance and denial to be able to focus on what is "perfect", not disabled, in their children: *"He had ten fingers and ten toes. I mean completely, little beautiful little boy."* Jessica also isolated herself from the

family in order to focus on her maternal love, and thus be able to uphold her sense of self: *"[U]ntil you* [her family-in-laws] *can find a place in your life where you can start respecting him for who he is, then we* [she and her husband] *are going to only associate ourselves with people that can accept him for who is, and accept us as his parents for who we are and respect us by how we are going to raise him."* Hence, mothers are challenged to accept their children and their selves, and to share this acceptance with those around them. This maternal challenge is also apparent in the literature, suggesting pressure to present socially as accepting of their children's disability, as well as to advocate for others to accept their children, and their disability (Kittay, 1999).

Arguably, mothers do not merely "introject others' projections regarding the more unpalatable aspects of disability" (Harvey, 2015a, p. 97). They also manage these interactions and the associated sense of shame and guilt by returning other people's feelings. Hence, there is an intersubjective aspect to this maternal experience. This process of projection is particularly evident when mothers try to protect their children, themselves, and disability generally, by retaliating in social interactions. Chloe was seen to shout at others: "*Go and look in the mirror!"* She called these people, whom she experienced as being derogatory to her child, *"freaks"* in the interview. Sandra also recalled insulting others: *"I see your one little girl has … many freckles, it looks ridiculous."* Joan shared how she stares at others as a form of revenge in hostile social situations: *"… sometimes I stare someone out. Like if they stare* [at her disabled child]*, I stare at them … I stare at them back. Not aggressively, but I'll just keep … I suppose it's just a form of retaliation, or just to show the person that it's not necessary to stare, you shouldn't stare."* Thus, these mothers of disabled children do not always "allow" others to treat them as "dustbins of disavowal" (Shakespeare, 1994, p. 287) or as projection objects (Goodley, 2011b). Moreover, they do

not become immobilised with a sense of powerlessness because of their children's disability (Burkhalter, 2010). Thus, the thesis enhances understanding of how disabled people (and those in their immediate proximity, including their mothers) manage other people's disability-related projections (Marks, 1999b; Shakespeare, 1997, 2000; C. Thomas, 2007). The maternal ability of the participants to name and make some sense of their behaviours and feelings in such instances suggests a fair level of working through of the more unpalatable aspects of disability, of their children, and of their motherhood. It demonstrates that a greater cohesive sense of self can develop.

The thesis has applied an uncanny lens in order to understand others' responses to, and encounters with, mothers and their disabled children, providing an additional perspective to the idea that "mothers manage the emotions of others" (Baraitser, 2009b, p. 10). Mothers of disabled children are not only confronted with their own, often overwhelming, feelings, as well as their children's (Raphael-Leff, 2010), as is the case with all types of mothers: arguably they are also flooded by others' affective responses to their children and disability. According to Marks (1999b), the experience of psychoemotional disablism arises when disabled people (and those close to them) are bombarded by non-disabled people's split-off feelings towards disability. Couser (2005) points out that disabled people are often expected to account for their disability to ease non-disabled people's discomfort – these are "the social burdens of disability" (p. 604), since disabled people are inspected and interrogated. Thus, disabled people, and in the case of this discussion, their mothers too, are "permanently stunned into its [disability's] own recognition as a consequence of the disablism which permeates everyday life" (Paterson & Hughes, 1999, p. 608). Arguably, fear and disgust are felt to brutally and predominantly mediate relations between disabled and non-disabled people, and specifically between mothers of physically

disabled children and those they encounter. This point differs from claims in the literature that pity and shame are the dominant mediators between disabled people and non-disabled society (Goodley, 2011b). Hence, mothers experience alienation, as they feel, and indeed are, cast out from society because of disability in their children.

The above two central facets of maternal subjectivity in the face of disability – making sense of previously introjected deficit perceptions of disability and digesting other people's projections of disability – bring about a very particular, amplified form of ambivalence, involving immense, yet uncomfortable, maternal love. Expected maternal ambivalence has been addressed in the literature in relation to non-disabled mother-child dyads (e.g., R. Parker, 1996; Pines, 1997; Raphael-Leff, 2010; Winnicott, 1949). This topic is far less prevalent in the realm of disability literature. Raphael-Leff (2000) and Welldon (1988) discuss the potentially grave ramifications when ambivalence is denied in non-disabled mother-child dyads, particularly where this includes intense anger that can escalate into mothers' wishing to harm their babies. Highlighting the more difficult facets of this maternal subjectivity by discussing the often amplified ambivalence in mothers of disabled children should not be read as pathologising these women. I maintain that it is imperative to attend to all the aspects which the mothers of the study shared with me, including the emotional experiences of having a disabled children which are more difficult to hear and even unpalatable. Consequently, maternal ambivalence is acknowledged and accepted as an experience that occurs in all mothers (R. Parker, 1996), but may take different forms because of different particularities in mothers and/or their children. Hence, maternal ambivalence is also highlighted as an expected and acceptable aspect of mothering in the face of disability. It is hoped that women can be given space to accept their own ambivalence, allowing them to continue to develop their subjectivities, and letting them

continue to mother their children in meaningful ways.

Disability in children can evoke a sense of unfamiliarity for non-disabled mothers, amplifying maternal ambivalence. The mothers expressed ambivalence at various points in their stories. An excerpt from one interview with Patsy illustrates contradictory maternal emotions, intricately bound up with the experience of having a child who is disabled:

> *I'm not saying it* [her child's cerebral palsy] *wasn't hard, and I'm not saying that I don't still wish that it never happened, I'd be lying to you. I really would be, but it is what it is and she* [her daughter] *is who she is and I tell you what, I wouldn't take it back for a second, not any of the experiences I've had with her, not any of it*.

The incongruity in her wish that her child did not have a disability, yet if given the option she would not change things, speaks directly to the emotional ambiguities that the mothers hold regarding their children, but more specifically, for their children's disability. And yet, the disability is so much a part of their children, leading to greater emotional incongruity. Landsman's (2003) claim that mothers of children with disabilities voice great ambivalence around wishing to eradicate their children's disability was supported by the findings in the current study. Disability in children is not straightforward for their mothers: "[A] mother stands at the centre of a great paradox, saying to her child both: 'I love you as you are' and 'I would do anything to change you'" (Landsman, 2003, p. 1949). An experience involving maternal feelings of love and disquiet is apparent (Landsman, 2003). Furthermore, Landsman's (2003) finding that mothers wish to eradicate the various social experiences and prejudice their children's disabilities bring is indeed a prominent maternal aspect in the experiences of the mothers in my study. Specifically, these mothers seem to wish for different social encounters – this speaks directly to the social model of disability, in which disability becomes a difficult experience because of the responses from the social

environment (Finkelstein, 1981).

The above comment by Patsy is also suggestive of the deep loyalty and admiration mothers hold for their children. Indeed, the mothers in the study express a vast range of emotions that seem to combine to create a very particular maternal ambivalence. This ambivalence is not a negative, unintegrated state; instead, these mothers revealed their ability to feel and hold very contradictory maternal experiences which enable them to love their children deeply. Fernandes and Robertson (2019, p. 48) advocate for maternal ambivalence in mothers of disabled children to be acknowledged as part of their maternal space, and acknowledging that "to speak of ambivalence towards a child with a disability, well, there is a different set of rules for that". Society's discomfort with mothers' feeling hate and other difficult feelings for their disabled children is sometimes palpable.

The mothers in this study do not seem to entertain as much shame and self-blame as findings discussed in the literature suggest they might (e.g., Sadat Nurullah, 2013). The great sense of loss and grief for their fantasised baby described by researchers such as Bruce and Schulz (2002) or Green (2002) was not so pronounced or chronic in these mothers. They also displayed a far more diluted sense of the maternal feelings of unfairness and anger for their unexpected babies posited by Ryan and Runswick-Cole (2008). Nevertheless, it seemed that a sense of pronounced shame and guilt was initially pertinent when their babies were born. Thus, the argument that "the *early* experiences of mothering a child with a disability may be that much more psychologically complex as they raise feelings of inadequacy, promoting an experience of ambivalence towards one's baby, one's self, one's partner, and society" is supported (Harvey, 2015a, p. 97, my emphasis). These maternal feelings were processed and diluted over time. Certainly, the more difficult feelings of anger and sadness eased and became more tolerable as time progressed and as the women made some sense of them in

relation to themselves, disability, and their children. In this regard, Burkhalter (2010) discusses the initial experiential hue to this parenting experience and how it is only with time that some sense of one's feelings be made. Sinason (2010) also describes the initial sense of feeling overwhelmed because of the very tangible issues of being human which one is confronted with in the face of disability (including difference, loss, and dependency).

Part of the growth that the mothers in the study illustrate involves re-envisaging their fantasies of what types of mothers they are and what types of children they now have – something all types of mothers have been described to do: it is a process of integrating both the loving and hateful parts so that both mother and baby can develop (Baraitser, 2006; Kraemer, 1996; Winnicott, 1949). This growth seems amplified in mothers with disabled children. Given the disability, the more difficult aspects of their children and motherhood are highlighted, in turn placing great emphasis on an undesired sense of hate. However, to counteract this hate, the mothers in this study also emphasised the pleasurable aspects of this experience. I would argue that a far greater cohesive sense of self was apparent in these mothers of disabled children than that which is intimated at in the literature (e.g., Bosteels et al., 2012). A sense of loss seemed to be balanced with what the mothers gained in having their children, and the positive attributes they identify in them. For example, Kirsty described her son as having an *"amazing strong spirit; he has bounced back from the operations* [for his cleft lip and palate]*"*. Such positive discourse is common in the literature on disabled experiences, and more specifically in the literature regarding mothers of disabled children: "[W]e [mothers] are expected to actively embrace our caring role and responsibilities as a blessing, for the only other position available is that of burden" (Fernandes & Robertson, 2019, p. 42).

This thesis thus argues for a both/and approach to understanding this maternal experience in the face of disability: it is a maternal position involving loss and inspiration, hate and love, joy and heartache. Thus, maternal ambivalence is accounted for, entailing both the mothers' subjective and objective realities (Watermeyer & McKenzie, 2014). Furthermore, the contradictions of the disability field are allowed: the external, material reality of others' responses to the mothers and to their disabled children, as well as the mothers' own feelings for their children and for themselves.

However, ongoing social interactions and various encounters with others can cause mothers to re-experience these difficult feelings, suggesting the need for an enduring, unasked-for commitment to re-processing and re-assimilating these emotions. Paradoxically, the interviews with me – a disabled person – became such encounters for the participants, a topic that I discuss in the second part of this chapter. Mothers have to continually engage with unwelcome social encounters, requiring great psychic work to uphold their sense of self and continue to love their children.

These repeated demanding experiences can be helpfully understood from an intrapsychic (psychoanalytic) *and* interpersonal (social) understanding of disability, together with a critical disability studies' perspective (Goodley, 2011a; Saville Young & Berry, 2016; Shakespeare, 2006; Watermeyer & Swartz, 2008). Psychoanalytic theory is a powerful tool to connect societal discriminatory responses of disability with the lived psychological accounts of disabled people (Goodley, 2011b; Watermeyer, 2012). This multi-lensed approach "enables us to hold onto the complexity and locatedness of maternal subjectivity for mothers of children with disabilities" (Saville Young & Berry, 2016, p. 1). This offers a way to avoid the harmful dichotomous approach (external versus emotional) to understanding motherhood in the face of disability.

Societal responses to disability prompt mothers of disabled children to activate certain psychoanalytic defence mechanisms so that they can continue to function effectively and to mother their children. Consequently, a more balanced view of their selves and their children develops. Healthily activating "unhealthy" defences is a specificity of this particular maternal subjectivity, including engaging in part-object relating, minimisation, projection, avoidance, and denial. The findings of my study confirm the suggestion in the (limited prior) literature that mothers of children with a disability do not always see their children in their entirety because of the great (medical, familial and social) focus on their children's disability (e.g., Bosteels et al., 2012). Initially in the mothers who participated in my study, a medical model focus on disability was often apparent as a backdrop to wrestling with their sense of maternal self in relation to having a baby with a disability (confirming the argument of Fisher & Goodley, 2007). This is a biomedical narrative of disability in which human variations are perceived as physiological flaws that require medical intervention (Garland-Thomson, 2005). Patsy recalled this early, deficit-focused stage: [She and her husband] *"went very quickly into rehab mode for her* [disabled daughter]*."*

These mothers seemed to display a sense of initially feeling overwhelmed when their babies were born with a disability. Several researchers have previously written about mothers' feeling engulfed by emotions, and even traumatised, as part of this experience (e.g., Burkhalter, 2010; Green, 2002; Ryan & Runswick-Cole, 2008; Sinason, 2004). This initial sense of engulfment can take various forms, including a need to delegate their babies' care. Trauma emanating from repeated disability-related operations often forms a central feature of this early mothering experience. Kirsty described the various operations that her son had to undergo for his cleft lip and palate, adding: *"[F]irst we had to cope with the trauma on our side"*. Joan described her child's operations as *"like a horror movie truly"*.

Mothers whose children did not require operations also used the word *"trauma"* when they recalled their early mothering experience of their disabled children.

Sinason (2010a, p. 76) describes how "being close to the experience of disability is being close to the deepest internal and external terror of annihilation" because people purportedly only wish to, and are expected to, have a "healthy" baby. However, over time these situations are seen to change, as mothers create more psychic space to process what it means for them to be a mother of and mother their children with a disability. Consequently, mothers rely less on the need to split, minimise, and avoid, although they can fall back on these defensive ways of relating in times of great anxiety and angst throughout their motherhood. Thus, this discussion furthers Burkhalter's (2010) claim that disability in children leaves mothers with little psychic space, and hence emotional availability for their children. Indeed, as their children develop, mothers may report personal development, as they find enhanced meaning in their mothering role (Beresford, 1994; Green, 2002; Todd & Shearn, 1996). However, the literature also reports maternal stress, anxiety and the personal cost to reach this point (Read, 2000). Nonetheless, despite these difficult initial experiences, the mothers in my study adapted and displayed mostly integrated, cohesive ego functioning: maternal growth that is also intimated at in the literature (e.g., Green, 2001; Landsman, 1998; S. Ryan, 2005). Ongoing development in maternal subjectivity facilitates effective maternal care for their children.

"Disability pride" entails an introjection of the more enabling aspects of disability (Goodley, 2011a). A reparative, compensatory defence (Bosteels et al., 2012) was apparent in the mothers in this study, who attempted to highlight the positive experiences with their children, and to manage the intense emotions of this motherhood. This strategy is apparent in Patsy's description of her daughter as *"the most precious human being that ever lived"*.

Kirsty also expressed such pride of her son, who she said has *"been blessed with a very fiery, happy personality, very bubbly"*. Janet described her child as *"a very happy kid"*. Consequently, the mothers can love and care for their children and continue to integrate their subjectivities.

The mothers' attempts to "purify" the abject (Kristeva, 1982) which they are re-confronted with in their disabled children, and consequently in themselves, is another defence mechanism. They used painfully evocative descriptions to name that which they found distasteful in their children and themselves, allowing appreciation on how these mothers' subjectivities are upheld in the face of having children with a disability. Such descriptions were most prominent in Joan's story – she used terms such as *"aberration"* and *"retarded blob"* and pointed out that having a disabled child *"can be very, very sinister"*. It was striking how honest the women were in their interviews, indicative of effective management of the abject that they initially saw in their children and, consequently again in their selves again. Joan's description of *"how unbearable her* [daughter's] *baby years were"* suggests that she has moved from her initial impression of her child as eliciting the abject, to a more coherent experience of her child, of disability, and of her self.

The mothers in the study also attempted to "purify" the abject and other intense mothering emotions by identifying the disavowed in me. Their very distinct interactions with me can be understood as another form of maternal psychic defence in the face of disability, and thus another facet of their subjectivities. Their various "uses" of me demanded that I continually engage with what it means to conduct research with mothers on the topic of disability, particularly as a disabled researcher, and also with how to manage the process in the most beneficial way for all involved.

Researching Maternal Subjectivity in the Face of Disability

The aim of accessing a detailed experiential understanding of the participants' sense of self as mothers to their children with a disability required a particular methodological approach. According to Hollway (2016) and Kristeva (2005), the psychic aspects of the mothering experience are difficult to access through language, because much of this experience is beyond conscious awareness. To access the conscious and preconscious depth of subjectivity of mothers, an interview approach using psychoanalytic concepts was designed.

Beyond the painful, disavowed feelings that these mothers are re-confronted with while mothering a child with a disability, they appeared to be greatly challenged by my presence during the interviews. Their subjectivities seemed threatened by my disability. Thus, I continually needed to engage with the process of conducting this study. Essentially, I needed to respond to the mothers in ways that facilitated their psychic functioning as individuals and as mothers, avoiding a re-enactment of their early maternal trauma because of my disabled presence. Managing these encounters facilitated greater space for the mothers to share their stories for the sake of the research.

Allowing the participants to engage with me and my disability in particular ways makes prominent the intersubjective nature of the research process. My presence allowed the mothers to process their sense of the uncanny, the abject, and other ambivalent experiences related to their motherhood, children and disability further. A prominent sense of relational triangulation between the mothers, their children, and other disabled people (including me) was apparent. It was in and from this engagement that the second focus of this thesis emerged: the implications of the process of researching motherhood and

disability, not least because in each researcher-participant dyad we were a disabled researcher and a non-disabled participant who are both mothers to disabled children.

Grappling with how to work within the transference-countertransference situation became central to this process and the project. The study demanded a deep engagement from me regarding my own sense of self in order to use it as a research instrument, and more so, to avoid intruding on the study. Hence, the notion of researcher depth reflexivity became paramount (Harvey, 2017b). The constant immersion in my responses to the participants and interview material required a psychoanalytic researcher thirdness (Harvey, 2017b). The adjustment of Ogden's (1994) psychoanalytic therapeutic concept allowed me to engage with my and the participants' experiences, as well as our intersubjectively created experiences, to facilitate another lens to the interview material. This engagement allows this thesis to develop the literature on using psychoanalytic concepts in research, and on the importance of researcher reflexivity (e.g., Cartwright, 2004; Kvale, 1999; Saville Young & Berry, 2016; Strømme et. al, 2010). Interacting with participants and working with the feelings produced in and from the shared identities in the researcher-participant dyad does not need to be feared, but should rather be embraced. Hence, the thesis addresses how to conduct research using a psychoanalytic and intersubjective lens in the fields of motherhood and disability, engaging with what it means to access data as a disabled researcher engaging non-disabled participants raising disabled children.

Various authors have argued for the use of a social and psychoanalytic lens in disability studies to highlight the inseparable relationship between the realms of the internal and external (including, Frosh, 1987; Goodley, 2011b; Hollway & Jefferson, 2000; Marks 1999a, 1999b; Saville Young & Berry, 2016). In such an approach, disablism is understood as a process produced between people, and not purely as a product of disability

itself. According to Goodley (2011b), subjectivity develops in the social domain. Arguably, taking a psychoanalytic perspective of subjectivity that intertwines the intrapersonal with the interpersonal – within the mothers, and between them and their children/other people/me – is a productive way to engage with this study. Hollway (2001) extends understanding on maternal subjectivity by focusing on intersubjective dynamics between mothers and babies, but this discussion extends an understanding of subjectivity in mothers of disabled children by centring intra and intersubjective dynamics: between mothers/their disabled children and society, including with me. Hence, mothers remain autonomous subjects who are also always in relation to other subjects (see the call by, e.g., Hollway, 2015; Raphael-Leff, 2010; A. Stone, 2014) and the ongoing development of maternal subjectivity can be understood better.

Consequently, this thesis starts to undo what Morris (1992, p. 163) has accused much of the disability research as doing, namely confirming "oppressive images of disability". Instead, this research achieves what Saville Young and Berry (2016) have called for: facing often discomfiting reports by mothers in order to facilitate access to a multi-dimensional, holistic and dynamic sense of their subjectivities. By giving a voice to the women in this study, non-disabled mothers in the realm of disability can be empowered, in that their multi-layered, complex, and mostly cohesive sense of self can be gleaned. Their external and internal maternal experiences are captured. By thoughtfully approaching the interview process and analysis stages using an intersubjective and transference-countertransference lens, various aspects of disability and motherhood are celebrated, including those that are difficult.

The intersubjective lens applied in this study was most useful in exploring how the participants responded to me in different ways because of my disability. At times,

participants perceived me as a positive introduction into their lives, primarily when they saw me as similar to their children because of my disability. In that case, they regarded me as someone who could potentially bring guidance and information. Allowing these positive identifications facilitated a particular openness from the various women, resulting in greater sharing of their motherhood, since they perceived me as truly understanding their experiences. The comment *"I don't get to speak to a lot of people with the same condition as my daughter … it's so nice … because I know you would probably relate to me ten times better than anybody else can"* is one example of this identification with me. Their sense of feeling understood by me also seemed to facilitate a space for the mothers to continue to integrate their psychic functioning. The participants' use of me in order to manage their resulting maternal conflicting emotions so that they can continue to love and care for their children offers particular insight into how to conduct research with mothers in the disability realm. Mothers of disabled children need to feel accepted in their maternal role, facilitating a deeper engagement with the topic under discussion, a stance I always sought in this study, because too often mothers raising disabled children feel judged (Sadat Nurullah, 2013).

At other times, participants identified with me as a successful professional, despite my disability. This identification seemed to elicit reassurance and hope for their disabled children's future, as well as their own. I was also seen as someone who could share knowledge: mothers asked me direct questions regarding my experience of being disabled and now being a mother to a disabled child. Carefully thinking through why the participants were interacting with me in these ways and how I could respond needed constant attention. Participants' positive engagement with, and use of, me can be argued to be a means to develop their subjectivities. I therefore chose to respond to these concerns, which seemed to encourage participants to share more nuanced material. Sharing particularities with

participants, especially if these particularities fall within a minority group, requires researchers to be reflective in complex ways. Reflecting on the process of the study and the various roles I was cast in, as well as the fruitful results of this conscious practice, supports calls for the use of psychoanalytical concepts in research (e.g., Saville Young & Berry, 2016; Watermeyer, 2012).

There were also moments in the researcher-participant encounters when some participants displayed ambivalent identification with me, and more specifically, with my disability. It became apparent that there was a very fine line between the participants' negative identifications with me, with themselves, and with their disabled children. Managing this fragile balance involved "a continual fluctuating process of projection, introjection and expulsion" (Harvey, submitted) resulting in the participants' subjectivities' continually wavering between integration and potentially becoming undone. Handling this delicate process was crucial in light of the intersubjective nature of this project and the necessity of working within the transference-countertransference situation.

I have already argued that some of the participants appeared to be initially re-confronted with the abject in the actuality of their disabled children. Furthermore, at times my visible physical disability also reminded some of these women of the abject which they work so hard to keep at the periphery of their selves – this was a painful process for me to engage with. I was left with an experience of feeling othered, since I was unexpectedly and unwillingly also pushed into re-meeting my own disavowal in such encounters.

The mothers' ambivalent responses to my disability was apparent in their focus on my disability, and even references to my mother's potential experiences of raising me as a disabled child, at the expense of engaging with me in my wholeness. Joan, for example, made many comments during our interactions which are indicative of this process – one

serves to illustrate this point: *"[Y]ou see now in your case with your mother, she wouldn't have felt in any way responsible* [for my disability].*"* Such participant responses demanded a willingness from me to engage with difficult, brutally honest aspects of the research topic, casting a new light on Cartwright's (2004) suggestion that from the outset researchers should think about why they want to study a particular topic and what associated feelings arise in them. At times, the mothers' ambivalence towards me, disability, and thus their children and themselves as mothers, was palpable. However, this focus on my disability may also be a positive identification for the mothers; indeed, they reflected on how they felt I understood them (because of my disability), leaving them feeling accepted.

Some of the participants also appeared to have an uncanny experience of me because of my visible physical disability. In turn, their sense of their children and themselves as strange was re-articulated. Such a peculiar impression in relation to me left them feeling ambivalent about themselves as mothers, about their children, and about disability in general – something I represented. Moments in which they experienced me as strange allowed some distance to be created from their more difficult emotions surrounding their children and disability. However, I was left with their projected disavowed, "not-me" aspects regarding their children, disability, and of themselves (Sullivan, 2013). This re-ignited my own sense of discomfort at being the "other". Reflecting on my thirdness became crucial in order to remain true to the research enterprise, to the participants, and to the experience of disability. I would argue that was only possible because of my training and experience in psychoanalytically based psychotherapy. The literature does not comment on these demands on researchers.

This uncanny process was perhaps most apparent when Janet "showed" me to her non-disabled children so that they could "see" me and she could see what their responses

were. I was identified as something I am not because of my disability, as she commented that *"maybe they* [her children] *just thought you were like a kid* [child] *or something"*. This peculiar experience of me because of my disability amplified her ambivalence regarding disability, herself, and her disabled child.

Not surprisingly, these engagements were painful, as they confronted me with my own sense of strangeness and rejected parts, a topic which I have engaged with in detail in the thesis, where it has served to enhance an understanding of maternal subjectivity and the process of conducting the study. A projection of the mothers' more distasteful parts of themselves and their children onto me, in an attempt to manage their ambivalence, created room for their more positive maternal feelings, resulting in continued psychic integration.

Since the process of conducting the actual study became central to this research endeavour, it is helpful to reflect on more tangible aspects of the process, illuminating further implications of this second focus of the thesis.

A Comment on Different Disabilities

Although I had carefully considered the criteria for the sample of this study, once the interviews began, it soon became apparent that different disabilities in the participants' children brought distinct hues to the research material and to our encounters. Each of these mothers had unique experiences of the research encounter, and of me, and thus had varied experiences to share. It was noticeable how unique each experience of disability is, and similarly, each woman's experience of motherhood and developing her own sense of self amidst this experience is unique.

One of the mothers who participated in this study said to me: *"I don't get to speak to many people that have children with achondroplasia."* This comment is indicative of the sense of connection that some of the mothers felt with me because my child and their child

share this particular disability. Mothers whose children have the same disability as I do seemed to value the opportunity to participate in the research and engage with me from a specific angle. One said: *"I feel that maybe you can relate better to me than anybody else can because you have probably been there, in those situations* [the same as those her child has been in]*."* The remark offers one such example of how the mothers felt connected to me because of my achondroplasia. They appeared to feel that they were gaining from the encounter on many levels. This experience seemed to assist these mothers in developing their maternal subjectivities.

However, I was also someone onto whom the mothers could project the more unsettling aspects of their children's disability because of our shared disability. One mother said *"Well I'm sure* [laughs] *you* [referring to me] *get it* [others staring and pointing at me] *all the time."* In this case, Chloe related to me in this way, which left her "free" to continue to integrate her sense of self, while I was left with the more disavowed aspects of achondroplasia. This instance suggests that Shakespeare's (1994) description of disabled people as dumping grounds for non-disabled people's unpalatable emotional responses to disability can also be applied to the case of disabled researchers. At various points in the study, I was left holding the mothers' discarded disability-related disavowals pertaining to their children and the encounters they have with others. Consequently, psychic space was created for them to continue to develop their subjectivities, and lovingly mother their children.

Mothers whose children have different physical disabilities to me also sometimes voiced a connection with me. This connection was less because of my specific type of disability and more because I too have a visible physical disability. They felt reassured by meeting me because they perceived my life as successful, despite my disability – something

they felt their children may now also be able to achieve: *"It* [the interview] *was really encouraging and a motivation to me you know, meeting you and* [it] *makes me aware that you know in spite what we have with* [son's] *special needs and whatever he's doing at this moment in time, it makes me aware of he is going to be turning out* [okay]*."* These mothers also seemed to value greatly the opportunity to share their stories and experienced the encounters with me as cathartic: *"It's good for me to be able to share and it's good to chat … I'm grateful that you came over here to come and chat to me so that we can ja* [yes]*, we can share."* The mothers also approached the interviews as potential opportunities to help other mothers raising disabled children: *"[S]ometimes listening to somebody else* [about their mothering experience in relation to disability] *can … maybe some little piece of what I say at some point might make you go actually, I'm okay or actually, you know…."*

The literature has addressed reasons for participants' participation in research and sharing so candidly, and one of these reasons is a sense of helping others in similar situations (e.g., Karnieli-Miller et al., 2009). Other reasons for agreeing to be interviewed include participants' interest in the topic under study, their personal wish to share their experiences and feel heard, and the perceived therapeutic benefit (e.g., Karnieli-Miller et al., 2009) – all of these were apparent in the current study. At times, the mothers shared information that they had never disclosed before, arguably not only because of how I interacted with them as an interested and compassionate researcher, but also because of the axes of identity that I share with the participants, including disability and motherhood. Rubin and Rubin (2005) suggest that participants may also wish to share their stories to help the researcher, an argument that seems particularly pertinent to this study, because of the particularities that I share with the participants.

The constant need for researchers to hold the ethics of research engagement at the forefront of their minds was highlighted by the responses of the mothers in my study. This is vital when participants are from minority groups in society, including those living in the disability realm. Participants' interests need to be served in addition to the interests of the study, stressing the need to create a non-hierarchical atmosphere in which the encounter is as free of power inequalities as possible, encouraging disclosure and an atmosphere of authenticity between researchers and participants (Gergen & Gergen, 2000; Karnieli-Miller et al., 2009). In such an atmosphere, "control over representation is increasingly shared" (Gergen & Gergen, 2000, p. 1035), a notion which is important in all research encounters, but is particularly relevant in studies with minority groups.

Although each mother had different experiences to share that were specifically related to the type of disability her child has, the mothers also had different experiences to share simply because they are all individuals. It is therefore important to recognise multiplicity as a crucial aspect of the critical disability perspective, as well as motherhood (Snyder & Mitchell, 2010). However, researchers should avoid further pathologising the experience of disability by individualising the more negative and difficult experiences (Goodley, 2011a). Achieving this nuanced equilibrium was a difficult ambition throughout the thesis, but was pursued with dedication, in itself forming a particular focus of the study.

Reflecting on My Self and My Disability

It would be remiss of me not to confront some of my reasons for interviewing mothers of visibly physically disabled children, given that I too am visibly physically disabled and am a mother to a visibly physically disabled child. Of course, the obvious aim of wishing to access women's maternal subjectivities was prominent in my mind, but I became increasingly aware that I was perhaps also enacting what Freud (1919) called the

compulsion to repeat, in an attempt to process my own experiences of motherhood and disability further. Perhaps, unconsciously, I wanted to confront my own repressed aspects to try to reach a resolution. Perhaps I was (initially unknowingly) putting myself into contact with participants who would make me re-face the abject and uncanny aspects of myself that I had long "forgotten". As the study progressed, I have realised that I was also trying to develop my understanding of my disability and peculiarity, something which I believe I have partially achieved by conducting this study and writing this thesis. In this sense, a popular phrase in disability studies rings true for me, namely that the personal becomes the political (Hollins & Hollins, 2005).

In some of the emotional encounters with various participants, my infantile repressed complexes have returned, providing me with peculiar experiences. My frightening interactions with some of the participants led me "back to what is known of old and long familiar", my "unacceptable" disability (Freud, 1919, p. 220). I have to acknowledge that my past haunts my present experiences, because in the uncanny encounters with participants I was forced to re-meet myself, pushing me to engage with my repressed aspects (Frosh, 2013). Consequently, I am aware that I am still in the continual process of becoming myself (Lacan, 1953), as are the mothers who are developing their subjectivities through their interactions with me.

Perhaps I am also activating a passive experience by researching disability and motherhood, an idea reminiscent of Freud's (1920/2003) construct of the "*fort-da* game" [away-back again game]: he interpreted his grandson's game of throwing a reel attached to a piece of string and pulling it back is symbolic of his "letting" his mother leave and rejoicing in her return. Hence, he was mastering his own distress and the symbolic return of his mother (Frosh, 2013). It is conceivable that I am trying to manage some of my own

disability-related anxiety. The mothers also appeared to engage in an unconscious attempt to contain their unease by engaging with me as something uncanny, and even disavowed, at times.

The varied encounters with the participants reminded me that my "primitive beliefs which have been surmounted seem once more to be confirmed" (Freud, 1919, p. 249). My reliance on psychoanalytic theory, specifically Freud's (1919) thoughts on the uncanny and Kristeva's (1982) ideas on the abject, have assisted me in understanding these most intimately challenging emotional experiences with non-disabled individuals. Accordingly, some of my own discomfort in being disabled was quietened.

From the outset of the study, I had a sense that my own subjectivity, particularly as a disabled person and as a mother, would be challenged. However, my own sense of self was greatly stretched at different stages throughout the research enterprise – much more than I was prepared for. At times, I was forced to re-encounter my more difficult aspects, something I would not have been able to do at an earlier stage of my life. My current life stage, after extensive psychoanalytically oriented psychotherapy, allowed me to engage openly with participants and the research topic so that the gathering of rich material could be facilitated. Nevertheless, the necessity to discuss my authorship and embeddedness within the process of writing this thesis continues to be a challenging, shifting, and very intimate position. Indeed, according to Kristeva, an authorial voice that is stable and single is an illusion, because of the notion of the subject-in-process (McAfee, 2004). Conducting the study and writing this thesis has required a continual balancing act not to cross the fine line between acknowledging the role of my subjective position and merely indulging in the personal.

Research and Advocacy

The mothers shared some brutally honest, vivid experiences in their stories relating to their sense of self in the face of disability. These aspects were painful to hear, but it was necessary to hear them, because they were what these mothers related.

People who enter into intimate spaces with disabled people, including those in relationships (non-disabled partners, parents), various types of therapists, and psychotherapists, need to hear and face the pain and darker side of disability, so that they can continue to relate in meaningful ways with those who are disabled. The authenticity of the experience of disability, for disabled and non-disabled people, occurs in the murkier affective states, which are often not encouraged or "allowed" because these darker areas stand in opposition to the more politically correct arguments around disability. In this regard, Sinason (2010a, p. 79) warns that it is "only when the therapist can bear the pain of the literal [that] is it possible for the client to think".

Similarly, acceptance of the more ambivalent, uglier states of motherhood needs to be encouraged, and these states need to be acknowledged by those relating to, and working with, mothers in various capacities. Mothers should be provided with spaces where they can experience enough openness to feel and share their more difficult, ambivalent experiences. Conflictual and darker feelings and experiences should be seen as opportunities for personal development rather than as disruptions and threats to the expected norms of society. I issue this call to researchers working in the fields of motherhood, disability, and in this combined field. This thesis highlights the need for researchers to be willing and able to face the more disavowed aspects of both motherhood and disability – indeed of being human. In the study I have shown that the fields of psychoanalysis and intersubjectivity can provide the tools to facilitate such research engagement, allowing for in-depth, complex and

nuanced material to emerge, while remaining ethical and true to the research enterprise and the participants.

Limitations of the Study and Directions for Further Research

The study has a number of limitations. These suggest four broad areas for further research. However, this is not an exhaustive list, given the vast, individual experiences of subjectivity, disability and motherhood.

A limitation of the study that is shared by much qualitative research is its limited generalisability, given the small sample and the psychoanalytic method of analysis, but it was not necessarily the intention of this study to generate data that could be generalised to a wider population. Instead, the contribution of the research lies in the detailed and nuanced understanding of maternal subjectivity of women in the face of raising their physically disabled children that the findings offer. Hence, I argue that the research design employed was appropriate for the purposes of this study.

Only nine women were interviewed, and the small sample size in the study may be considered a limitation, affecting the generalisability and transferability of the material. However, the sample size can be argued to be adequate for a qualitative study, particularly because each participant was interviewed twice and for a substantial length of time. The adequacy of the sample is supported by the fact that rich data was collected (hence, it was decided to cap the sample at nine participants, amounting to eighteen interviews).

Perhaps the characteristics of the sample may be regarded as a limitation, in that only women raising children of a particular type of disability, namely visible physical disability, were approached. This implies that the findings cannot necessarily be transferred to a bigger population, to claim an understanding of the subjectivities of mothers raising children with other types of disabilities. The aim of the study was only to access the impact

of having a child with a visible physical disability on maternal subjectivity, and the thesis offers insight into this aspect. Arguably, some of the experiences of this sample can be valuable in thinking more broadly about the often unspoken aspects of maternal subjectivity in general, as well as about mothers with children with other forms of disability. Each mother responded uniquely because of the specific disability in her child, and it was clear that even the mothers of children with the same disability told of different experiences. This suggests that further research exploring maternal responses to disability in their children would be valuable. Conducting studies with mothers with children with different disabilities to those present in the children of the participants in this project are likely to yield further data. Future research of this kind needs to continue to respect the singularity of each mother's experience with her child, as well as the uniqueness of experiences of disability itself. Furthermore, researchers need to continue to think carefully about how to depict the experience for disabled children accurately, not shying away from the difficulties, yet also celebrating the positives of disabled people's experiences (Robertson, 2010).

An associated concern regarding the sample may be the focus on mothers at the expense of fathers, or even parents. While I acknowledge the limitations in gender terminology and gender binaries, I have provided a clear rationale (specifically Chapter Three: Method) for focusing only on mothers, and in particular on birth mothers.

Since the topic of subjectivity in the combined fields of motherhood and disability studies is an emerging field, particularly from a psychoanalytic perspective, more research needs to be conducted in this area. Studies similar to this one would add to the understanding of the experiences of motherhood and disability. More specifically, the darker aspects of maternal subjectivity (including ambivalence, uncanniness, and those aspects that are disavowed) have led the discussion of this study's research material,

offering a specific lens on this form of motherhood. This theoretical focus may be criticized as being too narrow in developing an understanding of this specific maternal experience. Furthermore, highlighting the difficult and unpalatable experiences in the material has meant that some of the data have been excluded, which is a limitation. These aspects, along with other, perhaps more pleasurable experiences of motherhood, could be given greater attention in future maternal studies. Arguably, focusing on some data in detail is necessary to do justice to the mothers' experiences, and to the experiences of disability. Thus, the thesis avoids reinforcing, rather than challenging the subordination of disabled people and by implication those in intimate relationship with them, including mothers (Shakespeare, 1996; Sinason, 2002). Moreover, a constant focus in the study was to give adequate space to the mothers' stories so that they can really be heard, and this is arguably important, given their complex status. This is a partial attempt to redress accusations in other studies that mothers are ableist in their non-disabled positions, with some studies going so far as calling mothers a hindrance to their children's disabled statuses in advocacy circles (Ryan & Runswick-Cole, 2008).

Additionally, the thesis may be criticised for pointing out several of the more negative aspects of this mothering experience. Yet this dominant aspect is what emerged most clearly from the sometimes unfiltered experiences that the mothers related in the interviews. One of the aims of the research was not to "other" mothers of non-disabled children, but rather to see them as subjects in their own rights (Benjamin, 1995; A. Stone, 2014). It was difficult to achieve this fine balance, because I would argue that it is important not to shy away from the graphic horror that the participants shared regarding their maternal experiences. The counterpoint is that the thesis has also addressed what non-disabled mothers do with their sense of repulsion that they are re-confronted with in

themselves and in their babies, because of the presence of disability. Thus, disability is not merely portrayed "as a uniquely horrifying predicament" which maintains society's deficit view of disability (Grue, 2013, p. 50) – the thesis also explores how the participants manage to re-configure their own subjectivities while also developing immense love for their children. The study's psychoanalytic and intersubjective lens allowed for detailed and nuanced insight into the experiences of disability, motherhood and these two experiences combined.

The thesis thus contributes to a shift in psychoanalytic studies by acknowledging the complex process of motherhood (e.g., Hollway, 2001; Raphael-Leff, 2010). Mothers are recognised as being integrated works-in-progress with their own sense of self apart, yet entwined with their children. Future studies conducted from a psychoanalytic and intersubjective lens would be beneficial to glean even greater understanding in these areas. Future research on the experiences of disability using a psychoanalytic understanding would contribute to the call for such an approach in the field of disability studies (e.g., Marks, 1999b; Watermeyer, 2012).

This thesis has made a conscious attempt not to place the mothers of this study in a double bind (a daunting task, given that their stories and related intense affective experiences often contradict politically correct notions of disability). Hopefully maternal experiences in the realm of disability have been presented as integral aspects of people's subjectivities. By focusing on the perspectives of the mothers, I attempted to present them as the human beings they are. In exploring their perceived relational experiences with their disabled children, disabled people and disability experiences have been humanised.

The adapted psychoanalytic research interview method employed in the study may be criticised, as it is a unique approach. This critique may also extend to the fact that the

researcher is also disabled and is the mother to a visibly physically disabled child, and has chosen to interview non-disabled mothers raising children who are visibly physically disabled. In defence of the approach, the uniqueness of this methodological approach has been carefully reflected on and in fact became the second central focus of the study and thus makes a distinct contribution in the thesis. The fact that I am disabled facilitated the participants' particular engagements with me, allowing them to share rich material on maternal subjectivity in the face of disability, and throwing more light on what it means to research this particular form of subjectivity.

Further research is warranted on the process of researching subjectivity, motherhood and disability. The adapted psychoanalytic research interview method used in this study could be fruitful in other studies of this nature, particularly ones emphasising the subjectivity of researchers. Future projects that engage in depth with researcher personhood, and the impact of researchers' particularities on research are warranted. Such an approach to research, particularly with minority groups, is important, given the call not to treat disabled people to not be treated as objects of research, but rather as subjects in their own right (e.g., Lester & Nusbaum, 2017). Thus, as this study does, research must move away from the far too frequent tendency in disability studies to adopt a "personal tragedy theory" based on a medical model that does not hold others and society accountable for their responses to disability and relies on a deficit approach (M. Oliver, 1986, p. 5).

In Closing

Mothers of disabled children, like disabled people, have to function in a world where non-disabled people constitute the majority, and "psychical investments in normalcy and fears about stupidity and monstrosity" abound (Marks, 1999b, p. 170). For these mothers,

when their children are born disabled, developing their maternal subjectivity in this context is full of painful ambivalence. Mothers involuntarily become dumping grounds for other people's difficult feelings for, and encounters with, these mothers' disabled children, making these women experience their own children as strange, even disavowed, reawakening their own sense of the abject. The continual tussle with the embodied aspects of their children's disability and simultaneously with how this resonates with their own sense of self is palpable.

Yet, notably, the mothers in this study found some resolution regarding their ambivalence around themselves, their children, and disability in general, as they wrestled with what it means to be a flawed human being. Genuine maternal love becomes possible when they can engage with their contradictory feelings for their children and disability. The affective experiences of having a child with a disability are often in stark opposition to what is considered politically correct in the current social model of disability. Yet, somewhere in the realness between these intrapsychic and interpsychic experiences lies the raw, beautifully complex maternal subjectivity of women whose children are disabled. Mothers continue to develop their sense of self, and simultaneously their love for their disabled children continues to grow, deeply constituted with darkness. Such maternal functioning is made possible in the creative ways mothers manage their most complex experiences. Healthily engaging in "unhealthy" defences is one such creative maternal strategy; "using" others is another, including by relating to me in particular ways, given our shared particularities. Allowing such researcher-participant engagements allowed the mothers to "purify" the emotional experiences that they may have denied to some degree, extending understanding of their maternal subjectivity. This research engagement became central to

the study, demanding a focus on the actual process of conducting research on motherhood and disability.

The picture of maternal subjectivity in the face of disability as balanced – positive and loving, yet dark and difficult – is not reflected in society's continued tendency to deny vulnerability, and other more difficult aspects of disability. The thesis was not intended to resolve the discomfort of disability and motherhood experiences. Rather, it creates space to engage with these more challenging aspects of motherhood in the face of disability: to hold a nuanced position of this particular maternal subjectivity, embracing both pain and love. Thus, the thesis offers a refined understanding of how non-disabled mothers encounter disability in their children, and how they manage their subsequent emotional responses, and it reimagines and celebrates motherhood in the face of disability.

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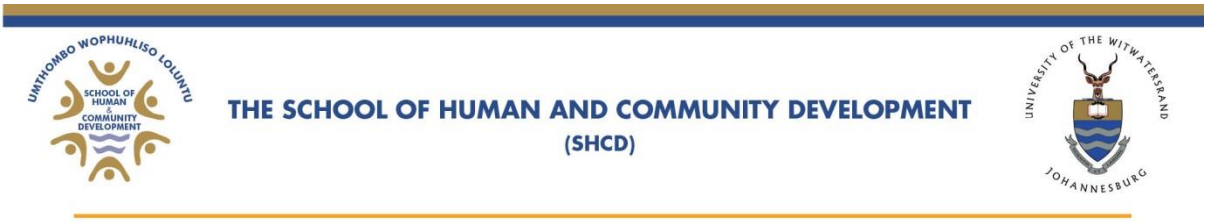
Appendices

Appendix A: Participant Information Sheet



Private Bag 3, Wits, 2050 • Tel: 011 717 4524 • Fax: 011 717 4556 • E-mail: Umthombo.SHCD@wits.ac.za

Dear Madam,

Good day. My name is Clare Harvey and I am a Doctoral (PhD) student in the Psychology Department at the University of the Witwatersrand. For the purposes of my studies, I am required to undertake research. I am conducting a research project which will explore the experiences of mothers of children with a visible physical disability.

I would like to invite you to participate in my research. I am contacting you because I believe you can add valuably to this area of study which has been minimally researched to date.

If you agree to participate, you will be asked to join in a conversation with me during two to four interviews around the topic mentioned above. These interviews will be arranged over the course of two months. In these interviews, I am interested in hearing about your experiences of raising your child and how you have thought about your mothering role. Each interview will be audio-recorded, with your permission. They should not take longer than one and a half hours each. These interviews will be held at a time and place of your convenience. Should you want to take part, you will be asked to sign a consent form, agreeing to participate in the interviews.

Taking part in the interviews will not advantage you in any way. You will not receive any compensation, monetary or otherwise, for participating in the study. No risks to participation in this study are anticipated. Participation in the two to four interviews will be completely voluntary and you may withdraw from them at any point. Withdrawing from the study will have no benefit or risk for you if you choose to do so. You may also refrain from answering any particular question(s) with no negative consequences. You will be treated with complete sensitivity and respect in all aspects of the interviews.

Your identity as a participant will only be known to me and my supervisor. The audio recordings and the transcriptions of them will be kept safe in a password protected computer file. Only my supervisor and I will have access to these files. To protect your confidentiality and anonymity in the write up of the research, your name and other personal information will not appear anywhere. Instead, pseudonyms will be used. Any information you give me that you feel might identify you to others, will be removed or slightly disguised. Some parts of the interviews will be directly quoted in the research report, however, this will be done under the pseudonym given to you and with identifying material removed or disguised.

Once the study has been completed, the PhD thesis resulting from this research will be available in the library of the University of the Witwatersrand, which offers access to material on the world-wide web. The findings will also potentially be presented at academic conferences and published in scientific journals or book chapters. Your identity will never appear in any form in any written report or publication. If you wish to have access to a summary of the results, you should contact me and I will arrange this.

If during and/or by the end of the interviews you feel the conversations have elicited sensitive and emotional effects in you and you feel you would like to speak to somebody

about this you are advised to contact the free counselling service below for emotional support:

Lifeline: 011 728 1331

Emthonjeni Centre (University of the Witwatersrand): 011 717 4513

Prior to participating in the interviews, it is required that you complete the two consent forms attached to this sheet. These will be kept separate from the rest of the data for the purposes of confidentiality.

If you have any questions about this research please do not hesitate to contact myself or my supervisor:

You can contact me via email at clare.harvey@wits.ac.za, or telephonically on 011 717 4509 or 076 473 8242.

You can contact my supervisor, Dr. Yael Kadish, via email at yael.kadish@wits.ac.za, or telephonically on 011 717 4547.

Warm Regards,

Clare Harvey.

Appendix B: Participant Informed Consent Form

THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
(SHCD)

Private Bag 3, Wits, 2050 • Tel: 011 717 4524 • Fax: 011 717 4556 • E-mail: Umthombo.SHCD@wits.ac.za

I, _____, consent to take part in the two to four interviews conducted by Clare Harvey, for her study exploring the experiences of mothers of children with a visible physical disability. The research study has been explained to me.

As a participant in her study, I understand that:

- My participation is voluntary.
- I am able to withdraw from the study at any time.
- I may refrain from answering any question(s) I do not wish to.
- There are no risks or benefits associated with participating in this study.
- All my personal details and information I provide will remain private and confidential, although I may be quoted directly in the final report.
- Although I may be directly quoted in the PhD thesis, I will be referred to by the pseudonym given to me, and thus my identity will be protected. No material which would allow others to identify me will appear. To make sure this is upheld in every aspect, I will draw the researcher's attention to any such information (that she may not be aware of as potentially identifying me) so that she can omit or disguise it.
- The results of the study will be used in the research thesis that is required for the completion of her PhD in Psychology.

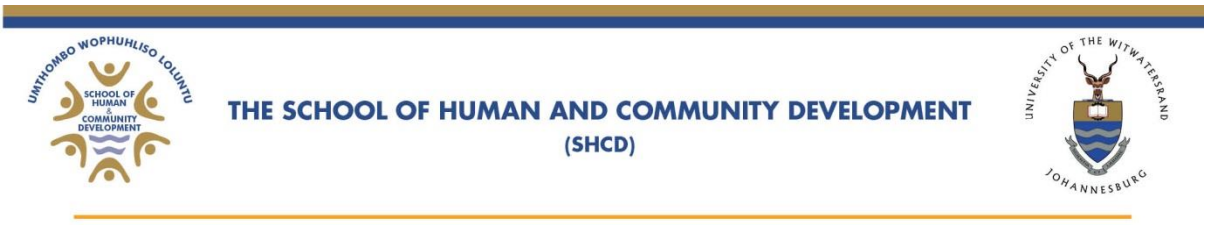
- The results of the research may also be presented at a conference(s) and/or published in a journal and/or book chapter.

Participant's name: _____

Participant's signature: _____

Date: _____

Appendix C: Participant Informed Consent for Audio-recording Form



Private Bag 3, Wits, 2050 • Tel: 011 717 4524 • Fax: 011 717 4556 • E-mail: Umthombo.SHCD@wits.ac.za

I, _____, consent to the audio recording of the two to four interviews conducted by Clare Harvey, for her study exploring the experiences of mothers of children with a visible physical disability.

I understand that:

- The tapes and transcripts from the individual interview conversations will be accessible to Clare Harvey and her supervisor only.
- The tapes and transcripts will be kept in a safe place (a password protected computer file).
- No personal information about any of the participants will be used in the transcripts or in the final research report or publications which arise.
- Although I may be directly quoted in the PhD thesis, I will be referred to by the pseudonym given to me, and thus my identity will be protected. No material which would allow others to identify me will appear. To make sure this is upheld in every aspect, I will draw the researcher's attention to any such information (that she may not be aware of as potentially identifying me) so that she can omit or disguise it.

Participant's name: _____

Participant's signature: _____

Date: _____

Appendix D: Psychoanalytic Research Interview Outline

Personal Details of the Participants

1. Age
2. Ethnicity
3. Marriage/relationship status and length of relationship
4. Employment
5. Number of children
6. Name of child with disability
7. Age of your child with disability
8. Type of disability your child has
9. Birth order of your child with a disability

Briefing

As you can see I have a physical disability; and the area of disability and mothering has always been an interest of mine. I am really interested in hearing about your experience of mothering your child with a physical disability, in as much detail as you would like to give. I would like you to be as honest and as open as feels comfortable for you.

I would like you to feel very comfortable in this interview on the topic of your mothering experience. Please feel free to tell me anything that comes to mind; or that you may wish to share, however small or irrelevant you may feel it is.

Interview Topics to be Explored During the Interviews

There are four interview topics that will be explored with each participant over the course of two to four interviews. Each topic has follow-up questions and, or prompts in the case that a participant struggles to free associate around each topic. The four topics below have been set out separately for purposes of clarity; however during the course of the

interviews it is anticipated that questions about the “mothering experience” and the “diagnosis of disability” may be explored together.

1. Mothering experience

I would like you to start with whatever you wish to tell me about your experience of being a mother to your physically disabled child.

Follow-up questions/prompts:

a) Tell me about your pregnancy with … (child’s name). Was it planned? Did you experience any difficulties or complications?

b) And the birth, what was that like?

c) Please describe your child to me …

d) How would you describe your mothering role?

e) What fantasies and images did you have about how you would be as a Mom before your child was born? Have these dreams changed at all?

f) What do you enjoy and not enjoy about being a Mom to … (child’s name)?

g) If you had to think about your feelings that are linked to mothering your child, what feelings do you find you regularly experience?

h) What aspects of raising … (child’s name) have been difficult or challenging for you? Please elaborate.

i) Are there aspects of parenting your child that upset you, or that you dislike?

j) Are there aspects that you wish you could change or eradicate?

k) Tell me about any positive aspects to being … (child’s name) mother? Please elaborate.

l) Is there anything that you love about being … (child’s name) Mom?

m) Have there been times when different feelings have predominated in you in response to raising your child?

n) What has happened around these times?

o) What thoughts and dreams do you have about your child's future?

p) What types of things do you worry about when you think of your child growing up?

q) Where do you see yourself in this future?

r) How do you think being a Mom to … (child's name) is different to being a Mom to your other children/to a child that may not have a disability? In what ways?

s) In what ways do you think being a Mom to … (child's name) is the same, or similar, to being a Mom to your other children/to a child that may not have a disability?

t) What is your relationship like with your other children? Please elaborate.

u) Has this been influenced by having a child with a disability? If so, in what ways?

2. Diagnosis of disability

Tell me about when you first learnt of your child's disability

Follow-up questions/prompts:

a) When was it? During pregnancy? At birth? Later?

b) Who told you?

c) What were you told about your child's disability (disabilities)?

d) Who was with you when you were told?

e) What were your initial thoughts and feelings?

f) How did your partner/husband/the child's father react? What was this like for you?

g) How did the rest of the family respond? What was this like for you?

h) How did others around you respond? What was this like for you?

i) Had you ever been in contact with a person with a disability before having your child? Please explain.

j) If so, how do you think this had an effect on your learning of your child's disability?

k) What do you understand about your child's disability?

l) What thoughts and feelings do you have when you think about this?

m) How do you refer to your child's disability when in social contexts?

n) What has your experiences been like with the medical professionals that you may have dealt with, with regard to your child's disability?

3. Support systems

Can you describe your support systems?

Follow-up questions/prompts:

a) (If the participant is currently in a relationship, as gleaned from personal details above) Can you tell me a bit about your husband/partner and your relationship with him?

b) How has your husband/partner adapted and made sense of … (child's name) disability?

c) What was it like for you as a couple when you learnt of … (child's name) disability?

d) Do you feel your marriage/relationship has been affected by having … (child's name)? If so, in what ways?

e) And his relationship with … (child's name)? How would you describe it? How do you view his parenting approach with … (child's name)?

f) Tell me a little bit about the relationship amongst all your children. How does … (child's name) and your other children get along?

g) If you work, who cares for your child while you are at work?

h) If you don't work, is this related to your child's disability? Please explain.

i) Who do you speak to, if anyone, about your child's disability and your experience of raising him/her?

j) What was/is your relationship like with your mother?

k) Has this changed at all since having … (child's name)? Please elaborate.

l) Are you currently/ever been in your own therapy? How has that been? What aspects of mothering your child have you worked on? How did the decision to enter therapy come about?

m) Have you ever attended a support group? If so, how was/is that? What do you find beneficial, or not, in such a setting?

n) What do you do for fun, in your spare time?

o) Are there ever times when you do not spend time with … (child's name)?

p) Do you make use of any other form of self-care that I perhaps haven't asked about, such as spiritual or religious engagement?

4. Social aspects

I am interested in hearing about your experiences when you are in public with your child …

Follow-up questions/prompts:

a) Do you have any particular memories of what it was like taking your child out into public for the first few times?

b) What is your current experience like when you are in the public domain with your child?

c) How do other people respond?

d) How does this make you feel?

e) How do you understand/make sense of these responses?

f) How do you manage these kinds of situations?

g) How was it for you when it was time for your child to start school?

h) How have the other Moms responded to you in relation to … (child's name)?

i) And the school staff? How have they adapted to … (child's name) and responded to you as a result?

Questions To Be Asked At the End of Each Interview

1. What was it like for you talking to me about your mothering experience of your child today?
2. Was there anything that you found surprising or unexpected in your responses?
3. Is there anything else you wish to add before we end this interview?

Debriefing At the End of Each Interview

1. Are you okay to stop for today?
2. How are you feeling?
3. Do you have any questions for me?

Additional Interview Questions

Any questions that were not asked in the previous interview(s) and any additional questions that arose during the last interview(s) will be asked of the participants in the second, third and/or fourth interviews. Further, any contradictions, conflicts and observed psychological defences that may have arisen in the previous interviews will be discussed with the participants in the follow up interviews.

1. How did you experience the previous interview?
2. Do you have any questions or thoughts after the previous interview?
3. What was it like talking about your experiences?

4. Has anything come to mind since your last interview?
5. Have you had any dreams about what we chatted about since the last interview?
6. Was there anything else about the last interview that you would like to mention or add?
7. I wondered what it was like for you to talk to me about your experiences of raising your child with a disability given that I too have a disability?
8. Do you feel the presence of my disability makes you share more or less of your personal experiences? Please elaborate.

Appendix E: Human Research Ethics Committee (Non-Medical) Clearance Certificate

Research Office

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

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER H14/10/06**
PROJECT TITLE	Mothering a child with physical disability: A psychoanalytic exploration of maternal subjectivity and meaning making
INVESTIGATOR(S)	Ms C Harvey
SCHOOL/DEPARTMENT	Human & Community Development/Psychology
DATE CONSIDERED	24 October 2014
DECISION OF THE COMMITTEE	Approved Unconditionally
EXPIRY DATE	03/11/2016
DATE 04/11/2014	**CHAIRPERSON** (Professor T Milani)

cc: Supervisor : Dr Y Kadish

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10000, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

_____ _____/_____/_____

Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES