A phenomenological investigation into the impact of parenthood: giving a voice to mothers with visual impairment in the UK

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A phenomenological investigation into the impact of parenthood: giving a voice to mothers with visual impairment in the UK

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Abstract

Issues around parenting and psychological support for parents have increased in prominence in UK public policy and discourse over the last decade. However, there has been minimal focus on parenting with a disability, and specifically scant information on the experiences of what it is like to be a parent with visual impairment. In this investigation, using Interpretative Phenomenological Analysis (IPA), I examined how the experience of becoming a parent impacts nine mothers with visual impairment, aged 32 to 47, living in the UK. The findings highlighted various aspects of the mothers' experience under four meta-themes: 1) struggles around independence, 2) visibility and the impact of the other's gaze, 3) "*life can sometimes be more complicated*" and 4) the changed relationship with time. The discussion raised the possibility of counselling psychologists and psychotherapists moving towards a new integrative model to conceptualise the experience of parenting with a disability. It also highlighted three major areas: (i) the need for increased opportunity, flexibility and access to emotional support services for mothers with visual impairment and their partners, (ii) an emphasis on the use of online social networks to reduce isolation and the risk of depression, and (iii) the mothers' daily experience of stigmatisation and marginalisation in interaction with the other (including an exposition of how the mothers use humour as a way of dealing with this experience).

Keywords: motherhood, mother, visual impairment, sight impairment, blindness, sight loss, parenting, parent, counselling, counselling psychology, psychotherapy, disability

Introduction & purpose

"You start to think is it me?" Sarah:346

The desire to engage families at an earlier point and facilitate access to support services has been central to many of the UK's social policy initiatives over the past decade. This is evidenced in recent programmes such as Parentline Plus, children's centres and the extended schools policy. However, within this recent impetus towards improved support services, mothers with visual impairment, (or indeed parents with disabilities), suffer from the following paradox. There is a tendency towards invisibility at the public policy level, within the fields of counselling psychology and psychotherapy, and in academic discourse generally. Yet the mothers report marginalisation and stigmatisation of visibility, apparent through societal attitudes experienced in daily life. This unwanted exposure and visibility can lead to damaging effects on the mothers' self confidence.

This study aims to offer a contribution to counselling psychologists and psychotherapists working with parents with visual impairment, who face issues such as those raised by the paradox above. My initial research at the start of thinking about the project, both with parents with visual impairment, and with psychotherapists and psychologists working with clients who are visually impaired, narrowed my focus. This investigation is therefore solely focused on the experience of mothers who are visually impaired. My aim is to give sufficient time and space to their experience (with the possibility of exploring fathers' experience at a later date).

Over the past three years, I planned the research, then recruited, interviewed, transcribed, coded and analysed, using Interpretative Phenomenological Analysis (IPA) (Smith et al, 2009), the material gained from nine mothers with visual impairment, each of whom had at least one child aged under ten living with them.

The research began as an exploratory piece around my main research question: what was the participant's experience of the impact of becoming a mother? Sub-questions within that included: what part did being a mother play in the participant's sense of self, on the intra-psychic, interpersonal and wider public levels, and

importantly what, if any, was their experience of therapy and access to psychological services generally. These questions underpinned the semi-structured interview within the exploratory framework I used with each of the nine mothers.

A piece of "*contextual*" research, as opposed to explanatory, evaluative or generative (Ritchie and Lewis, 2003, p.27), this investigation described and explored phenomena as experienced by mothers with visual impairment and elucidated the meaning behind their experience. Rooted in my philosophical values as a counselling psychologist (explored in detail below), my hope is that this piece of research informs and extends practice within counselling psychology within the postmodern context that includes both therapeutic and social concerns (Kasket and Gil-Rodriguez, 2011).

By using IPA on data derived from accounts from a small number of participants, my aim is to explore the lived experience of the mothers such that my findings help inform theory and practice for therapists working with people who are visually impaired. Both the meta-themes and nuances of the mothers' experience emerge through the verbatim extracts. It is their voices that drive the findings and enter the wider debate in the fields of counselling psychology, psychotherapy and visual impairment.

Two points on key aspects in writing up of this project are that in the main, I have employed the terminology used by the majority of the mothers themselves: that is "visual impairment" as opposed to "blind or partially sighted". The latter are used only in reference to the original author or piece of work cited. Secondly, all names have been changed to preserve confidentiality and anonymity.

Contribution to the field

Overview

In my choice to use IPA as my research methodology, the participants' accounts are placed in the foreground, with relevant psychological research and literature added in subsequently to shed light within the discussion on what has emerged from the mothers themselves. However, I believe it is useful to give (1) some facts and figures about the field of visual impairment as a background, and (2) the rationale for this investigation and this field as my choice of doctoral research topic. This is followed by (3), a look at previous literature as a contextualising piece for the mothers' accounts.

Visual impairment is a term that encapsulates everything from partial sight loss to total blindness. Those who are registered blind possess varying degrees of sight loss, and "*how people refer to their visual impairment probably says more about how they perceive it than their actual degree of sight*" (Supple and Corrie, 2004, p.5). The functional vision of those with sight loss is itself idiosyncratic, dependent on numerous internal and external factors, e.g. environment, lighting, concentration, tiredness and brightness. It is estimated that 49% of blind and 80% of partially sighted people can, in fact, recognise a friend at arm's length (Dale, 2008).

The Royal National Institute for the Blind (RNIB) state there are an estimated 2 million people with significant sight loss (which means that, while they wear glasses, they have difficulty recognising someone across the road or reading newsprint). Nearly two-thirds of people living with sight loss are women. As at March 2006, 364,615 were registered as severely sight impaired (blind) or sight impaired (partially sighted) (Tate et al, 2005).

The majority with sight problems in the UK are down to age-related conditions, e.g. macular degeneration and diabetes. Seventy percent of adults with sight impairment have other disabilities or long term health problems in addition to their sight loss (Tate et al 2005). A significant minority are affected from birth, losing their sight as a

result of an inherited condition (e.g. retinitis pigmentosa or glaucoma). A small minority are due to accidents.

The UK population is an ageing one (one in six of the population in the UK is currently aged over 65 years old, and this is set to increase to one in four by 2050 (Office for National Statistics, 2011). This fact, combined with the growing and earlier occurrence in the incidence of the key underlying causes of visual impairment (e.g. obesity and diabetes), has led the RNIB to predict that the number of people in the UK with sight loss will increase dramatically over the next 25 years (similarly predicted in the US, Congdon et al, 2004). The RNIB estimate that, without action, by 2050, the number of people with sight loss in the UK will double to nearly 4 million.   Many of this ageing cohort will be caregivers themselves to a spouse or relative (Martinez et al, 2009).

Both the practical and emotional difficulties of living with visual impairment have long been documented, with vision loss potentially compromising the ability to read, drive a car and perform other daily activities with ease (Pey et al, 2007, across adults of all age groups; Crews and Campbell, 2004; Knudtson et al, 2005, specifically focusing on age-related loss).

One of the common themes among adults of all ages who experience visual impairment is their perception of sight loss as a major challenge, prompting the need to re-establish ways of relating with others (Wang and Boerner, 2008). Issues around isolation and the importance of social support for people diagnosed with visual impairment is well documented in the research literature (Thurston, 2010).

Visual impairment has been found to be associated with a higher than normal risk of depression (Crews et al, 2006, on older adults with visual impairment experiencing co-morbid conditions and the effects on social functioning and health). Carabellese et al (1993) found that older adults with vision impairment had a 2.3 times greater risk of depression than those without a vision problem.

Psychological services play an important role at each stage of diagnosis, treatment and rehabilitation for those with issues around visual impairment.   It is therefore vital

that, as counselling psychologists and psychotherapists, we better understand and respond to the needs of those who present with issues deriving from their experience of living with visual impairment.

In particular, I agree with Supple and Corrie (2004), who take visual impairment as an example of one specific form of diversity, in arguing that substantive guidelines for therapeutic practice are lacking.   The findings of an online survey being conducted by the Disability, Pregnancy & Parenthood International (June 2011) discovered that 93% of health and social care professionals said that they would like more training on working with parents with disabilities. Additionally, a thorough exploration of meaning around disability and therapeutic practice remain underexplored in many counselling psychology and psychotherapy training programmes. Yet "*the representations and expectations held by psychologists and the institutions that train them will directly affect the lives of disabled people.*" (Supple and Corrie, 2004, p.5).

Against this background of trends within vision loss, and the part played by psychology and psychotherapy within this, there are two main reasons why I chose to focus this study on mothers with visual impairment: one drawn from the professional field, and one from the personal.

(i) As a response to calls to action made by recent research

Pertaining to the professional, this piece is in response to five main pieces of work, signposting towards further research and the methodological ethos and approach of this investigation:

Firstly, there has been a notable impetus to look towards a difference in methodological quality and process within research on issues of visual impairment. Following Kitchen (2000), Duckett & Pratt (2001, 2007) conducted a review of visual impairment research, commissioned by the Thomas Pocklington Trust, into the opinions of visually impaired people on visual impairment research.

Amongst their findings, they called for research practices where there was empowerment, and "*greater inclusion of visually impaired people*". With regard to attitudes and stigma around people with visual impairment, the findings showed participants wanted research to map out the pervasiveness of such stigma, and research to change attitudes.

Duckett & Pratt (2001) also talked about "*getting people out of the woodwork*", finding a large number of visually impaired people remained hidden from services. The findings also emphasised the importance of making research more transparent, attending to power dynamics. They talked about the need to ensure that the work is congruent, practical, relevant and understood by all those who can gain by it: those who are visually impaired, academics, practitioners and so on, such that findings can be put into practice.

Secondly, within the field of visual impairment research, there has been a move towards greater investigation into the 18-64 year old age group. The majority of research into visual impairment is polarised in its focus either on children or the 65 plus ageing population, (De Leo et al, 1999; Green et al, 2002). As a result it is difficult to estimate exactly how many parents with visual impairment live in the UK today.

Tate et al (2005) in their review of the literature noted the scarcity of information about those with visual impairment of working age and estimated about 80,000 registerable blind and partially sighted people in the UK. The only other available figure of relevance is that there are over 2 million parents living with a disability in the UK today, a large number of whom have a sensory deficiency (Disabled Parent Network, 2010). The charity Disability, Pregnancy and Parenthood International reported in the early findings of a survey in June 2011 that 67% of disabled parents felt they received unsatisfactory support as parents, and more than half (53%) were unhappy with the support they received during pregnancy and birth.

One major piece of recent research which cited parental needs and views is a longitudinal study (Douglas et al 2006) from the Visual Impairment Centre for Teaching and Research (VICTAR) based at Birmingham University. Funded by the

Big Lottery and Vision 2020 on behalf of sector organisations such as the RNIB, VICTAR ran the first longitudinal study of its kind with major sector wide involvement. The project consulted with 1,007 blind and partially sighted people aged 18 and over, with a view to capturing statistically useful data on their changing views, experiences and needs. Recruiting equal numbers of people from five different age groups: 18-29 year olds; 30-49 year olds; 50-64 year olds; 65-74 year olds; and 75 years and upwards, 109 of these were described as living with children under the age of 16.

In addition to the quantitative element, participants were asked a series of open-ended questions by telephone interview. The project touched on the experiences of parents with visual impairment caring for a child or children under the age of 16. However, it was a minor aspect of a project overall that looked at issues of independence, transport, finance, leisure, employment and support.

In particular, participants with young children talked about difficulties in caring for their children and being able to offer them the same opportunities as children with sighted parents, noting the lack of support services in this area; for example, this comment from a working mother aged 37, (Douglas et al, 2006, p.88): *"My main issues at the moment are being a blind parent to sighted children, my main gripe is that there's no support, I don't fit into any group. You get help if your child is disabled or you have a different disability. Things like taking the child to the park – or having curriculum books that I can read to/with them. And generally support for me to help with his homework. There are lots of info sheets, but not enough practical doing, people to help do things."*

Two further recent studies in this area were the RNIB Bristol Counselling Project report (Dale, 2008), funded by the Department of Health, which talked about the need for an increasing diversity of client groups within counselling for people with visual impairment; and the mixed methods study by Thurston et al (2010) on the socio-emotional effects of the transition from sight to blindness. The latter in particular sought to examine the counselling experiences of blind and partially sighted adults, and give them a voice. It had the direct aim of building up an accurate picture of their needs, proposing the transition to blindness model

(Thurston, 2010, p.9), with a view to future policy and practice recommendations, and, together with Dale (2008), has been a major influence on this project.

One of the findings of Dale's collaborative narrative-based research was that many of her participants with sight loss commented on how difficult their lack of vision is for their close family. In combination with changing relational dynamics, their sight loss upsets long-held roles and expectations for the future. This is particularly true when the person with sight loss is at the centre of the family, in the role of primary caregiver. The impact stretches out from partner and immediate children beyond through the generations (with decisions around the possibility of genetic counselling for conditions such as Usher Syndrome or Stargardt's Disease).

Finally, at the level of public policy and professional practice, VINCE (Visual Impairment Network for Counselling and Emotional Support), was established in 2007. Its campaigning and research has highlighted the need for an increased awareness of the experiences of those with visual impairment, in order for psychologists, psychotherapists and others to offer the emotional support to those with visual impairment across all age groups. This was confirmed by the comments of support when I presented this project as a work in progress at the VINCE conference March 2011.

(ii) Researcher-practitioner: placing the project in the personal realm

This project also has a strong personal element. My family has a history of poor eye health, with glaucoma on both sides. My paternal grandfather was registered disabled at the age of twenty-two after fighting in the RAF in World War Two, with disabilities that included poor sight and diabetes.

My mother was diagnosed with total sight loss within months at the age of forty due to a rare and aggressive form of glaucoma in both eyes. She was fortunate to be offered the chance to receive pioneering surgery at Moorfields Eye Hospital in London, and the majority of her sight was preserved. However, since then we have lived with ongoing six-monthly check-ups to preserve and monitor the outcome of that operation.

Now a parent myself, it remains important that my children and I have regular check-ups given my family history. Additionally, I am extremely myopic and, during the course of this research, was involved in a car accident which itself has led to long term minor vision problems, plus anxiety over the possibility of further retinal damage. My experience of the anxiety surrounding sight loss is an aspect that has placed the personal figural in a unique way with this study (which I explore in depth later) and in my hopes for setting up this specialism clinically as a counselling psychologist and psychotherapist for people with sight loss.

I have been careful to observe and note the reflexive piece throughout this project. I am aware that my own biases, interests, values, experiences and characteristics will naturally play an important part of this research process. Supple (2005, p.421), a counselling psychologist, herself visually impaired, comments that "*psychological practitioners need to be aware of what representations and assumptions they hold regarding disability, as well as how the institutions they train and work in deal with the topic of disability*".

Comments on my reflexive process at the micro level are found throughout the report, as well as more macro issues such as questioning assumptions around the chosen methodology, part of what Wilkinson (1988) calls "*disciplinary reflexivity*". An important part of this reflexivity has been around my position, as both insider (a mother of young children) and outsider (a sighted mother). It has been interesting for me to consider where I sit in this process of opening up a space for conversation between visually impaired and sighted communities, in an attempt to empower and give voice to those who are visually impaired and encourage research which does not negate their experience (Dale, 2008).

Review of related literature

Overview

Baumeister and Leary (1997) outline five possible diverse goals that a facilitative and well-structured literature review might incorporate. This section, as a contextual piece for the mothers' accounts, aims to illustrate two of these, being (1) to summarise the state of knowledge (both published and unpublished) on my research topic of the experiences of mothers with visual impairment, and (2) to locate where this study may contribute by identifying and critically evaluating the potentially controversial areas or "*mapping a field of knowledge production*" (Kamler and Thomson, 2006).

Keen to place the arguments in a historical context, and to illustrate some of the philosophical perspectives and theoretical models in the field, I examined two main areas in previous literature around the topic: 1) on a macro level, psychology and psychotherapy's relationship with disability; and 2) the psychological aspects of living with sight loss as a mother.

Conventional searching of peer-reviewed scientific and practitioner literature revealed a small body of materials discussing motherhood and visual impairment. Only one article (Kent, 2002, a first person autobiographical case study) focused on the impact of becoming a mother with visual impairment. Two further major recent studies concerning the experience of parents who are visually impaired are described in detail in the sub-sections below (Conley-Jung and Olkin, 2001 and Rosenblum, Hong and Harris, 2009).

They follow the lead taken by Ware & Schwab (1971), the first to expand in a systematic way on anecdotal evidence (Arsnow et al, 1985, Branson, 1975, DiCaprio, 1971, Hirshberg, 1960 and Kendrick, 1983). Ware & Schwab interviewed ten mothers with visual impairments with regard to their role of being a mother and child rearing activities, e.g. children's clothes and personal hygiene. They found the mothers learnt and performed most child care tasks through trial and error rather than receiving any specific support. The recommendation (which Rosenblum et al,

(2009) comment has yet to be followed up) was that these practical basics of childcare tasks be covered in a training programme, to allow the mothers to concentrate more on the emotional aspects of bringing up a child.

As early as 1971 (before the work of Adamson et al, 1977) there was evidence of the strength of the emotional bond between mother and child, and the importance of that within the attachment process. The key finding of the Ware & Schwab (1971) study was that despite the trial and error childcare approach, "*nothing about their visual impairment changed the fundamental aspects of parenting – nurturing, loving, decision making and guidance*" (Conley-Jung and Olkin 2001, p.17).

In addition to the formal academic pieces, I found more material in the grey literature collated and held at the RNIB library, plus a growing incidence of blogs and discussion groups on the internet (e.g. Vision Aware's Blind Bloggers: Blogs by People Who Are Blind or Have Low Vision, based in the USA; and in the UK, the RNIB's Parents Place and on the Action for Blind People website, Sandi Wassmer's blog, a mother registered blind in 2008, sharing the "*shenanigans of visual impairment*").

Scant research around parenting with a disability

I discovered two key points about research studies into parenthood with impairment or disability of any description (physical, sensory, mental, learning).

Firstly, there is scant research in this area generally. As Olsen and Clarke (2003) highlight, most searches with the terms "parents" and "disability" centre largely on childhood disability, not parents with a disability and their experiences. Hence articles on the experience of being a parent with a sight impaired child were in the majority covering issues such as the emotional, social and educational aspects, and the overall impact on the family through parenting a child with a disability (de Klerk and Greeff, 2011, Garber, 2007, and Jenks, 2005).

Notable exceptions in the field of parenting within the disability movement (Olsen and Clarke, 2003) include the feminist perspective put forward by Morris (1991,

1996), and social science research undertaken by Wates (1997) and Morris and Wates (2006). This presents the idea that a disability rights perspective is necessarily entwined with the feminist perspective, on the basis that a disabled woman faces oppression from two angles, one being disabled and the other, a woman. Both Morris and Wates emphasise the part played by the barriers created in societal attitudes and practice to participation in parenting, and their effect. These are seen against their understanding of the dominant social norms that see caring roles in general, and child-caring in particular as an important element of female adult identity. However, I hold the feminist agenda to be fluid, and even within the last decade the shift in such identity is palpable e.g. one in five women in the UK will not have children, many by choice (Hakim, 2011).

The second point I discovered about the field of parenting with a disability was that early on in my search, a review of the psychological literature between 1999-2001 (Supple, 2001) confirmed my suspicions that negative, individualised medical notions of disability remain prevalent in psychological research. This is not just true of psychological research in this field but research generally concerned with parenthood disability or impairment. With the important exception of a few voices in the field (Olkin, Kirshbaum, Conley-Jung, and Rosenblum et al (all US based) and Olsen and Clarke, discussed below), there is still at best an ambivalence or exclusion from the mainstream.

At worst, a pathologising exists within psychological and mainstream literature towards parents with disability (where the presupposition is one of the negative effects of parental sight impairment towards the children, leading to problems around their safety, or physical and mental well-being). I believe there is a vital need for accuracy in the field to guide policy and inform clinical services. Olsen (1996, p.41) points out that much of the relevant research "*has tended to involve the search for the negative impact of an adult's disability on a child's growth, intelligence and adjustment*".

I recognise that a strong and sometimes violent expression of such antipathy has been apparent throughout history (e.g. the compulsory sterilisation legislation for the purposes of eugenics across numerous US states from 1907-1956, which targeted

among others, those with sight disabilities; and approximately 275,000 people with disabilities were killed by the Nazis under their T4 eugenics programme).   I remain shocked that, within my lifetime, the wish for people with disabilities to want to be parents has been interpreted as a way to "*brighten up their dreary lives*" (Heslinga et al, 1974, p.178).

Research sponsored by the Maternity Alliance (Goodman, 1994), found that professionals were counselling women with a disability to avoid pregnancy or choose abortion, citing the impending problems they would face in parenthood.   Lutz & Bowers's (2005) exploration of how people with disabilities experience everyday life described how genetic testing for disabling conditions and ensuing family planning and abortion counselling were further evidence of the perception of devaluing of the life of a person with disabilities.

As recently as May 2010 in Missouri, USA, Erika Johnson, a mother with sight loss, had her two day old daughter taken away from her by the authorities for 57 days. A nurse on the maternity ward deemed her to be an incompetent mother, having noticed her struggling with breastfeeding.   This is an experience common to the majority of new mothers, whom as Lawrence & Lawrence (2005) point out are not born knowing how to breastfeed, and it is therefore normal to struggle or have questions and concerns.   The nurse had written on the chart "*the child is without proper custody, support or care due to both of (the) parents being blind, and they do not have specialised training to assist them.*"   As Erika, stated in the Kansas City Star, "*We never got a chance to be parents, we had to prove that we could*".

As Kirshbaum and Olkin have concisely commented, parenting can be seen as the "*last frontier for people with disabilities*" (2002). Therefore, in carrying out this piece of research, I recognise there still remain very real threats around the right to parent (Olkin, 1999, & 2002) and the cultural and political sensitivities around this research and its possible misuse. This can be seen from studies such as Wright (1983) who highlights the so-called spread effect of disability, where limitations due to disability in one function, e.g. sight, is assumed to spread to other sensory or cognitive abilities.   Similarly as Olkin (1999, p.126) emphasises, one of the problems with the

literature on parents with disabilities is that "*reports on parents with mental retardation are often generalised to parents with physical disabilities*".

Theoretical models in disability research

At this point I feel it is important for me to draw a distinction between the two main theoretical models in the field and where I feel this research sits. As Supple (2005) highlights at the start of her review of the portrayal of disability in the psychological literature, physical impairment has been a constant in the lifespan of the human race, and stigmatised at least as far back as the first century AD (as challenged by Jesus in John 9:1-12).

From these ancient beginnings, what was apparent when I started my literature searches, was that much of the research concerned with sight impairment comes philosophically from a positivist viewpoint, – a medical-based model of the causes of sight impairment (e.g. Notis et al, 1996). The emphasis tends to be towards treatment and rehabilitation (Marks, 1997), even when a psychological angle is uppermost (De Leo et al, 1999).

The underlying assumption within this model in understanding issues around sight impairment is that medical science is working towards a "cure" to help restore vision. The visual impairment, the physical limitation, is seen as a parental deficit, located within the individual. The person with the disability is perceived as requiring care, support or treatment. Although the medical model identifies some of the needs that a person with visual impairment might have, it can be argued that this view does not give sufficient weight to factors external to that person which clearly impact on their quality of life.

An alternative model, favoured by social science research (Finklestein, 1980, Barnes, 1991, and Oliver, 1996), and in particular disability studies, locates the problem as emanating from societal attitudes rather than intra-individual. I see this model as the theoretical basis of the work of the major researchers in the experience of parents with visual impairment described below: Olkin (1999, Conley-Jung and Olkin, 2001, Kirshbaum and Olkin, 2002; and Rosenblum, Hong and Harris 2009).

Thus, impairment (an embodied limitation viewed at a functional level) is distinguished from disability, with the latter defined as "*the disabling barriers of unequal access and negative attitudes*" (Morris, 2001, p.2). Thus the limitation of the disability is located not in the parent, but in discriminating and prejudicial attitudes that create inequality for disabled people. Oppressive attitudes cast those with a physical impairment such as sight loss into a disempowered and devalued position within society.

This socially constructed model of disability shifts the emphasis away from differences within the individual parent and towards the social barriers and contextual factors faced by parent(s) with sight impairment. Solutions to issues around disability in this context therefore centre around policy changes and the removal of attitudinal barriers, rather than looking for a cure. Disability is seen as part of a diverse range of possible embodied ways of being within the human condition, as opposed to lack of ability (Oliver, 1996).

This socially constructed model has an immediate appeal for me as a counselling psychologist as it offers a basic theoretical framework where both the social and personal factors can be examined that shape a visually impaired mother's experiences of parenthood, seen as less significant on the medical model view. However, the emphasis on social factors, within the former model, almost to the exclusion of the embodied reality that underlies an individual's experience of the physical realm (Merleau-Ponty's (1962) notion of the "lived body") to me also does not necessarily provide access to what is a complex overall picture.

I acknowledge the main criticism made by Lutz & Bowers (2005) concerning both the medical and social theoretical models prevalent in the literature. They argue that neither model conceptualises disability adequately, resulting in a polarisation that occurs with research and services designed from either the medical or social perspective.

Lutz & Bowers' findings, using dimensional analysis from thirty-eight interviews plus analyses of four previously published data sets on how people reported experiencing

having a disability in their everyday life, point to a more integrated approach. With an average sample age of forty (and where all but two participants had limited mobility), they found the extent to which integration of the life of the person with a disability varied according to three disability-related factors: (1) the fundamental effects of the disabling condition, (2) others' perception of the disability and (3) the need for and use of resources; with important contextual conditions of environment, time and experience.

As an integrative research-practitioner myself, I am drawn to the philosophical and practice-based attempt made by Lutz & Bowers (2005), to aim for a conceptual model of disability that better reflects personal experience of disability. I am persuaded of the importance of integration within the complexity of the relationship between the individual person with the physical impairment and the society where they live.

The current position outlined in the conceptual framework by the World Health Organisation in its World Report on Disability (2011) goes some way to attempting to integrate the medical and social. It understands "*functioning and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental. Promoted as a "bio-psycho-social model", it represents a workable compromise between medical and social models. Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)*". However, I also note that despite the quotation just given, the WHO still appears to regard the disabling health condition (physical or mental) as the primary construct in its International Classification of Functioning, Disability and Health (ICF) and thereby, I would argue, it subscribes to the medical model.

Expectations of self and other around being a good enough mother

Having briefly outlined where I believe this study fits in terms of the main theoretical models in the field, I now turn to the key issues raised in the psychological literature around the impact of parenthood on the mothers' sense of self.

A number of these issues falling under Winnicott's (1965, p.145) concept of the "*good enough*" mother. He asks "*What is meant by the term good enough?*", and frames this question in terms of the mother's adaptation to the infant's needs. As stated in my philosophical perspective in the methodology section later, I see the micro-interactions between the mother and child as crucial to the internal development of the infant and her sense of self (Stern, 1985), with the infant primed for relationship from birth (Fairbairn, 1994). Evidence shows that infants and young children readily adapt the nature and type of these micro-interactions (touch, vocalisation and visualisation) to sustain and develop their relationship with their parents with visual impairment (Adamson et al, 1977; Collis and Bryant, 1981 and Rattray and Zeedyk, 2005).

Therefore, any model of the mother-infant dyad that places particular emphasis on one aspect of a single communication channel, (e.g. the visual, or the auditory), would appear to underestimate and oversimplify the complexities of the attachment process. I agree with Conley-Jung and Olkin (2001, p.16) that such a singularity of approach stigmatises and "*unnecessarily pathologises*" parents with disabilities.

For me, the ideas around being a good enough parent are encapsulated in Josephine Klein's concept of a parent that "*recognises the depths of their baby's feelings, good and bad, gives solidity to that baby's experience of itself. Such recognition helps consolidate the baby's integrity and sense of self: its identity. Joyous recognition will encourage a joyous identity.*" (Klein, 1987, p.2) How that "*joyous recognition*" is carried out will vary enormously from parent to parent, depending on contextual factors, their capabilities and own sense of self.

I initially came across this internalised sense of self as an inadequate mother, purely as a result of having a visual impairment, expressed in Kent's (2002) reflective piece

on her experiences with pregnancy, birth and raising a child, as a blind mother in Chicago in the 1980s. In her article entitled "*Beyond Expectations: Being Blind and Becoming A Mother*" Kent recalls facing the impact of the stigma of her disability early in her teenage years, when her desire to be a babysitter is crushed by parents in her local neighbourhood unwilling to have faith in her abilities as a carer.

This sense of self, reflected back by others, as the helpless incompetent one, a second class citizen, as opposed to fulfilling her desire to experience the nurturing role seemingly open to her sighted friends, is deepened as she enters late adolescence and develops a fear that "*my friends would marry and have children and I would be left behind*". From a socially constructivist perspective, the constant exposure to negative attitudes from others, such as those that Kent faced, could lead a person with a disability, to internalise such attitudes, what Olkin (1999, p.228) has called "*internalised ablism*".

Now a mum, Kent cogently expresses through autobiographical case study, one woman's experience of the impact of facing not just the "*performance pressure*" felt by many a new mum when her baby will not stop crying out in public, but a sense that "*wherever I went people were observing me, wondering about me, at time doubting my abilities*" (2002, p.85). For Kent, discovering other visually impaired mothers living across the country willing to exchange ideas and feelings about their experiences via letters (this is pre-email) proves to be a supportive lifeline in her initial sense of isolation.

The "*Beyond*" here in the title, encapsulates not just her sense of the challenges of becoming a mother with visual impairment under others' scrutiny, but "*Beyond*" too in a more positive sense, that her experience of motherhood is more fulfilling than the author had hoped. I was also interested to note that it takes her "*Beyond*" in a different way again - Kent comments that motherhood gives her, felt to be an outsider through her disability, access to a new kind of inclusiveness – "*pregnancy proved to be a common bond with women of all ages*" (2002, p.83).

In their mixed methods study interviewing forty-two mothers with either total or partial sight loss, Conley-Jung & Olkin (2001) found that the mothers voiced a number of

concerns common to all parents, but also some unique to their experience as a minority parental group. Thirty-seven of the forty-two mothers interviewed had been visually impaired since birth or childhood, and five since adolescence or early adulthood.

Again the impact of others' reactions on themselves and their children to their status as a parent with visual impairment emerged as a theme of significant note. Strategies in managing others' reactions and their impact constituted a significant part of their experience of being a partially sighted mother. A key factor around this issue seemed to be support from others, especially family and healthcare providers.

This is best summed up by one parent who felt she has to "*give (of herself) 110%*" to be viewed even on an equal level with other (sighted) parents (2001, p.23). This links up strongly with the good enough parenting theme. Approximately, 10% of the mothers in this study experienced active interference in their becoming mothers (i.e. steps to remove the child or pressure to have an abortion).

Conley-Jung and Olkin's (2001) study is the first methodologically rigorous (collecting both quantitative and qualitative data) study that also has at its core the goal of presenting authentic voices of the mothers involved. Conley-Jung is herself a mother with visual impairment, thus also key to this study is the researcher-as-insider, similar to Dale (2008).

Another aspect of the parenting experience reported by the mothers was that they needed more time for their parenting – everything takes longer. However, they reported significant benefits such as increased time for mother-child bonding and fostering intimacy, e.g. a mother who does not drive spends time walking and chatting to her son as they make their way to his destination.

One of the limitations of the study was that the data originated from self-identified, motivated volunteers (who were mostly well-educated, middle-upper class) as opposed to a random sample of mothers with visual impairments. They were therefore possibly keener to reflect on or discuss their experiences, either as being particularly positive or negative. Additionally, all had fairly long and stable histories

of visual impairment. The study did not, therefore, investigate the experiences of those trying simultaneously to adjust to becoming a mother and a sudden or gradual decline in their sight.

A more recent and larger investigation, also in the US, by Rosenblum, Hong and Harris (2009) added weight to many of the findings of Conley-Jung and Olkin (2001), particularly in the areas of the challenge of transportation and restrictions on mobility and spontaneity. They interviewed, via telephone, sixty-seven parents who were visually impaired, with one or more children who was a senior in high school or younger and living at home full time (70% of the participants were mothers, 87% of whom lost their sight prior to the age of eighteen).

The results fell into three main topic areas: the social and emotional aspects of being a parent with a visual impairment, practical ways of dealing with various aspects of raising children, and advice and information needed or desired that would be helpful for the participants or future parents with visual impairments.

Focusing on the responses concerning the social and emotional aspects of being a parent with sight loss, the participants emphasised many positive aspects: for example, they noted their children as more compassionate or empathic towards others, plus many children were confident in problem solving when faced with a challenge (supported by others who have speculated that the development and functioning of children whose parents have disabilities is better than average Buck and Hoffman, 1983, Cohen, 1998 and DiCaprio, 1971). There was also an acknowledgement too of a sadness expressed by some who felt left out of activities that their children were doing, e.g. unable to see their drawing, or taking part in a football match.

The parents also emphasised added anxiety around transportation and monitoring their child's safety. A few parents reported they believed they were being watched by others who questioned their ability to parent simply because they were visually impaired, commenting on "*that intensity of curiosity*". The medical model view, represented here in the experiences of some of the parents' interaction with members of the medical community, causes significant distress to the parent

involved (e.g. where Child Protective Services are called because of the mother's visual impairment). Thus this medical deficit-led approach promotes the idea of the parent as in some sense inadequate purely because of their visual impairment.

Worryingly, the default level of suspicion around in societal attitudes around in 2009 towards a parent with sight loss does not appear to be significantly different than that shown above in Kent (2002), who also details unexpected visits from Child Protective Services. With little evidence of an improvement in this aspect, Rosenblum, Hong and Harris (2009) suggest that the medical community should be advised about the abilities of parents who are visually impaired.

However, the main focus of the study and the majority of the findings were focused on strategies for practical aspects of the parents' daily life with their children, e.g. practical challenges of negotiating a pram and a guide dog. There was a strong sense of daily resourcefulness and initiative that came across, e.g. using assistive technology to help with homework, and peer support.

One of the limitations of this study was in the recruitment of the participants largely through the Internet or in third sector newsletters. This meant that they were a essentially a "*connected group*" and may not have been representative of the population of parents with visual impairments.

A further possible weakness of both the Conley-Jung and Olkin (2001) and Rosenblum et al (2009) studies is the lack of openness and freedom to follow the participant during the interview. Both use structured interview questions, with Conley-Jung and Olkin (2001) following four specific a priori hypotheses and four research questions, addressed over two parts.

Highlighting the phenomenological approach

Aside from these few formal research studies, I reviewed over twenty personal stories recorded in the RNIB library and via blogs and message groups. These included articles entitled: Surviving Teen Driving, Tips for Blind Parents noting the tension, thrill and anxiety involved when your child becomes old enough for a driving

licence, also citing the importance of maintaining your independence; A Day in the Life of a Blind Mother of Four (Angela Kimball, 2011 Associated Content) keeping a check on her kids busy social life while getting dinner for six each night. UK-based mums were also represented, e.g., an article in Insight magazine about Louise Holden, a mum of two small boys living in Leeds, born with oculocutaneous albinism and nystagmus with a squint, and the charity worker Croydon mother of two, deaf and blind, nominated for top employee at Sense in 2011.

These narratives often conveyed something of the frustrations of life in a world where most others have sight. Overall, however, like any parent, the spirit was one of the enjoyment and frustrations in bringing up children, combined with creative consideration of ways round the challenges sight loss presents. There also were a number of articles written by adult children who had grown up with one or more parents with sight loss, providing another perspective on family life and dynamics (e.g. Reid, 2006).

I found one account particularly interesting, written by John Hull (1997), a theology professor based in Birmingham (although it is a father's, not a mother's, account, I feel it is important to highlight his experience due to the detail of his recording and phenomenological approach). In his book Professor Hull presents a detailed diary account of what it is like to change from living as a sighted parent to losing sight, recording his feelings, thoughts and dreams.

Influenced by the phenomenological philosopher Merleau-Ponty, he talks about the tension between the sense of deficiency in the "*wound of the original loss*" in contrast with the "*terrible gift received*" (Hull, 1997, p.xii). An example of the "*terrible gift*" is his entry "*Between You and Me, a Smile*" (1997, p.184) where he reflects on a conversation with his four-year-old daughter where she observes that her father, now totally blind, can no longer tell when she is smiling at him, and how she receives a smile back from him. He is touched by her "*fine distinction ... between smiling at someone and the smiling which takes place between people*" and the "*in-between smile*" that father and daughter now fashion together in his visually impaired state.

Looking into this topic area in the grey literature, it seems that there are a number of interesting points not raised by the formal research studies, e.g. the prevalence of Pre- and/ or Post-Natal Depression, poverty of access to psychological services, and the emotional impact of sudden or gradual sight loss while being a parent, plus issues around the barriers to employment for potential working mothers with sight loss.

In summary, therefore, my aims within this investigation were (1) to develop understanding for theory and practice within the field of counselling psychology and psychotherapy in an area where there is scant existing research, particularly in the UK, (2) to use a new methodology that centralises the subjective experience of the participant, highlighting awareness of the participants' experiences in their own voices, (3) to voice that authenticity through analysis resulting in a wide variety of meta-themes and themes that emerge to the wider community, and (4) thereby to question collective assumptions around parenting with a disability, (including the two main current theoretical models in that field), with a view to encouraging further debate and improving services.

Methodology

Overview

My aim within this section is to give the reader a full appreciation of the philosophy and methodology behind the study. I also discuss some of the tensions and choice-points that arose through the methodology process, including important areas such as ethics, validity, reliability and trustworthiness.

Philosophical perspective

At this point I believe it is helpful to expound a little on how I work as a counselling psychologist and integrative psychotherapist, given this naturally has had a significant influence over (1) the philosophy behind this piece of research, and (2) the methodological choice of IPA (Smith et al, 2009) as the exploratory mechanism for managing, organising and transforming into meaningful units the data of the participants' experience.

After six years on the joint programme in Doctorate in Counselling Psychology and Psychotherapy by Professional Studies (DCPsych) with the Metanoia Institute and Middlesex University, I gained UKCP registration in May 2011. I am now based in a large house in Southampton, a long established private practice with a number of other psychologists and psychotherapists, on a freelance basis.

My integrative model, developed over the course of my training, and ongoing, working as a counselling psychologist in training and integrative psychotherapist sees humans as fundamentally relational beings. Whether my clinical focus pertains to the intrapsychic, interpersonal, socio-political or transpersonal realm of my client's experience, any change in my client's sense of self takes place within the relationship (Clarkson, 2003, Maroda, 2010, Lapworth and Sills, 2010). While I situate my work in the existential-humanistic tradition, emphasising the here-and-now (Orlans and Van Soyoc, 2009), I also recognise the strong influence of the past on the present, by emphasising the developmental.

I work with aspects of the implicit relationship, which informs me of what my client is conveying to me about their feelings and struggle (Maroda, 2010), as well as the more explicit real relationship (Clarkson, 2003).   At the heart of my integrative model lie three tensions around this fusion of existential and developmental traditions.

Firstly, I consider that we all face anxiety (often the starting point for therapy), evoked by our state of existential isolation: we come into and exit the world alone (Yalom, 2008). Yet, I believe this position is mitigated by our basic stance as human beings primed for relationship (Fairbairn, 1994), with the relational central to the way we experience life: through relationship to body, self, other and the wider environment.

Drawing on compelling developmental evidence that centralises the infant/caregiver dyad, I attend to my client's early attachment history conceptualised through the Internal Working Model (Bowlby, 1988) and its effects in adulthood (Main et al, 1985).   The self begins within another, prior to physical separation at birth and continues to emerge through relationship thereafter (Stern, 1985). I also emphasise the importance of my client's "*lived body*" (Merleau Ponty, 1962) as the basis for that experience.

A second tension centres on responsibility.   I hold the existential belief that my clients are responsible for the way they direct their lives (Van Deurzen, 2002), but also acknowledge present behaviour, actions and emotions that appear to be out of awareness and beyond their responsibility. These may be rooted in environmental factors and my client's developmental journey (Lapworth and Sills, 2010).   Our ability to relate to self and develop self-care begins at the most basic level with the emergence of self through relationship with her caregiver, by mutual processes such as "*attunement*" (Stern, 1985).

The third strand of my existential-developmental model explores the tensions in the space between the individual and collective experience, described by the dialogic theorists as the "*interhuman*" space (Hycner, 1993, p.4).   I see my client as an individual *standing out* (the original root of existential – *existere*), caught in the tension between detachment from the world and being part of it. I hold that people's

interactions are often grounded in the wish either to unify and merge, or differentiate and separate. My interest in the "*interhuman*" has been of particular importance in this study, as many of the themes that emerged were concerned with how the participants were impacted by the other's discomfort or rejection of similarities and differences between them (and implicitly vice versa).

Within my integrative model of working, as a research-practitioner, I am conscious of the complex historical and socio-political contextual piece in conducting research around the concerns of people with visual impairment. I have deliberately positioned this study apart from the hegemony of traditionalist social scientific enquiry with its claims to objectivity and value neutrality. This work falls instead within the developing genre of post-positivism research, preoccupied with the ontological and phenomenological realm, looking to address the real socio-political concerns faced by minority groups, such as mothers with visual impairment.

I believe the assumptions about the nature of reality, knowledge and goals of enquiry within the study are consistent with my theoretical stance as a integrative psychological therapist and researcher. A phenomenological approach and the spirit of IPA includes at its very heart a basic collaborative stance, a respect for multiple perspectives and a curiosity about exploring the other's meaning.

While there are many constructionist models, they all hold to the post-positivist epistemological belief that is not possible to capture access to a totally objective reality, one that stands apart from the knowing subject (Singer, 2005). Instead, all human knowledge is viewed as constructed through social experience. As individuals we are engaged in a complex and ongoing process of understanding the world, developing our own perspective on it.

The chosen methodology of IPA is rooted in my aim to examine the experience and perception of each mother interviewed with an attempt to get as close as possible to my participants' experience and its essential structure (Smith, 2003). I conceptualise the framework of this piece as coming from a contextual constructionist perspective (Madill et al, 2000), where all knowledge is necessarily contextual and stand-point dependent.

This contextual constructionist perspective can also be seen to fit within the critical realist tradition (Guba and Lincoln, 1994). I hold the idea that there is a single reality to be explored but that meanings are fluid and there will be different views or explanations as to what might be happening. Thus, I therefore have difficulty with the realist claim to objectivity and the notion that the researcher and the researched participant are independent of each other.

IPA methodology also recognises the interpretative role played by me as both interviewer and researcher. Thus my research participants help to construct the "reality" with me as researcher. As such I was unable to establish conclusively the totality of research questions ahead of time. However, the main exploratory questions held in mind during the semi-structured questioning were:

- What did the participant feel was the impact of becoming a parent?
- What part did being a mother play in the participant's wider sense of self?
- How did being a mother affect the participant's relationship with family, friends and the wider community?

As well as a basic stance of openness and inclusion in planning the project strategy, I tried to follow the good practice recommendations for research that emerged from the review into the opinions of visually impaired people on research, Duckett and Pratt (2001, p.815): "*to respect people's individuality; be practical and action-orientated and contribute to an empowering and emancipatory research agenda*".

Choice of methodology

Dr Graeme Douglas, Research Fellow at VICTAR (the Visual Impairment Centre for Teaching and Research), commented in the RNIB research newsletter, in May 2007, "*there are many valuable types of research open to us, but one of the most valuable approaches surely involves trying to capture visually impaired people's own views about their circumstances and lives.*" Given the overall idiographic aims of this project that lie within the spirit of this quotation, I was naturally drawn to a

methodology that places the subjective experience of the participant as figural. Thus these aims tend more towards the qualitative than quantitative side of research analysis, being concerned more with the question of classification and exploration; what is X?, rather than that of enumeration, how many X? (Pope and Mays, 1995).

The phenomenological philosophy and method, founded by Husserl (1859-1938) and extended by his student Heidegger (1889-1976) with the concept of "dasein", is based on the premise that everyday experience is a valid and rich source of knowledge. IPA, which emerged from this school, appeared to be a natural fit, being a form of phenomenological enquiry that aims to capture an understanding of the "*lived*" experience of the participant, with me as researcher employing interpretative skills through a systematic approach (Smith, 2003).

Through a detailed analysis of each case, this study aimed to highlight typically silent voices in the fields of visual impairment and parenting, using them as a resource with an important contribution to make. With a small and purposive sample size, my aims were to explore the divergences and convergences within this idiographic approach, rather than say, the use of grounded theory, which seeks to establish claims for a broader population (Brocki and Wearden, 2006).

The interpretative element of IPA appealed to me, as my background is one of grappling with meaning at the granular micro level through to overall macro themes. My training in this has been honed through a decade of textual literary analysis (I hold an MA in classics, where I engaged in the struggle of coming up with an adequate translation from the original language that might convey something of the complexity offered by Greek dramatists such as Sophocles and Aeschylus; historians such as Thucydides and Pliny; and philosophers such as Plato and Lucretius). IPA is a methodological choice driven by the "*phenomenon under investigation*", allowing a movement from broad stroke to fine tuning (Lennie and West, 2010, p.83).

While this project firmly remains the mothers' story, it is one that has been co-constructed in many senses by me as the researcher. Unlike, say, hermeneutic analysis (Van Manen, 1990) (which also does not seek objective meaning but the

meaning as reported by the participant), I am not looking to entirely bracket off myself in the process. I believe it is impossible for research not to be contaminated by the researcher, and this is an aspect that should be fully examined. This reflexive and important element of the research is commented on throughout. However, a specific section within the discussion as a reflective summary piece gives a transparency to the process, my argument and investigation.

A phenomenological approach fitted with my critical realist stance because of its respect for a collaborative take and a basic position of curiosity and openness in exploring another's meaning (Crotty, 1996). I adhere strongly to phenomenology's goal to establish a close connection with another's experience to understand it better and to transform that experience into consensually validated knowledge (Boss, Dahl and Kaplan, 1996).

A single research approach, qualitative in form, was used because of the nature of the phenomena under investigation – feelings, thoughts and beliefs about being a mother with visual impairment – and as the participants required considerable time and sensitivity to explore the issues for themselves. A sense of engaged exploration was my main aim with this investigative study: there was no attempt to test a pre-determined hypothesis, and in that sense this methodology could be described as inductive (Smith, 2003).

IPA's particular appeal for me in this study is that it allows me to try and fully inhabit the world that my participant is elucidating with me in response to a series of semi-structured open questions. Through individual interviews in the IPA process, using co-constructed audio and written documentation, I was able to have an undiluted focus on the participant (as opposed to a focus group).

IPA seemed to be a natural choice for this project and for me as a researcher-practitioner for the reasons outlined above. However, I recognise that other qualitative analysis methodologies would have been possible – another way of analysing the participant material and a good fit with an idiographic approach is to use narrative analysis where narrative is seen as a key means by which people produce identity.

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The main reason I chose not to use this method, was because of my interest as a clinical practitioner in phenomenological philosophy and technique. This interest naturally led me towards IPA as a type of analysis that has phenomenology at its core, as opposed to the emphasis on the story and the construction of the self through oral history with narrative analysis.

A final further point of favour towards the use of IPA for this study was the idea that "*it is also thought to be interrogative in its capacity to contribute to and question existing psychological research. The results of an IPA analysis can be placed within the context of relevant psychological literature and research, and may illuminate as well as constructively critique previous findings*" (Rizq and Target, 2009, p.68). It is an essential aspect of this study that the voices of the mothers interviewed are heard, and make a contribution not just within counselling psychology and psychotherapy research and practice, but into the wider world.

Selection and recruitment of participants

I started by looking to interview ten female participants (including one pilot interview): all the mothers were registered either totally or partially blind.

For recruitment, I used two different sampling methods. First I made contact with potential participants by placing notices on relevant websites, e.g. the RNIB's Parents' Place Forum, Insight magazine, Opensight, a Hampshire based eye services charity, and the eye departments of an NHS hospital in the South East. I was also interviewed about the project by Insight Radio (run by the RNIB). This purposive sampling resulted in five participants, the first of whom I used for my pilot interview.

I then used snowball sampling (Patton, 1990) (through a website set up by one of the participants specifically for mothers with visual impairment) and referral sampling (Smith et al 2009) through a contact at Opensight to obtain the remaining five. The participants were drawn from across the UK (see Appendix 1 for participant statistics and information).

The key criterion was that the participants be registered blind or partially sighted and have at least one child aged 10 or under, so that the experience of motherhood was immediate to them. I spoke initially to interested participants on the phone, having advertised a number for them to call, giving them further details of the project and level of commitment required. After the pilot interview, the next nine mothers to fit the criteria who contacted the project were then invited to take part, and all agreed.

Over a five month recruitment period, I set up ten interviews to run over the next few months, beginning with a pilot. In the event, only nine of the mothers recruited actually went through to the interview stage, as one dropped out. The confidentiality of the recruitment process meant I am an unable to analyse the characteristics of the mother who did not participate through to interview stage.

After consenting to take part in the project, each participant was emailed or called to set up a suitable time for the interview to take place, emphasising the need for minimal distractions (i.e. children being looked after by another adult if at all possible). Individual verbal or written consent was obtained prior to the commencement of the interview, with information and details in an stamped addressed envelope sent out for signature at the set up stage.

Description of participants and researcher

I interviewed a diverse range of mothers, varying in levels of visual acuity, sight conditions, geographical location, employment status, marital status and age (from 32 to 47). Five of the mothers were registered blind from birth or early childhood. The remaining four had experienced sudden or gradual decline in their sight in adulthood when they had already had at least one child. The conditions reported included: bilateral retinal blastoma, early onset glaucoma, macular degeneration, diabetes related eye conditions, lebers amorosis, retinitis pigmentosa, impairment through birth process (lack of oxygen) and eye injury.

An interesting observation is that, despite investigations at hospital, 33% of those interviewed held ambiguity and no exact diagnosis for their eye condition. Also, 33%

of those who took part reported that they had long-term health problems or disabilities other than their visual impairment.

Two of the mothers were in paid employment, with a further mother employed as a volunteer. Three had a background and professional interest in counselling, which they explained as being partly what had prompted them to volunteer for the study.

Eight of the mothers had a husband or partner to support them on a daily basis, with one mother (Penny) currently without a partner. The majority of the mothers had two or more children, with Priyanka and Gail having one child.

Participants were drawn from England, Scotland and Wales, in both city and rural locations.

Data collection: interview preparation and procedure

The data was generated by nine in-depth interviews (originated specifically for this research study). The interviews, guided by semi-structured questions, enabled open and free discussion of thoughts by the participants. The basic guiding interview questions and prompts were developed beforehand, based on input from adults with visual impairment, and professionals who work with adults with visual impairment (here I was mindful of Hefferon and Gil-Rodriguez (2011): good quality data-gathering for IPA entails maintaining a careful balance between guiding and being led). The questions fell under the following four themes (see Appendix 3 for list of specific questions):

- Visual impairment
- Previous history of counselling
- Becoming a mother
- Practicalities of childcare and accessing support services

Early on in the research, taking the precedent of the VICTAR 1000 survey, (Douglas et al 2006) and Rosenblum et al (2009), I decided to use telephone (recorded

interviews via Skype) as opposed to face-to-face interviews as the data collection method. The primary reason was because the target group was inherently hard to access as they were busy with child-care commitments, (Tausig and Freeman (1988, p.420) on the benefits of telephone interviews for groups who are otherwise difficult to access in person). Telephone interviewing proved also to be a cost-effective method of data collection, enabling me to access a wide range of potential participants across the UK with ease, at a time and place suitable to them (Sturges and Hanrahan, 2004).

It had the benefit of putting me as the researcher and my participant in some senses on an equal footing from the start, as neither of us had visual contact. Instead, focus for both was the verbal: how and what was being said (or not said) in a way that made for an intimate and concentrated interview experience.

Possible disadvantages could be greater difficulty in achieving a rapport, and a lack of visual cues to aid interpretation of speech (Robson, 2002). Some researchers consider that interviewing by telephone is an inferior method of data collection in comparison with face-to-face, due to the lack of data observable from body language (Rubin and Rubin, 1995, Sturges and Hanrahan, 2004). However, findings indicate there are few consistent differences in data quality between face-to-face and telephone interviews (Lavrakas, 1998). Kirsch et al (2002, p.75), on researching fathers' views of the mother-child relationship, found the data "*to be thick in description and thorough in detailing the father's perspective*".

Yin (2009) pointed out one possible benefit in terms of obtaining quality data through telephone interviews is that the participants may feel more relaxed and able to speak more openly about the situation than may occur in face to face interviews. Certainly it was important to attend to verbal cues (sighs, hesitation, etc) and "check out" regularly with the participant how the interview process was going. I found that an unconscious negotiated pace developed naturally in most of the interviews, and the "checking out" process was reflected back to me by the participants – a sense of are "you getting me, are you understanding what I am trying to get across" (see Priyanka:382; Caitlin:258,282,559).

The interviews took place over a period of six months, with each interview lasting approximately an hour to an hour-and-a-half (the pilot being the longest). As the interviewer I made detailed verbatim notes of these interviews plus observational field notes immediately following each interview. I ensured that I was also up-to-date on safeguarding children legislation and child protection issues in practice (and made this known to the participants), should this arise in the interview material.

In terms of an informed consent process, there were several steps. This began at the recruitment stage, explaining the project to charities or health professionals involved in helping to promote the project to potential participants. All participants were provided with information sheets (Appendix 2 - in large print or Braille as required) and informed consent obtained (a form was signed and posted back to me). The participants also confirmed oral consent prior to the interview taking place. Participants are able to withdraw from the research at any time and to withdraw consent for any written or audio material to be used.

They were given confirmation of confidentiality throughout the research process. In written, Braille and verbal dissemination of the research their anonymity will be maintained. Transcripts are stored securely without identifying information about the participants. Participants were offered the chance to take part in a debrief session.

Pilot Study

A number of helpful points came out of my experience of running a pilot interview. Some were practical, e.g. around technology (to gain a better understanding of how best to record a telephone conversation using Skype such that both researcher and participant are clear, and the recording device unobtrusive). Others centred around the process of interviewing: the pilot was good for seeing how questions could be better rephrased or to be reminded of the "*nuts-and-bolts issues*" (Janesick, 2004, p.119).

I was keen to use the pilot interview as a way of trialling my interview technique, seeking to establish an egalitarian research relationship between interviewer and

participant, plus to establish "*an atmosphere in which the subject feels safe enough to talk freely about his or her experiences or feelings*" (Kvale 1996, p.125).

Starting out, I was particularly conscious of the need for, to use Supple's description, "*an openness*" such that the work is "*collaborative*" (Supple and Corrie, 2004), using my participant as the expert of and for themselves. Through the experience of doing the pilot interview, I realised the vital importance of guiding the participant, such that the material does not deviate substantially from the research aims and goals.

My pilot interview ended up being very long with, towards the end, considerable amounts of personal history from the participant. While I was keen to achieve empathy as an interviewer, I also recognised through this experience the importance of not becoming overinvolved (Rubin and Rubin, 1995).

Looking back, I recognise the progress I made in my effectiveness as an interviewer, from the pilot to the ninth mother, in seeking a way verbally of moving between the informal to establish trust and reassurance, and formal to help move process along. Another aspect learnt from the pilot was to add in structured stems or follow up prompts, in order to help the participant remain within the context of the open question they were responding to, and the prompts to help amplify, continue or clarify an answer.

Analysis process

I view the IPA methodology as a step process, from initial impressions of the interview to meta-themes, in which knowledge is transformed at various stages, with each transformation taking that knowledge further along the path from private to public (Reinharz, 1983). This process was worked through by handwritten notes plus the use of Excel to aid effective searching and collation of the data.

The first stage in this process is to transform the recorded data into a written transcript ready for division into meaningful units and coding. So once all the interviews had been completed, each recording was transformed into a verbatim transcript. This process was done using the help of a professional transcriber, plus

my own listening, marking up the scripts from the transcriber, re-listening and working through the scripts again.

Secondly, after the iterative process of transcription, I prepared the data for analysis by breaking the text down into numbered lines in Excel – each new phrase or sentence (meaningful unit) corresponding to a number (and a possible code) (see Appendix 4). My approach in this aspect could be said to follow more the type of coding known as a "*splitter*" as opposed to a broad-brush "*lumper*", to follow Saldana's (2009, p.19) definitions.   However, I tried to note the delicate balance between the two, in that a "*splitter*" could be overwhelmed by the amount of data categories, while the "*lumper*" is in danger of superficial analysis.

I then began by annotating a print-out of the transcribed text in Excel with my initial interpretative responses (performed by hand – see Appendix 5 for example sample piece of interview).   This was a process of noting down separately any thoughts around emerging themes, images, significant metaphors, and explicit and implicit processes around the intentionality of the emotions expressed.   This became the start of a cyclical process of analysis and engagement with the text (Saldana, 2009), as I then transferred my annotations to my computer (creating a preliminary coding column).   I also noted down pieces in my research journal.

Whilst undergoing the coding process in general, I kept a copy of my main research question, philosophical perspective and ethos by my side (recommended by Auerbach and Silverstein, 2003, p.44), as a way to keep the process on track and help focus coding decisions.   After researching different approaches to coding (Saldana, 2009), I became aware of the perils of deviation from the main task or perhaps being overwhelmed by the material, and the potential for drowning in endless coding, Richards and Morse have said "*If it moves, code it*" (2007, p.146)!

I tried to hold in mind Emerson, Fretz & Shaw's (1995) general list of questions: *What are people doing? What are they trying to accomplish? How exactly do they do this?   What specific means do they use?   How do members talk about, characterise and understand what is going on? What assumptions are they making? What do I see going on here? What did I learn from my field notes?*, which again, I

found helpful in focusing on the task in hand, given the amount of material to code. I especially looked for things in the data that I found surprising, unusual and conceptually interesting (Cresswell, 2007).

I went on to make further reduction to the material at the next level in the creation of a coding column, extracting and interpreting to a more psychologically based level. Finally, in the third column, I drew out "*emergent themes at one higher level of abstraction*" (Smith and Osborn, 2003) represented by this column entitled themes (see Appendix 6 for coding column breakdown example).

I finished up with a set of approximately 30 themes for each mother, and a clear trace line back to the coding and supporting data. Having completed this process for each individual case, I created a pivot table for each mother giving a frequency of theme information (see Appendix 7). I also created a large table within Excel with all 95 themes generated across the nine mothers and from this identified four overall meta-themes for the group. I did this by making an editorial decision grouping individual themes into meta-themes, such that each theme only appears once under the four meta-themes.

Further process in the detailed analysis of the interviews involved: (1) noting the frequency with which certain themes appeared by creating an overall frequency table, and a top themes table (see Appendix 8 & 9); (2) creating a table of top quotations from each interviewer – that is to say, the comments that most stood out to the researcher in the process of the interview and remained so at coding; (3) noting the participant's use of metaphor across the piece, and (4) various diagrammatic ways of presenting the data being employed, such that connections between themes became apparent and were explored, and 5) adhering to a list of checkpoints that acted as enforced points for me to reflect on how I was reporting and analysing (Janesick 2004, p.109). Through these different techniques, it is hoped that the richness and quality of the original data has been retained through the necessary reduction to the theme and meta-theme level and subsequent results and discussion.

Validity and Trustworthiness

In considering quality, trustworthiness, and coherence within qualitative research, for me, validity is seen as a process of interactions between the participants, researcher, critics and community (Atkinson, Heath and Chemail, 1991). As opposed to "*the trinity of reliability, validity and generalisability*" (Janesick, 1994, p.215) to be expected within the positivist paradigm, I have attempted to adhere to those outlined by Elliott et al (1999) - researchers located within the hermeneutic/phenomenological tradition and therefore a good fit with this study's epistemological background (Willig, 2008).

These guidelines Elliott et al argue, are, in fact, applicable both to quantitative and qualitative research. They are: (1) owning one's perspective; (2) situating the sample; (3) grounding in examples; (4) providing credibility checks; (5) coherence; (6) accomplishing general versus specific research tasks, and finally (7) resonating with readers.

To take each briefly in turn: throughout this process, with regard to (1), I have stressed and attempted to evidence transparency in terms of my own values and assumptions, particularly important given my choice of IPA as a methodology and my position of researcher analysing and interpreting. This has also been addressed by the self reflexivity and observational pieces recorded during the research process in the form of a research journal (both written by hand and recorded using iPhone).

Among other aims, these have helped me to consider my assumptions, and track the history of my research process, ideas, connections and observations (and therefore a resource to identify new issues and gain new insights, Torre (2005)). This has been a particularly helpful feature in the dual process of learning how to do a doctoral piece of research, at the same time as exploring and learning about my interested topic area.

As a phenomenologist, one of my primary tools in this study was to ask myself constantly "what am I taking for granted here?", so as not to obscure or bias the meaning of the participant's experience. Also, learning, as with therapeutic practice,

to hold with the "stuckness" – seeing it as part of the process (Lennie & West, 2010, p.85).

This real-time recording of my thoughts helped me in tracking my counter-transferential feelings around living with sight impairment. These included anxiety, feelings of incompetence or my idealising the heroic nature of parents facing the demands of a visual disability. There was also the potential power imbalance with me as an able-bodied therapist dealing with issues of the other. I am aware too that as a fully-sighted individual, I am part of the majority in society, as opposed to some of my fellow researchers who have a more "insider view" (e.g. Dale, 2008).

Elliot et al (1999)'s (2) situating the sample, refers to this study's attempts to describe the participants and their life circumstances at a level of detail such that the audience for this research can assess the relevancy and applicability of the findings (this point in some sense maps onto the transferability concept). (3) Grounding in examples, I believe, is shown in the detail of the findings section below, combined with the appendices.

I have attended to credibility (4) both at the data analysis and write-up stages, where peer-readers were given the opportunity to read, listen to and comment on research findings with a view to checking the trustworthiness of the research. This is on the basis that my research will be considered valid and trustworthy if the findings are faithful to the data (Crotty, 1996). One advantage of using a semi-structured approach to the questioning entailed flexibility, to go back and validate the meaning of a mother's answer within the interview.

Parts of the interviews were coded and presented early on in my learning about the coding process within a peer supervision group, plus two tutors separately coded a piece to allow me to see others' perspectives and interpretations at this early stage of grappling with the material. Later post coding and themes, two interviews were examined by two separate peers (one from my DC Psych programme, the other being a psychotherapist and researcher who is visually impaired), and I fed their comments back into the analysis. Additionally, during analysis I presented part of

my initial write up of the findings, to a day seminar with peers and incorporated comments based on the useful discussion we had.

Reading and discussing the project with peers over the course of planning, executing and write-up has also been an aid with regard to point (5) – coherence. I have strived for an internal consistency and coherence in my approach throughout the process of planning, recruiting, interviewing, coding and analysing. In the analysis this proved particularly challenging, holding and processing so much information at the micro level whilst also stepping back to view the macro level of where the themes and meta-themes overlap.

Accomplishing research tasks (6) tackling both general and specific has been considered through careful planning at each stage, with the help of my research journal as prompt, and discussion with my research supervisor.

Finally, my hope is that this work does indeed resonate with the reader. Feedback from peer readers from the world of counselling psychology and psychotherapy so far has been positive in terms of their interest in the project overall. This has been immensely encouraging to me over the whole piece of this project, particularly at the times when being a researcher can seem an isolated activity.

Ethical considerations

Some of the practicalities in terms of the ethics of setting up and running this investigation throughout this report have already been touched on in some of my reflections above. Additionally, this study was undertaken within the context and ethical guidelines of my academic institution (with the ethics form submitted and approved by the Metanoia/Middlesex ethics committee), and guided by my training as a therapist governed by the British Psychological Society (BPS) and the United Kingdom Council of Psychotherapy (UKCP). I have endeavoured to hold these principles for research in mind, to include issues of fidelity, autonomy, beneficence, non-maleficence and justice as specified by the British Association for Counselling & Psychotherapy (Bond 2004).

I am fully aware of the theoretical, moral and practical application of the BPS' guideline for consideration of the psychological consequences for participants in the research. This is shown through my commitment to confidentiality (changing names for the research), and support for participants within my role as "researcher". If further support is needed, a referral for counselling was possible to the RNIB Emotional Support Service (free of charge) or one of my peers from my course, who offered a psychotherapeutic session (explained as part of participant briefing).

I remained conscious of my position as a researcher, and the possible role of value judgements within that research. Those with visual impairment do not constitute a vulnerable group in the way specified by Robson (2002, p.70) (unlike children or captive audiences such those in a retirement home). However, I remained aware of the sensitivities within the field during the research. This point is perhaps best highlighted by the parents in Rosenblum et al (2009) speaking about "*that intensity of curiosity*" purely because of the difference in being visually impaired. From the outset, when speaking to the RNIB compared to Opensight, a local organisation supporting blind people in Hampshire, there was a sense of protectiveness around their clients and initial suspicion from a sighted outsider. This suspicion turned out to be around who might be behind the research, with apprehension around a political motive that might have implications for funding of services.

This is a point made by Hammersley (1995, ch 6) in his analysis of the question "*is social research political?*". It is one of four ways whereby values are embedded in research, such that peoples' lives are affected either by being in the research or in a context where they are affected by the research findings.

Findings

Overview

During this investigation, I was privileged to obtain a wealth of data from the respondents who gave their time to the interview process. The participants varied in their response to the process of being interviewed: for many this represented an important and rare opportunity to be heard. Others commented on how the process of being a participant clearly brought them to reflect on their experience in a way not considered prior to taking part in the study.

The process of being a researcher-practitioner and interviewer on this project has certainly caused me to reflect on my feelings and position as a mother. Some of my thoughts appear in the piece as I illustrate points but my reflections overall are largely summarised within the discussion section. One particular point, however, I believe is worth highlighting here. This study's aim has been to maintain the phenomenological focus on the experience exclusively of mothers with visual impairment, with a view to ensuring that their voices gain a wider audience. As a contextual piece, it is interesting to consider how many of the themes below might arise in a similar study which incorporated all mothers, an obvious example being the theme *less time for self* or even, *wanting to prove self as good mother to self and others*. Three of the mothers themselves were keen to point out that many aspects of their experience are indeed similar to that of any mother, hence the in vivo theme "*like any mum*".

However, as I argue in the discussion, there are a number of key aspects of the participants' experience (e.g. stigmatisation, marginalisation, heightened frustration), which occur primarily due to their status within society as mothers with sight loss. Thus, I believe, these aspects and their psychological effects, as evidenced in the data, should at the very least lead to greater discussion amongst professionals looking to offer support services to this participant group, over and above those services available to the new mother, such as post-natal depression check, midwife after birth counselling service, Sure Start and so on.

So, overall, the data from the nine interviews revealed four meta-themes which elucidate the mothers' experience of the impact of becoming a parent:

Table 1: Meta-themes

1	struggles around independence
2	visibility and the impact of the others' gaze
3	"*life can sometimes be more complicated*"
4	the changed relationship with time

I view these meta-themes not as distinct but interconnecting entities. My exposition below demonstrates this, beginning with the strongest two meta-themes (in terms of frequency of theme and metaphor across the data) with the two final meta-themes adding detail and depth to this picture.

Below I discuss each of the four themes in turn, bringing out points of similarity and difference between the 95 original themes that lie behind them.

Table 2: List of all themes in alphabetical order, segmented by meta-theme

1	**Struggles around independence**
	accepting and appreciating others' support
	angry at others for lack of support
	angry in rejection of professional support
	children as important helpers
	children protective and defensive of their mother
	feeling in control, resourceful and independent
	feeling trapped into having "to rely on everybody else"
	frustrated that life has to be a series of battles
	frustration and anger at self and others
	growing in confidence through motherhood experience
	guide dog as tipping point to gaining a sense of independence
	increased use and awareness of senses
	insecurity in sense of self within wider society
	internal struggle in accepting help
	loss of previous freedoms, knowledge and skills
	modelling and encouraging independence in child
	rejecting dependent self
	rejecting out of control and dependent self
	resigned acceptance
	restricted freedom

	secure sense of self and family unit within wider community
	security gained from reliance on supportive partner
	self as dependent and fearful of experts' power
	using knowledge as a means of feeling in control
	wanting to prove independence to self and others
2	***Visibility and the impact of the other's gaze***
	"almost to prove a point that we are just as good parents as anybody else"
	"like any mum"
	"they seem to think they have a right to, to, to comment on or pass judgement on your – the things that you do in your life."
	becoming a mother central to reducing anxiety around others' perceptions
	being a target for others' assumptions about visual impairment
	boost to confidence through visual impairment group
	defensive, withdrawn and feeling secondary to others
	enjoying shocking others
	feeling invisible in mother role
	feeling part of isolated minority
	feeling responsible and guilty as a mother with visual impairment
	resistance to inversion of parent – child caring role
	self as detached and not understood by others
	self as distrustful and wary of others' motives
	self as secondary to others' needs
	self as unique and challenging to others
	self included by other mums
	self seen as victim by others
	shame and anger at others' perception of self as unfit parent
	shame around internalised assumption of stigma of visual impairment
	shame at loss of job and sense of identity within community
	viewing self identity within mainstream experience
	wanting to please and get it right
	wanting to prove self as good mother to self and others
3	***"Life can sometimes be more complicated"***
	celebrating positive birth experience second time around
	celebrating self as proud mum
	difficulties of living with severe PND
	envy at differences within family
	isolation and envy at differences within family
	life feels more difficult and complicated than for others
	living with the difficulties of gradual sight loss
	loss of previous life and support network
	needing space for self as a mother
	pregancy as shock
	pregnancy as time of heightened anxiety with self in flux
	self as source of pain to family
	self as strong and determined
	self as victim of violence
	self as vulnerable and isolated when a new mum

	self gaining identity through working
	self in mother's role as giving unconditional love and support
	sensitive to difference within family
	shock at sudden atrophy & sight loss
	sight loss accepted as biological "given"
	struggle of living with pain and chronic poor health
	survivor through cumulative loss and trauma
	taking responsibility for own anger & frustration
	true self emerging through meeting similar other
	using humour as a way to deflect pain
4	*Changed relationship with time*
	"I didn't feel like I was me anymore"
	"I have to get on with it"
	"I just felt like I was like one person ...in the middle of nowhere on my own"
	"I just have to get on with things"
	"it's having the kids makes you hang on in there"
	"you just sort of get on with it"
	advocating carpe diem
	anxiety living with the unknown
	awareness of self within context of intergenerational visual impairment
	centrality of mother's role to own identity and sense of purpose
	conscious rejection of attachment history with own family
	excited and investing in the future through child
	extra effort and time required
	fear of self or children missing out
	feeling hopeless about the future
	less time for self
	motherhood entails responsibility and curiosity about own embodied state for next generation
	prior to becoming a mother, self full of anxiety around life's purpose
	reflecting on many changes within self
	reflecting on self as constant
	reflecting on self as happy and confident

Beneath each meta-theme I have taken four themes from the above 95 to act as sub-headings to guide the reader through the analysis (though further themes from the data appear in the commentary). Both meta-themes and themes are brought to life by direct quotations from transcripts (in the extracts (...) indicates omitted text). I have used the term children as a generic for child or children, as the majority of mothers interviewed had two or more children.

1) Struggles around independence

Overview

Common to all the mothers interviewed was the latent, or in some cases, overtly expressed frustration, anger and envy in comparing the perceived freedoms and automatic right to independence of lifestyle enjoyed by mothers with sight. The different constituent parts that make up the feeling of independence were represented in the discussion of many aspects of motherhood: from direct access to ante-natal material (rather than having to rely on someone to read out literature) to mobility (getting around with their children with ease) to being able to have the full flexibility to do domestic tasks, such as supermarket shopping, when and where they choose.

One way of conceptualising the differences between the mothers on this issue, is as a spectrum of attitudes and emotions, from the theme of "*resigned acceptance*" of dependence on others to totally "*rejecting the dependent self*" and "*wanting to prove independence to self and others*" with independence central to their perception of being a mother. At the latter end is the mother who describes herself as: "*fiercely independent almost to the point of being belligerent*" (Sarah:123)

At the former, there are those who gain security and confidence through dependency upon a solid, reliable partner/husband as daily helper: "*They didn't offer like a letter in large print or letter in Braille or email or – or no nothing like that....But then I never asked to be honest because I've got Jeff*" (Caitlin:333-336). Below are some of the differences in approach along this spectrum illustrated through the richness of the material.

(1) (i) Restricted freedom

A sense of extreme frustration at the lack or loss of the ability to drive was expressed by all mothers. An inability to drive potentially leads to a serious curtailing of spontaneity, freedom and independence, especially if the mother is based in a rural location. Two of the mothers conveyed their sense of isolation, vulnerability and anxiety as a new mum, trapped in a rural location, experiencing the effects of post-natal depression: "*And when I first had John I literally felt like I was the only blind*

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mum in the world, which sounds so silly because I knew I couldn't be and I kept saying to people, "I can't be"" (Claudia:574).

In contrast with life before motherhood, all participants expressed a need for greater mobility as soon as they became pregnant, which only increases as the children grow. The mothers are keen to take their children not just to toddler group or school, but brownies, swimming, etc and the many activities available to primary school age children. However motherhood with visual impairment often militates against this aim, hence the mothers report experiencing frustration towards themselves and others.

This is highlighted through the in vivo coded theme of "*having to rely on everybody else*" (originating in Sharon:39, but appearing also in Claudia); whether that is family, friend or public transport. This appears particularly the case where the mother is the only parent, or equally where their partner is sight impaired. This frustration also emerges in the sub-heading theme "*restricted freedom*" appearing across six of the mothers' interviews.

Several mothers reported often waiting for public transport, which can prohibit or make very difficult, going to activities in the winter months: "*So it's buses and everything. And I've done this for Oonagh you know, get the bus to the girl guides or get the bus to brownies. And I have to hang about for an hour somewhere else miles away, because by the time you get home you have to turn round and come back again. So there's a lot of sitting around and not doing anything. Whereas most people will just drop the kids off, go back, do something and then go back and pick the kids up. I don't have that luxury. And there's no help with that.*" (Bridget:458-465).

The palpable strength of anger and envy in feeling the difference between the mobility and freedom opportunities available to mothers with sight is best expressed by Sharon:277 when she says *"Some people can just get on with their life and do things on their own, whereas if I want to do stuff its generally I have to go with somebody else*", and Ayesha:219 "*And I think oh these other mums don't know how lucky they are, they can just go in their car and take their children wherever.*"

The two mothers at the "*fiercely independent*" end of the spectrum, express their hatred of the felt necessity of relying on others for lifts, etc. For all its downsides, they are keen to embrace using public transport (bus, train and plane) as much as possible. One motivation for this appears to be a fear of the total dependency that may creep over them should they fail to maintain an independent lifestyle themselves while they are able to do so.

The courage in facing up to the fear of the unknown underlying this desire for independence is shown clearly in this quotation, Sarah:126ff "*I don't know whether it's – sometimes I get on journeys and I'm almost in tears because of the fear of what that journey could (laughter) – how I will get lost – or – 'cos so many things could happen and I sit on the train when I like wave goodbye to whoever I've been with or whoever dropped me at the station or – and its just dawned on I'm now stuck on a train for the next five hours or travelling for the next five hours and I just think – why do I do this? But I do it because I know that I then I can do it. If I started accepting lifts I think my fear is that I wouldn't be able to do it anymore. That if I really then needed to get up off my backside, and go and do something, that I wouldn't be able to do it.*"

This quotation conveys the internal conflict of holding both the fear of what could happen on that journey (nervous laughter combined with tears), and the strong impulse to engage fully with life (links with the theme below of "*advocating carpe diem*"). The existential piece also shows through with the powerful image of Sarah waving goodbye to a last link with familiarity and security, before journeying into a unknown void, with a sense of being "*stuck*".

For these mothers, feelings of fear and anxiety, appear twinned with courage and strength beneath both the theme of "*restricted freedom*" and that of "*modelling and encouraging independence in their child*". They show a strong desire to maintain their level of independence (and in the mothers working outside the home, their employed identity). This could be seen as being pivotally linked to the unconscious decision of the importance of modelling independent behaviour for their children. In the process they report testing themselves and their families almost to the limit to

prove this independence to themselves and others   This almost overwhelming internalised drive to prove one's own actions to the world appears again in meta-theme two (visibility and the impact of the other's gaze).

(1) (ii) Loss of previous freedoms, knowledge and skills

This next theme relates chiefly to the four participants (already mothers) that experienced sight loss in adulthood. Having experienced visual impairment as a trauma in adulthood, these mothers brought up in their interviews many of the emotions described by Kubler-Ross's (2008) five stage model of loss. The cycles of denial, anger, bargaining, depression and acceptance, were clearly still live and vivid.

The frustration and anger around the loss of her visual ability to communicate independently with her child during a school play was movingly expressed by Sarah:243ff: "*I've got two of the most gorgeous girls. They are so – everybody tells me how beautiful they are....I was at my eldest's school assembly today and I had one of the women standing there saying some of the things that Ellie was doing ...but she was saying you know – and that was the hardest thing is not being able to, to smile at her, acknowledge her, this person said, "oh she's waving now" so I'm waving but there's not the – that is, that is a hard side.*"

While the visual contact may be lost or severely impaired, common to all the mothers is their challenge to the sighted world's assumption that as humans, sight is our primary sense. This is particularly pertinent in terms of the bonding behaviour that underlines the attachment configuration between mother and child. This point is illustrated effectively again by Sarah:256ff who goes on to say, "*But then there's – you know I do a lot of making little movies of them and their giggles and stuff, which is just as precious...I mean I think I much more tune into the little giggles and the little subtleties. I can tell, particularly my older one, her mood. From the way – I can – when they are in bed at night I can tell whether she's awake, what's she's doing, just from her breathing...I do have very acute hearing, very acute sense of smell. And I'm a very touchy-feely mum, which I'm not sure that I would be if I wasn't blind*".

However, for Penny:45ff describing her reactions to the initial diagnosis of sight loss through severe early onset macular degeneration in both eyes less than a year ago, the sadness and loss of opportunity, future dreams and potential freedoms feels devastating and unreal: "*I couldn't see anything. 'Cause, I, y'know, I never passed my test. I literally was going to take my test. I'd been driving like with, y'know, like with a proper driver for ages and my driving was at a standard where I would have passed and I actually put in to take my test, just y'know, not long obviously and then all that happened and obviously that was it. That was like my driving out the window and that couldn't happen and then it was just like – y'know everything, – I thought that was it, you know, oh what am I supposed to do now?*"

(1) (iii) Angry at others for lack of support

This was the one and only theme of the 95 common to all the mothers. It highlights the anger and sense of being let down by others at the time when support was most needed or requested. At best, the root cause of the anger was the inflexibility of a health professional in offering a home help service. At worst, the mother experienced discrimination and thoughtless behaviour resulting in a serious impact on her feelings about her ability to cope (for example, in the face of a sister refusing to help because "*oh you don't want to depend on people guiding you because you know you've just got to do it for yourself*" Penny:456). This proved a particularly damaging situation if the mother was already absorbed with negative thoughts and feelings in post-natal depression (Claudia, Bridget and Caitlin). This theme links strongly with that of feeling "*frustrated that life has to be a series of battles*" which appears primarily under meta-theme three "*life can sometimes be more complicated*".

Support here is defined by the mothers in both emotional and practical terms. While some reported they had good access to practical support through public and third sector services, the majority felt there was a deficit in terms of emotional support. Of those who lost their sight in adulthood, none were offered the chance to talk through any emotional difficulties around their sight loss. Eight out of the nine mothers interviewed said that they would have liked the chance to have had access to some form of emotional support (in addition to friends and family) on giving birth (and two

had partners still waiting on counselling lists as a result of their own issues coping with their partner's sight loss).

Thurston (2010) highlighted participants' experience of being a patient at the time of diagnosis as something characterised by a lack of autonomy, with a clear power imbalance between clinicians and patients. In a similar vein, what emerged from a number of the mothers' interviews, was that at diagnosis of sight loss, the strong feelings of anger and loss around the immediate trauma were often projected towards professionals: Caitlin:50 "*no apologies, no nothing, no counselling offered*".

In her anger and shock at her diagnosis appointment, Caitlin goes onto to say that, without any supportive enquiry into the emotional impact of the news she had just been given, she found herself being so "*wound up*" that she almost fell under a train. Penny:34ff comments: "*And I didn't have any offer – I had offer of, you know, I went for the treatment and after they said you know 'it hasn't worked and we can't do nothing else – this is – you know, we've done what we can do' and that. I had – after that it was a case of 'you know, here's, here's the name of your local authority, here's who you need to ring – they'll come out and show you magnifiers and things'. I had that support and I had like the information on that side. But, I didn't have any like emotional support.*"

In preparing to give birth, some professional services aim to provide a flexible and helpful service, e.g. offering tour of the labour suite and leaflets in Braille as part of their ante-natal service. However, the quality and level of support seems to vary across the UK. The frustration was clear in the rising tone and fast paced verbal account given of how one mother had perceived the attitude of some of those professionals trying to provide help as rigid and patronising, clearly not listening to how she was describing her needs, e.g. Caitlin:435ff's angry retort "*I told the boss of Homestart, "you try and blindfold yourself and go somewhere on your own". Or, or "I'll get somebody to help you but you only limited in your village and you've got the grocery stores and post office. And you're not allowed boundaries out of your village*".

In three of the interviews (Bridget, Caitlin and Penny) I was deeply affected by the mothers' experience of not just lack of support but active bullying behaviour from partners or family members ("*self as victim of violence*" theme). Penny:283ff speaking about the turning point in dealing with her alcoholic partner, the father of her first daughter "*And he was just like – it was like I went to hell and back. And putting her through that and putting me through that and like doing what he did and then saying what he said the next morning when he'd sobered up that if, you know, he could kill me and he wouldn't even realise he'd done it. You know that was like, you know a kind of a wake up call that I'd got to get out of this relationship and if it means being on my own, you know and struggling scared and that then you know that would be the better option than being with him and not knowing what he would do.*"

While the details of each case were different, the impact of experiencing violent or emotionally abusive behaviour from a partner led to a lack of confidence, depression and a dependency on the abusive partner. There was a fear of being unable to cope as a mother alone and paranoia that the children would be taken away (Bridget:360ff): "*And he, he ... I was nine years with him and he really was awful. And it took a long, long time for me to realise I actually had the guts to just go "d'you know what I don't need to do this". He had me thinking that you know, I was useless, I was helpless and that if I tried it on my own the kids would be taken away. And he actually managed to get me to that level which is not me.*"

Two of the mothers described feelings of inadequacy, fear and insecurity, and periods of dark thoughts and suicidal feelings. In both case, the children are the prime motivation for the mother to stand up to the abusive partner, as highlighted in the quotation above from Penny. The participant's sense of herself as mother and her responsibility with that role, entails that she puts the children first, driving her bravery to stand up to her aggressor in the dangerous situation of domestic violence: Caitlin:146ff "*I didn't want him (her son) turning out like that. Thinking it's normal and acceptable*".

Reflecting on these traumatic experiences, each mother expressed the desire to have had access to better emotional support, both at the time where the focus is

immediate and one of survival, and afterwards, Penny:330: "*And I feel ok, but I just – there are elements like you know, that I wished, with relating like to my sight and that, that I would have just had a little bit more you know something that I could have – you know helped me like get through it emotionally. Because I think that obviously wasn't helping my situation with Sophie's dad because I'd got so much going on with that, You know, I mean that on its own to deal with was really hard, and then obviously with Emily and her problems, you know trying to deal with that on top of it and then obviously him and you know his drinking and different things. So I do think at the time I wished I'd have been able to access some help for me and to talk to somebody on how I was feeling.*"

(1) (iv) Accepting and appreciating others' support

The previous theme clearly demonstrates the strength of anger and resentment towards others where help and support could be better provided. Motherhood is cited as the central driver in an internal and external shift in the participant, in the face of violence and bullying. The theme of "*accepting and appreciating others' support*" highlights the other side of the story: the praise and appreciation of the good, reliable but flexible support provided (whether that was a professional, volunteer, family member, friend or on a community wide level – locally or online). Ayesha, Gail, Caitlin and Penny appeared to have a good supportive family and, in the case of Ayesha and Gail, the wider community. They reported clear benefits in the secure feeling that arose from that support.

This was especially true towards helpful and understanding partners, reflected in the theme: "*security gained from reliance on supportive partner*": Ayesha:340ff Researcher: "*So would you say that having a partner who can drive you places and who is sighted is an important factor? Ayesha: "Very important, yes...It would be appalling without it, yes. You either have to have that, a husband or partner, or someone else who is willing to do that for you.*"

In particular, all the mothers' expressed how useful it was to have the online group for mothers with visual impairment (brought out by the theme: "*boost to confidence through visual impairment group*" appearing in five of the interviews). The ease of

accessibility combined with the trusted space to share frustrations and celebrate achievements makes for an effective and empowering way of meeting those who face similar challenges.

Being able to access others with similar experiences through the website appeared to reduce feelings of isolation and give the mothers a way of sharing knowledge and experience; Penny:420ff "*You know, like you put your post up and get your messages and people will help you if they can, and if they can't they'll probably know somebody that can. And it's a, it's a fantastic site and it's – I think it was really nice to know that I wasn't on my own. Because where I live and like where I've always happened to live, there have never really been visually impaired people that I could like meet up and make friends with.*" (which comes through in the theme: "*true self emerging through meeting similar other*").

The positive value of such support contributed to feelings expressed in the following themes: "*reflecting on self as happy and confident*", "*feeling in control, resourceful and independent*" and a "*secure sense of self and family unit within wider community*". Key factors to the mothers' positive sense of well-being and independence included (1) the opportunity to choose whether to take up the services of a guide dog. Two of the mothers saw obtaining the services of a guide dog as a major tipping point to gaining a satisfactory level of independence: Claudia:202 "*Having a guide dog makes all the difference in the world really*". And, (2) a helpful relationship with the school and parents with clear thoughtful communication.

However, one interpretation of what emerged from the data was an implicit paradox that lies at the heart of the feelings expressed towards accepting relevant and helpful support if offered. Here the unsaid around accepting support from others was as important as what was said by the mothers – a point expressed by Bridget:789ff, "*there's an awful lot of acting goes on and cover up and you know doing things in a different way and pretending and stuff like that, so that other people don't pick up that you are needy in any way. A big cover up job*".

This comment picks up the fear and paranoia held that they may be judged by others as failing in some way as a mother. The paradox is thus: though a mother might

crave support, her anxiety around asking for help is that by doing so, she fears it indicates a lack of competency and therefore casts ambiguity about her ability to look after her children. An example of this fear comes across in Claudia's explanation of why she will not allow health visitors into her home anymore: Claudia:446ff "*She put a lot of pressure on me to send John into nursery. Into the Early Years, the Sure Start as well. So that's when I sort of gave up with health visitors really because I'd been told that, you know, he'd been much better off.*"

In conclusion, I would like to highlight a self-reflective piece of great depth from Penny. Through the interview with her, it was possible to gain something of the internal struggle, still ongoing, that she has faced in the short while since losing her sight in the last couple of years. A progression can be tracked: beginning with her expressing her initially low state with feelings of loss, hopelessness, depression and dependency Penny:132 "*Because before like I had my eye condition and that, I was very independent, I'd go anywhere. I'd jump on the bus, on the train. I would do anything. I'd do everything by myself. And obviously when that happened I just – all that stopped. Because I thought you know, I'm never going to be able to go on the train on me own again, I'm going to have to have somebody with me all the time, and it was, it was um, it was just a complete nightmare.*"

She goes on to describe her daughter as the motivating factor to keep going (common with all the mothers) Penny:159 "*I just – it was kind of stages that I went through. I think the first stage, it's a bit like as I say when somebody dies, you go through – however many stages you go through I think I went through all of them, you know, and, and for quite some time you know, on every stage But I was – I think the main thing was, because I was on my own and I had Emily, and I know that although she did have contact with her Dad, I was the main one that had to look after her, so I had to kind of, you know, take myself out the situation. You know, get as much help and support as I could, and then keep going for Emily. Because obviously she still needed me to be, you know, the mum that I was two months ago.*"

Her sense of child-centred responsibility and purpose in life in her role as mother comes through strongly in the repetitive "I" in the above quotation. Her sense of loss

through her analogy with bereavement has been cited by other participants in qualitative research on coping with the deterioration of sight (Thurston, 2010).

She goes on a few lines later (Penny:170) to describe the struggle between her determination to remain independent but a felt recognition that support would help, and the feelings of shame, inadequacy and rejection of dependency that came up: "*It takes something pretty big to make me think 'oh I can't do it'. But then on the other hand I also did learn that if I need help to ask for it. And to not be ashamed to ask for it either. And that was quite a hard step to take. 'Cause being like – you can do everything yourself and you like to do things for yourself, and then obviously knowing that you can't do some things and you need to say, oh, you know 'can you help me do that?' Its like you know, in the first instance it was like I'd rather struggle and like not cope, but still think that I could do it. Rather than say look – like I do these days you know, I think if I can't do it, I can't do it. Have a try and if I can't do it I'll just get some help, that's fine. That was quite hard to accept that as well that you know, I needed to ask for help when I quite liked the idea that I used to do it myself – do you know what I mean?*".

For me, Penny cogently summarises the internal struggle experienced by many of the mothers. She effectively illustrates how she personally has managed to find a balance along the spectrum of independence and support, and minimise the feelings of fear that underpin the paradox. Interestingly a paradox emanating from the internalisation of others' possible negative response towards the self as a mother with visual impairment is a significant theme in the second meta-theme, described next.

2) Visibility and the impact of the other's gaze

Overview

The second meta-theme focuses on the complex mix of thoughts and emotions in the experience of interacting with others as a mother with visual impairment in a sighted world, and its impact on the mother's sense of self and confidence in her abilities as a mother. Here, other is defined as the object other than the mother herself, and therefore spans out from her domestic situation (the impact of partner and children's attitudes, and extended family) through to the wider world (friends, work colleagues, parents at school, health professionals, members of the public).

It can be argued that as with the first meta-theme: *struggles around independence*, a paradox is evident. The mothers report experiencing both a sense of invisibility to others (the theme of *feeling invisible in mother role)*, but also feeling noticeably visible and different. This latter feeling is expressed by two themes: *being a target for others' assumptions about visual impairment*, and secondly, an in vivo theme from Sarah, "*they seem to think they have a right to, to, to comment on or pass judgement on your – the things that you do in your life*." I have looked at different aspects that emerge from this paradox, brought out by the four themes as sub-headings below.

Two of the nine mothers did express a sense of security in their identity within their family and the wider community. However, the majority of the mothers' experience indicates there is some way to go before others' judgmental and often discriminatory attitudes towards those with a physical impairment (such as visual impairment) are minimised or changed to a level where they no longer impact deleteriously on the psychology of those affected.

(2) (i) Defensive, withdrawn and feeling secondary to others

This theme appears across all but one of the mothers' accounts. It highlights that through their interactions with others (outside of their family), the majority of the mothers frequently take away from such exchanges a sense that they are in some

way inferior to other parents, simply as a result of their visual impairment. As a result of this feeling of being in a one-down position, their response can involve feeling highly defensive of their parenting style or ability, and a tendency towards avoidant behaviour.

Several of the mothers report a poor experience socialising with parents at playgroups or school. Claudia and Caitlin talk about the decision to leave parent and toddler groups feeling isolated and judged by the sighted parents: Caitlin:280-1 "*Ah the mothers in the playgroups can be terrible, they completely isolate you*".

Caitlin describes how difficult she found the playgroup context with her son: "*Because in these playgroups you have to look after your own child, there's no teacher. And, and for a person like me it's awful difficult. And some mum would come – "Your son just nicked a toy off of from my daughter!" And I said, "I'm sorry for that, I didn't see him do that". Obviously, do you know what I mean?" But they wouldn't say, "Oh my daughter just snatched a toy off your son", would they?*" Feeling in a one down position, she decides to leave. One possible interpretation here is that of a splitting process in the participant's experience of good parent/bad parent, where sighted parents are labelled as unhelpful, judgmental and hostile.

Ayesha, Sharon and Sarah report that they do get help from friends and experience good relationships with other parents. However, the feeling of being in a one down position remains, and perhaps too an implicit defensiveness around asking for help (as discussed in *struggles around independence*).

I was very struck by one example of what could be seen as the extreme position of this theme of *defensive, withdrawn and feeling secondary to others.* Penny, in the midst of withdrawal and depression, following diagnosis of her sight loss, reported Penny:73 "*I just felt like I was like one person ... in the middle of nowhere on my own*".

Her interview is particularly interesting because, (now at a distance from that depression), she reflects on her awareness of people with visual impairment prior to her own experience. Conscious of the stigma which she held prior to her own visual

impairment, she expresses shame and sadness in her process of accepting her new embodied state and what it means for her and her children. Her feeling of being isolated is explained by her guilt now in being visually impaired herself towards people who have been visually impaired from birth, as she feels she has at least had an awareness of the sighted world. With no offering of counselling, she recalled feeling stuck in a no man's land, and judged by both those with sight and those experienced in many years of sight loss.

Interestingly, Gail expresses sympathy for a position just such as Penny, stating; Penny:328 "... *there are some people who are having to cope with losing their sight and being a mum. And I think that, that must be very, very hard. I take my hat off to them really, because losing your sight's bad enough and you know being a mum's hard enough, so to have them both*."

The idea of feeling defensive and a second class citizen links with the general theme of *shame around internalised assumption of stigma of visual impairment.* This emerged from the data concerning the mothers' experience of what it is like generally to be in the world as a person with visual impairment (not just a mother). Desperate to avoid negative assumptions embedded in the other's gaze, two of the mothers (Sharon and Caitlin) express views that suggest they have internalised the stigma they feel those in the sighted world too often put upon people with obvious visual impairment. "*I'd probably rather fall over and hurt myself than use a stick and have people look at me I guess*" Sharon:125.

Some powerful introjects are apparent here around the stigma of dependency and difference from social norms. Conscious that her appearance provokes comment, Caitlin adds "*I'm not too bad, it's just I tend to wear dark glasses, for, for the sake of, not actually for any vision improvement or whatever, it's just for the sake of people leaving me alone*." Caitlin:579.

These are two examples from those reported where the mothers actively change their behaviour (in one case even to the point of where she would risk falling) in order to avoid the negative consequences of being at the end of another's inability to deal with difference. Such avoidant behaviour suggests that the result of

consistently meeting others' negative assumptions can be a shift from external views held by others about the self to the taking in of an introject of shame and stigma, or as Sarah:346 said: "*You start to think is it me?*".

I have identified three main responses in the data to this first theme of *defensive, withdrawn and feeling secondary to others* within the final meta-theme visibility and the impact of the other's gaze. These responses are explored in the remaining three theme sub-headings.

(2) (ii) "*Almost to prove a point that we are just as good parents as anybody else*"

The first response is illustrated by a theme taken as an in vivo quotation from Sarah in her explanation of her defensiveness around her parenting style and even her right to parent. The mother's anger and defensiveness is strongly evident by her delivery on the recording with the alliterative "p"s in *prove a point ... parents. She is angry at an assumption made by the CAMHS worker on seeing her autistic daughter for the first time, that her mother's visual impairment is at the root of the her daughter's behavioural and emotional difficulties: Sarah: 545-6 "*And when she first saw the lady from CAMHS, the lady from CAMHS said – 'it must be incredibly difficult for a child to have a blind parent'. It's like, why? It doesn't have to be.*"

Together with the theme *shame and anger at others' perception of self as unfit parent*, this in vivo theme "*Almost to prove a point that we are just as good parents as anybody else*" gives a thorough and sad picture of the level of discrimination, thoughtlessness and stigma reported in the interviews as experienced by six of the nine mothers.

Within the public realm, this often results in the mother's anger directed towards their perception of medical professionals as being at best thoughtless, and at worst incompetent, such as the time when a doctor failed to read the notes about Caitlin's glaucoma and damage to the optic nerve, and instead assumed that she had been taking drugs: "*I went to hospital when I had a pregnancy test with Tessa. And this doctor, he goes to me "what have you been on?" I said, "What do you mean?" "Well what have you been on, what have you been taking?" I said nothing you cheeky so*

and so." Caitlin:595-6, (linking with the theme "*frustration and anger at self and others*" in meta-theme three below).

Even more distressing is the impact of others' judgmental attitude towards the mother in the domestic and personal realm. "*He (partner) had me thinking that you know, I was useless, I was helpless and that if I tried it on my own the kids would be taken away.*" Bridget:363; "*Yeah it was, yeah. And it was like, you know, would I get it right, would I mess up, would I be a good mum, you know would I be able cope?*" Penny:247.

While stated explicitly, the fear of not being a good enough mother is implicit in the data in different ways across all nine mothers' experiences. The splitting here is the opposite of that mentioned in the section on the theme *defensive, withdrawn and feelings secondary* to others above: now it is sighted mother – capable mother; mother with sight loss – not good enough.

One aspect of this theme "*Almost to prove a point that we are just as good parents as anybody else*" reported by several of the mothers as particularly difficult to hear is an assumption frequently made by others. This is that, purely due to their mother's visual impairment, their children must be there to care for them i.e. an inversion of the natural parent-child relationship. "*And that's something that pops up time and time again 'how do you manage? I suppose the children help' It's like, no actually they don't, they're children.*" Sarah:552-3.

Here, you can hear the frustration in Sarah's voice in her emphasis of the frequency with which she faces these ridiculous and offensive enquiries: *time and time again*. Again, there is the implicit question posed by the enquirer of the mother's right and ability to parent, placing the mother on the defensive. A further example I found particularly shocking was given by Caitlin, where her personal life becomes a matter for public debate and unwanted visibility and public exposure: "*There was a time when his Dad left and me and Mark would go to town on our own, as you do. And even a local, what would you call them, health visitor, put it through to social services that I'm using Mark as my guide. And there was a big debate about it and in the end of it came my way, because like I said, well yes ok he does help me, but I can't leave*

him behind because there's nobody to look after him. He's got to come when I need to go somewhere." Caitlin:372-379.

(2) (iii) Self as detached and not understood by others

The second response to the theme in the data of *defensive, withdrawn and feeling secondary to others* comes from five of the mothers: Priyanka, Claudia, Bridget, Caitlin and Penny. It takes up the idea of the self actively withdrawing from the sighted world, as something that is hostile and populated with those who have little understanding of the difficulties and realities of motherhood with visual impairment. Here the theme of the *self as unique and challenging to others* is adopted as primary motivation to becoming detached from the sighted world.

All but one of the mothers are keen to seek out those with similar experiences (the theme of *the true self emerging through meeting similar other*). This response in its strongest form leads one mother to express extreme ambiguity about the value of interacting with those in a sighted world. "*My closest friends are my blind friends, and I think that will always be the case. I think I've reached a stage now where it doesn't particularly – I'm not really fussed about forming proper friendships with sighted people. ... I can, you know, I can get on fine with, with sighted acquaintances, but the sorts of thing that people do say to you, you can't really feel on a level with people who have very little understanding of what life's like I think behind closed doors... It's like, there's such a gulf between what it is like for me and what you think. I haven't the energy anymore to try and explain. I just kind of can't be bothered...*" Claudia:258ff

This quotation brings out how for this mother, there is a big "*gulf*" between her and the sighted world, including me as a sighted person interviewing her. It is clear that ultimately she feels others do not and cannot understand her experience of the world. Claudia seems to have settled into an essentially avoidant stance towards the sighted world, based on the sheer energy required (and implicit fear of rejection) involved in the more active engaged strategy employed by the "*fiercely independent*" Sarah for example. Or the quietly observant Priyanka who remarked that for the first time, due to her daughter, she has been moved to consider, in a less angry and

rejecting way, the world from a sighted person's point of view and what it offers (Priyanka:610ff discussed in further detail under meta-theme four).

Interestingly, the outlier of the nine, Cailtin, presents an opposing view. She was the only one of the group who remained ambivalent about accessing other mothers with sight loss. As she explained it, "*If you, if you stick in your own environment, say now like deaf with deaf and cerebral palsy with cerebral palsy people – you know there's these clubs – and blind with blind or whatever, you tend to be enclosed and cooped and lose a touch of reality. I don't, I don't mind having disabled friends or whatever. I don't mind. But they just part of the environment. I don't want to be surrounded by people exactly like me because then you just lose touch with the rest of the world, do you know what I mean?*"

Here, Caitlin's fear around being cut off, "*losing touch with the rest of the world*", indicates how much she already feels isolated by her glaucoma and accompanying sight loss. For her, spending time on a website specifically for mothers with sight loss, brings an anxiety that she will be ever more be trapped ("*enclosed and cooped*") in a world where sight loss dominates, and losing "*touch with reality*" as she sees it looms.

(2) (iv) Secure sense of self and family unit within wider community

The third and final response apparent within the data to the theme of feeling *defensive, withdrawn and feeling secondary to others* is found only in four of the mothers' accounts. It is the one where the mother recognises and comments on aspects of these feelings. However, these appear to be outweighed largely due to a strong support network, including a supportive partner, which contribute to a feeling of security around her parenting style.

Ayesha comments on how she feels welcome, supported and enjoys her identity as a busy mother going places with her children and guide dog in tow: Ayesha:233ff "*We're quite famous around (the town) wherever we go. We go round with the guide dog and two children. Whenever one of them is missing people always ask, they say 'oh where is such and such', or 'where's your dog today' or 'where's one of your*

boy's today'. So I think they know us very well, and they look out for us, which is nice. And even people in (a major London train station) remember me. It's such a busy station and they still remember me. So I've never had any negative response at all'

To conclude this section, I would like to focus on the related theme of *becoming a mother central to reducing anxiety around others' perceptions.* Claudia shares with me how having children has made her re-evaluate her default view, which tended to internalise others' judgmental attitude *Claudia:543-6 "I think that the – I think that it's having the kids makes me not mind so much about what other people think anymore. To the point where I don't really care anymore. Because it makes up for it all. So if you are going down the road with a small child skipping on your hand, you, you genuinely – you're not just telling yourself you don't care if people stare anymore because you genuinely don't care because it's all made up for by what you've got yourself now. So, so it really doesn't matter."*

3) "*Life can sometimes be more complicated*"

Overview

The third main strand in the findings is expressed through this in vivo meta-theme – a direct quotation that seemed to encapsulate so much of what the mothers were expressing to me. The idea that life feels sometimes to be more complicated in most aspects than other mums' lives was common across eight of the participants' accounts.

Having already teased out some of the areas of complication around issues around independence, and others' attitudes, below I discuss some specific areas that evolved from the data around the mothers' perceptions of living with added complication. These include anxiety around the time of pregnancy, and, the frustration created by and held towards others in their thoughtlessness that can foster further barriers. The picture that emerges is not simply the frustration and fears around facing parenting tasks as a mother with sight loss, but an appreciation of the enhanced aspects of life the mothers gain from complication.

(3) (i) Pregnancy as a time of heightened anxiety with self in flux

One topic area explored where the participants felt being visually impaired gave added complexity to a period of life already filled with a range of emotions was pregnancy. The mothers spoke openly about how they experienced pregnancy and whether they felt they received relevant, helpful support. What came through is that good quality and reliable ante and post-natal care and support (from family and professional services) is critical to reducing the risk of anxiety and post-natal depression (PND).

While two of the nine mothers spoke highly of the ante-natal care they received, without exception, all participants explained that they would have preferred an increased level of emotional support available to them either before or after having their baby. To quote Penny, speaking about facing her second pregnancy in 2008, this time as a mother with visual impairment, Penny:327 "*Um, I think, I think now, I think the situation I was in, and obviously going through the motions and trying to get the help and the support you know like I was then, it was really hard.*"

Her comment would disappoint Bridget, who expressed the hope that it is easier to access emotional support than twenty years ago when she had her first child Bridget:103ff "*It was just pure post-natal depression where you didn't want to do anything, didn't want to be there, didn't want to do, you know anything whatsoever, didn't want to get dressed or anything. And that lasted about a year and a half, it was awful. And actually that had a much more tragic effect on my life than, than my eyesight. And I managed to sort that out, again by myself, because there was no help around in those days.*"

Four of the nine mothers interviewed reported experiencing severe post-natal depression that lasted more than a year, as in the case of Bridget above, with feelings of vulnerability, low mood, lack of motivation, feeling isolated and at times suicidal. Claudia:136 "*It was hard, it was a really hard time. It was actually very hazy looking back as well. You know I don't have, I don't have great memories of those, I*

don't have many memories of those sort of early months with him. It was a very difficult time.... you know it was just everything really."

For this mother, the emotional and practical support offered by a guide dog proved to be the turning point and way out of the isolation of feelings around PND, 2:165 "*And gradually – you see I was still in a pretty bad way until – I got my next dog when John was just turned two.*"

A further three mothers spoke about how pregnancy proved to be a time of great anxiety, both over the actual pregnancy and birth process but also in terms of planning how they would look after the baby. Penny:239ff "*Um, I think because of my sight loss I was really scared, because I didn't know how I would cope. And yet although I knew I was a good mum, and I know you know, I'd done my best obviously you know, that anybody can do..., I was really scared. And I think, I think although I was like, you know obviously I was pleased I was pregnant and you know I was gonna obviously carry through with it and whatever, but it was, I think it was a very anxious time.*"

In just this brief quotation many themes appear that run through the mothers' presentation: *wanting to prove self as good mother to self and others, anxiety of living with the unknown,* and *defensive, withdrawn and feeling secondary to others*. The underlying tension of holding the fears, self doubt and excitement over the prospective new baby is audible in the anxious pace and "*I was really scared*" on the recording.

Pregnancy's physical changes can prove to be a challenge to any prospective new mother (Nicolson, Fox & Heffernan, 2010). However, for two of the mothers (Gail and Sarah), pregnancy brought not just excitement but the complication of ill health for themselves or their baby. For both pregnancy was itself the trigger for becoming visually impaired or further decline, highlighted in the analysis by the theme "*living with the difficulties of gradual sight loss*", e.g. Sharon:6 "*But it (Stargardt's disease) didn't affect me then it was only when I got pregnant with my first child when I was twenty one... Then it suddenly took a turn for the worst*". For Sarah, having experienced the trauma of multiple unexplained miscarriages and receiving only

negative expectations from the medical professionals, a successful live birth seemed too much to hope for: Sarah:207 "*Then when I found out I was pregnant I was, I was really, really excited in one respect but horrified in the other, because I'd so convinced myself I wouldn't have children*".

(3) (ii) Celebrating self as proud mum

Once through the ante- and immediate post-natal period, each mother had different strategies for dealing with the added complication having children brought to life. Linking in with the theme *centrality of mother's role to own identity and sense of purpose,* three of the mothers talked explicitly about embracing that complication as part of their experience of motherhood and what it brings. They were clear in holding their role as a mother to be an important and proud part of who they are, including an awareness of the barriers they face in that role, Penny:337ff "*But then you know on a level for like obviously you know, looking after Emily when she comes, and obviously looking after Sophie and that, it was, it was, it was tough and it was hard but it was worth it, do you know what I mean?*"

For example, Sarah explained that she works hard to ensure that she and her children have a life full of activities, travel and opportunities (linking with the themes of *advocating carpe diem*, *fear of self or children missing out* and also *wanting to prove independence to self and others*) Sarah:271ff "*So – pause, I suppose I think I probably do more with my children because there are so many more obstacles, which seems almost ironic, um, but we go for an awful lot of, sort of days out. We just hop onto a bus and take off somewhere sometimes.*"

She makes a disparaging comparison with parents who make less of an effort and just spend time at home. An internal struggle is visible here around the idea of what makes a good parent: her own fears of inadequacy around this.

Several of the mothers commented on the benefit that technological advances have made to their lives in terms of improved communication. For example, with talking text message or email services if a school activity venue changes at the last minute, they are more likely to be kept in the loop.

An important part played by the email group is its function as a place to celebrate and be proud of each other's achievements and share the joys of looking after children. Claudia:386-7 "*One of the great things about the email list, which is "vi mums" only, is that you're allowed to say 'my god, today was so difficult, it's so hard work being a "vi mum"'. And you're allowed to say 'wow you did so well getting out with two kids and a dog' because you know when you're with sighted people you spend so much time saying 'well of course it's possible, well of course I do it, well of course I manage'.*

This quotation highlights the benefit of the insider aspect, of the website such that members feel able to relax their usual position of defensiveness (theme of *defensive, withdrawn and feeling secondary to others*, appearing in all but one of the accounts, e.g. Claudia:394 "I, *I feel like I have to be quite, yeah, quite on my guard with people*". This idea is explored at length in meta-theme no. 2 *visibility and the impact of the other's gaze*.

An important aspect of this appears to be receiving and giving emotional support to each other, rather than an outsiders' misunderstanding and opinion which can feel patronising: Sarah:462 "*I mean we've all been there and been patted on the head and been told what fantastic people we are and won't it be good when the children can look after us. And it's like – 'no – that's not why we had them!*" The hint here of the inverse parent-child relationship in a caring role is also explored in greater depth in the meta-theme *visibility and the impact of the other's gaze*, and evokes indignant anger and distress, as shown in this quotation.

While it requires that the mother has access to the internet, the website proves to be a reliable, low-cost and accessible way for mothers to find others who face similar issues. Through the network of information, the mothers report feeling empowered by being able to both share and gain from the process of meeting others (theme of "*true self emerging through meeting similar other*"); Sarah:447ff "*And somebody lent me a locator, which you clip on to the back of their dungarees. And when they've gone off and hidden – as little people with blind mums quite often do – you press a*

button and your child rings, or your baby rings. And you find them hiding under the sideboard. And stuff like that, which you just don't know about."

(3) (iii) Using humour to deflect the pain

Listening back through the recordings of the interviews, I reflected again how much laughter and humour there was in response to some of the questions (such as that in the quotation immediately above). Often the laughter appeared in the recalling of a happy event or something funny a child had said. What also caught my notice was the different ways that humour and laughter was being used to deflect the anger, unhappiness, anxiety, pain or trauma that the participant was describing. As Sarah succinctly and movingly expresses it, Sarah:408 "*We (husband and I) do deal with a lot of things with humour, because otherwise we'd just cry.*"

This theme around humour has been highlighted under the meta-theme that "*life can sometimes be more complicated*", as one of the ways the mothers deal with that complication. Humour also came up in relation to the theme of "*I have to get on with it*" and the sense of necessity that comes with becoming a parent: Caitlin:16 "*But it was difficult but then I got used to it and I sort of – I, I don't stay miserable like "oh you know help me, I can't do this, I can't do that". I try get on with it. If I walk into something I just laugh*".

However, humour is not always used in such a self-deprecating manner, with shame and anxiety implicit. One mother seemed proud of the unique and special nature of her family situation as a result of her visual impairment, gently recognising the humour for herself in how they appear to others in their local community: Ayesha:445 "*Yes, I've got my guide dog as well, yes chuckle. Quite an entourage when I go out*" (linking with the themes, *celebrating self as proud mum* and *self as unique and challenging to others* (appears in meta-theme two).

Often sarcastic humour was seen to explicitly express anger. Claudia talks about how hurt and cross she was at a local parents meeting when she perceived the others as dismissive and showing a lack of understanding the fact that "*life can sometimes be more complicated*", Claudia:376ff: "*And these are the sort of things,*

going back to what I was saying about, that divide me I feel like from the other mums a lot of the time. That just casual chit-chat. That was a committee actually where everybody was saying 'oh you know, well at least you can just move and find somewhere else'. Yeah. (Laughter)."

Her laughter in the interview to me, with the implicit awareness that I too am a sighted mother, and perhaps a hint of a dismissal, expresses her anger at how easily the complications of her life are dismissed by others, sitting, from her perspective, in their easier existence. Similarly Sarah 8:65 shows her sarcasm at missing out on a venue change for an activity "*There's been a notice on the door all week, but well yeah, being registered blind that's a tad difficult for me to notice.*"

In such instances intense frustration is behind the humour. All the mothers expressed it when they spoke about the frustration of dealing with "*silly little things*" – i.e. relatively trivial tasks which appear to them to be far easier for those with sight to complete, but are often full of complication from the perspective of a visually impaired mother operating in a sighted world.

(3) (iv) Frustrated that life has to be a series of battles

The final theme under meta-theme three again shows up in all the mothers' experience (with the exception of Gail whose baby is under six months old). It follows on from the idea cited above, that living in a sighted world as a mother with visual impairment involves coming up against barriers which cause immense frustration. As many of these barriers involve the challenge of being at the end of others' assumptions about visual impairment, there is also a natural link in this theme with the second meta-theme discussed above: *visibility and the impact of the other's gaze*.

The metaphors and violent imagery around doing battle, for me, illustrate the level of frustration the mothers feel in their interpersonal relationships both on a one-on-one and community wide basis: e.g., Priyanka includes phrases such as "*barrage*", "*assault*", "*fight for*"; from Gail, of her son, talking about her belief that he is not visually impaired and the impact that will have on his life, 131"*He's got fewer battles*

to fight", 144"*fight these battles*"; and a final example in Penny:462 "*it's a bit of a battle at the moment*" talking about how unhelpful, hurtful and alienating she finds her sister's uncomfortable and judgmental attitude to her sudden visual impairment and ability to cope as a mother.

In dealing with professionals in the public and voluntary sectors (e.g. social services, health visitors, medical staff), the sense conveyed in the interviews was that the resourcefulness, persistence and ingenuity expected of a soldier in battle, is required. Claudia:467 declares "*I'm happier to stay off the radar*" in speaking about staying out of the way of social services and the education authorities, who persistently questioned her choice of home-schooling her children, a philosophical choice which she argues, makes her sufficiently different from the mainstream, and therefore doubly visible, leading to a feeling of being persecuted by social services.

Ayesha describes her experience of giving birth to her first daughter Ayesha:305 "*I would have liked – my consultant the first time she tried to organise some support for me, in terms of you know, support workers coming to the house once the baby was born. That never happened. The social services took two and a half years to sort out my care plan. So, they just forgot me. I think my file just got lost, like they do.*"

This experience also fits into a theme from meta-theme two, that of *feeling invisible in mother role*. In this instance, Ayesha had the confidence, autonomy and tenacious spirit to ensure that "*the second time I was determined this time it wouldn't happen. So I got in touch with the RNIB and they actually helped write letters and, and er, threatened to go to court. So in six months it was all sorted the second time*". It is shocking that even with a resourceful mother who is on the case (as opposed to at the other extreme, someone coping with severe PND), it still took six months before adequate support was in place.

The challenge of having to face such battles, reported by some participants as experienced on a daily basis, results in the emergence of another important theme across the mothers' experience: "*frustration and anger at self and others*". Energised by frustration and anger throughout most of her interview, Sharon explains that much of it is directed towards herself for not being able to do the

activities she used to do prior to sight loss, with her two boys, and therefore has lost some of the enjoyment in her life, Sharon:49 *"I just get – I'd say I probably get more frustrated about the things I can't do any more and you know if they ask, if they ask me to do something for them and I can't do it I get frustrated that I can't do it"*.

There is a sadness too felt by many of the mothers, who have become visually impaired in adulthood, in their reflection that the loss of the ability to perform certain domestic or child-rearing tasks in the same way, generates frustration or incomprehension in their children, many of whom are too young to understand: Priyanka:144 *"And um, she would get very frustrated because I couldn't read her the books she wanted me to read her. But it wasn't reading her the book, it was talking about the colours and the pictures and all that kind of stuff which I couldn't do. So she would get very frustrated and I would feel dreadful, because you can't explain to a sixteen-month year old why you can't read the book to her, you know, she doesn't get it. (Ironic laughter). So, so you know it's not been easy. It's much easier now that she's older. And it's much easier now she can do more."*

A couple of the mothers talk about dealing with this issue by obfuscating or lying so as not to cause their children hurt or upset, Sharon:105-6 *"Yeah, I mean, they are sporty kids as well and it does frustrate me you know like my youngest plays football in a team, and although I can generally see most of his team because they are in differing colour whereas the other team aren't – I can't distinguish my one. So you know he says 'oh did you see me do that mum' and I have to just lie to him and say 'yeah that's really good' whereas I can't, I can't really see what he's doing."* Implicit within this quotation is the guilt she feels in lying to her children, and the anger and sadness that she feels she has no other option.

The themes of *"frustration and anger at self and others"* and *"frustrated that life has to be a series of battles"* appear in the data from eight out of the nine accounts. They appear at the domestic level, Penny's anger towards her thoughtless and abusive partner: Penny:215 *"Obviously you know you have to be careful where you put things – you need to be organised, you need everything to be where it is. And, and he wasn't like that so that obviously was a constant battle trying to find everything all the time.*

The knowledge that their being visually impaired causes pain and a sense of loss to their partner or husband, can understandably put a strain on family life:Sharon:200-1 "*I mean he's the worst one of the lot to forget that all the time that I can't see. He is the most unhelpful one really.*"

Sarah:409ff talks about her awareness that her visual impairment has had a deep impact on her husband.   In her reflections can be heard both guilt at being the root cause of his distress, and anger and envy at that basic embodied difference between them: he retains his sight, while she has the necessity of getting on with it, "*He's found my blindness a lot harder to deal with than I have ... He's the one who needs the counselling. He's found – I suppose it is harder in many respects because he's lost, he's lost my sight as it were. I have to live with it, I have to get on with it. And he also has frustrations round it and, and its sort of 'what's going to fall off next', type thing, I think. And he did see it initially as the end of the world.*"

These two themes also appear at the public level, Priyanka:499 "*we've had to fight for better support every week*" concerning her struggles for resources and help from a local third sector organisation that she believes discriminates against her because she has a sighted child, as opposed to a child with visual impairment. In discussing her future plans and hopes to get a job, Ayesha is well aware of the battle and barriers she will face: Ayesha:463 "*Employers don't have the best attitude towards visually impaired people.*"

4) The changed relationship with time

Overview

Ayesha was one of only a couple of the mothers who spoke with any degree of certainty or interest in speaking about the future. This final meta-theme shows how the IPA process highlighted a number of themes concerned with how becoming a mother has had a direct impact on the participant's attitude to and relationship with time.

Many were deeply existential in their nature: such as i) how becoming a mother has given a purpose and meaning to life, ii) the interrelationship between time, motherhood and necessity; iii) how participants experienced an intensified understanding of the fragility of life and iv) comments on how becoming a mother themselves raised awareness of the intergenerational aspect of being visually impaired.

Like most mothers, the participants reported feeling that they do not have enough time in the day. However, importantly, the themes below explore what emerged for the participants around the nature and effect of the extra time and effort required in everyday child rearing tasks. This sense of not having enough time for daily tasks was often expressed as being behind or ignored by other parents (connecting with meta-theme two: visibility and the impact of the other's gaze). At a deeper level, a strong felt sense emerged of how best to use and engage fully with the time available in life generally (the theme of *advocating carpe diem* below). Several of the mothers' felt experience was recorded in the interviews that visual impairment and its consequences had given them a better appreciation of this than many sighted people. These ideas are discussed below using four themes taken from the text as sub-headings as a guide through the analysis.

(4) (i) Extra time and effort required

This was a recurring theme across four of the mothers' accounts, with all but one (Gail) expressing frustration at the length of time tasks concerning the children can take. The frustration (highlighted also in the theme of *frustration and anger at self and others*) touches on the intrapersonal (feeling of anger held within themselves), interpersonal and public. The latter is shown by the feeling that came through of being secondary to those in the sighted world (linking with *defensive, withdrawn and feeling secondary to others*). The mothers felt angered by those who have little understanding or appreciation of the extra time and effort needed for basic tasks, and through thoughtless errors making life harder still. In this way, this theme of *extra time and effort required* has strong links with the other three meta-themes: a drive for increased independence entailed extra time and a level of added complication not fully appreciated by others.

One example from Sarah's daily routine (mother of two girls), was that of turning up at the wrong time in the wrong place as a result of the only way of communicating change to parents being only via a notice on a door: Sarah:68ff "*So they're (the nursery staff) meant to email it to me in a, in a text format – but they'd forgotten. And it's just – it's stuff like that just makes it so hard work. When you've got all the, all the normal things that are extra hard work – you know when somebody moves their keys they can look around for them. I have to grope round the house, you know, literally feeling each side – and stuff like that. If I've missed it by a millimeter, I've missed it. And its – that side is very, very frustrating.*" The intensity of her frustration, shame and anger is felt in her emphatic "*very very frustrating*" and the alliterative almost vituperative delivery of "m"s in missing it by a millimetre.

For Gail, with a six month old baby, Gail:9 "*It doesn't, it doesn't stop you doing things, you just have to be perhaps more organised and more determined perhaps than, than – to do something than maybe a sighted person, that's all it is really*", an attitude of strength and determination that, as someone blind from birth in a sighted world, she feels she has held throughout her life. In contrast to the mothers with two or more children, this mother is more relaxed about the fact that tasks take a little longer. One factor here may be that there is no imperative to get ready to a school timetable, for example; Gail:126 "*I don't think it's – I guess the only thing that might be different is that obviously with my lack of sight, things take longer. You know getting him ready perhaps takes longer, changing a nappy takes longer and – not that that matters particularly.*"

Priyanka reflected on the effect having a daughter has made to her life overall. Her response came back noting the difference both in terms of the increased level of enjoyment she experiences through having her daughter, and the decreased level of energy and time: Priyanka:448ff "*Oh I think, I think she has enhanced both our lives – I know that you are not really focusing on, on my husband, but I think she has enhanced both our lives. And I think that, you know, life is better, it's more fun since we've had her. Yes it's more tiring and yes there's more to do and yes, you know you, don't have the time to do the same things that you might used to do for yourself.*" This view was expressed by a couple of the mothers, with an additional

emphasis and awareness explained on the experience of being exhausted and having less time for yourself being common, in their anecdotal experience, to most mothers.

(4) (ii) Advocating carpe diem

One aspect of the data to strike me during analysis was that six of the nine mothers expressed an appreciation of the fragility of life. With multiple health traumas and also loss (miscarriages) experienced by a number of the mothers, the notion of life as something precious that can be taken away at any moment is highly prevalent in their responses.

With my personal experience of loss of visual acuity and anxiety over further vision loss following a serious car accident in 2011, this theme became a deeply personal one during the period of this research. I began to appreciate as an insider, that for those mothers living with the fear of their sight declining further (theme here of "*living with the difficulties of gradual sight loss*"), there was a felt imperative expressed to engage with life now – Sharon:148 "*Yeah it's – I guess I try to do stuff now in case I can't do it later.*"

Becoming a mother with visual impairment appears to have propelled the majority of the participants to seize the day. Perhaps connected with this is a commitment to try the best for their children, Sarah:280 "*I don't know I suppose we only get one chance and I want to do it right for them*". As this quotation demonstrates, this theme links closely also with meta-theme two: *visibility and the impact of the other's gaze.* There is a sense of both looking to others for approbation and holding the fear of being judged as a failure as a mother as a direct result of having a visual impairment.

Advocating carpe diem can also be seen as a response to the frequently expressed fear of being left behind or forgotten as a result of being visually impaired: the theme of "*fear of self or children missing out*". This is Penny talking about how hard she finds it that she is responsible for restricting her daughter's freedom for reasons of safety. As she perceives it, she is guilty of having a negative impact on her

daughter's childhood: Penny:372ff "*Um, just really I suppose the main thing is, is obviously just the fact that you know, I can do everything I can for them and make sure that they don't miss out on anything. I think that's, I think that's the main thing, it's just like that – you know, I mean that's always is in the back of your mind like, you know I try and make sure, because obviously things like taking Sophie to the park, that frustrates me because I used to go – you know Emily used to say 'oh mum can we go to the park today', you know off we'd go to the park and Emily would be running round and running off and you know getting lost and whatever. But obviously now that's not an option. Sophie loves going to the park so I do try and make sure that she gets to go, but obviously I need somebody sighted to come with me, just in case, I mean I'm not saying that somebody would walk off with her, but you never know these days. So it's things like that. It's me really just wanting to make sure that they don't miss out on anything.*"

This fear of missing out can be well founded, as the mothers often appear to be the victim of poor communication from the school, nursery, other parents. Busy Sarah with a job, two daughters, pets and further responsibilities shows her frustration with others assumptions that help fuel her underlying sense of being left behind in a sighted world Sarah:78 "*People seem to just assume that you'll know things because they've seen something somewhere that tells them about something, and I do find that I miss out a lot in school life just because people haven't bothered to tell me.*"

Similarly, Priyanka describes the paradox mentioned above in *struggles around independence*; wanting help but also not wanting to draw attention to yourself as a mother who needs help for fear the response is negative and fundamentally disempowering Priyanka:65 "*There are very, very simple things that they (the staff at her daughter's school) could do. And the thing is you don't really want to go up to them and say 'could you do this because it would really help me', because you're singling yourself out. It would be easier for me to drop Jasmine off at the office to be honest. But that means she misses playground time, and she needs that*".

One possible way of viewing the *advocating carpe diem* theme is as a response to the existential anxiety apparent in eight out of nine of the mothers' interviewed, identified through the theme of "*anxiety living with the unknown*". At its most basic

level, this theme includes how the mothers' coped with anxiety from daily challenges such as dealing with a growing child's independence: here, Bridget talks about the added anxiety she faced with her second daughter, who is sighted, in comparison with her first experience of motherhood with her eldest daughter who is totally blind, Bridget:264ff "*But as she (second daughter) got bigger and more independent you know, trying to get her to have the independence to ride a bike, that scared me because if she moved at any speed I couldn't keep up with her, And if she went off it's like 'well where's she gone, is she all right? Has she fallen off, has she gone in front of something, has she knocked into anybody?' And I wouldn't have been able to see that. So it was just her independence if you like.*"

At a deeper level, the theme of "*anxiety living with the unknown*" connects with numerous others, e.g. meta-theme three above "*life can sometimes be more complicated*", plus the themes of "*living with the difficulties of gradual sight loss*", "*struggle of living with pain and chronic poor health*" and "*awareness of self within context of intergenerational visual impairment*".

Much anxiety is evoked by uncertainty around their own eye condition and diagnosis, and therefore ambiguity over the prognosis for their children's sight. Sharon:143ff "*But you know, with the condition that I've got my consultant says it could stay like this now for the rest of my life and not get any worse. But then it could, you know, within a year I could be almost completely blind. They just don't know – that's because with the disease I've got there's not, there's not a huge amount known.*" The difficulty of living with such ambiguity can clearly be heard in the pauses and inflection on the recording at key points in the interviews.

(4) (iii) Reflecting on the many changes within self

This theme brings together some of the mothers' reflections on changes to their intrapsychic state over time; from childhood experiences that have influenced them as a mother, through to reflections on their imagined future self in old age.

Bridget talks movingly about the impact growing up as one of three in a family where her father suffered terrible depression as a result of his own sight loss in adulthood.

Witnessing her father's frustration, anger and violence towards himself and others, has led her to reflect on her own feelings and behaviour as a parent with visual impairment. She has a strong sense of wanting to model and encourage autonomy and self responsibility to her own children. She describes how her confidence in this view and her role as a mother has grown over the period of having her three children. By the time of her third child, Bridget says:336 "*You know I want him to, to find ways out of things, his own solutions for things, rather than me fixing it all.*"

She comments on how her tenaciousness and strong character have emerged almost as a survival response. She feels she now has some control over her environment (in a life where in some situations, she has felt trapped and powerless, e.g., as a young mother with post-natal depression in an unhappy marriage).

The importance of now, as a mother, feeling more in control than felt possible in childhood and early adulthood, occurs in a different sense for Claudia. With the traumatic effects of being bullied at school fresh in her memory (the hurt, sadness and anger apparent in the hesitations in her voice and response), Claudia explains why she doesn't "*bother*" going to local playgroups, where she experiences similar behaviour, this time as an adult: Claudia:275ff "*And I just left in the summer – the last time I went in the summer I just thought 'I cannot do this anymore'. Being so – that was more negative. Just being ignored. Just going along, John plays with the other kids, and just being ignored. And I just – I just think I'm too old to put myself through that anymore. I'm not at school, why do it? And I hope that the kids don't miss out as a result really. (pause) And every now and again I wonder if that's – if I'm doing the right thing.*"

As a mother she holds the tension of deciding how to deal with the feelings of an unfriendly and hostile nature that she picks up from the other mothers, with the guilt of feeling what is best for her children, and the fear that they might miss out (*fear of self or children missing out*).

For those mothers becoming visually impaired in adulthood, diagnosis was initially devastating and started a changing process of loss and acceptance: Penny:65 "*I didn't feel like I was me anymore*". This theme links strongly with that cited above of

loss of previous freedoms, knowledge and skills (in meta-theme one *struggles around independence)*, and the theme of *frustration and anger at self and others* (in meta-theme three *"life can sometimes be more complicated"*).

An example of this is Penny:124: "*..., you know she's (eldest daughter) doing fine and that but it was like, you know, I'd, I'd get angry at myself because you know, she'd say, you know 'read to me, I want you to read to me', and I'd say 'Emily, I can't see to read it, I can't read it, Mummy can't read any more, I can't see'. And, and, and it would be like 'yes you can, yes you can', because obviously like, you know, last month and the month before you know I'd pick a book up and I'd read it to her.*" It is moving to hear here just how difficult, painful and bewildering it is for the mother to explain the change in herself to her daughter, when she has barely processed what it means herself.

Sarah also touches briefly on the painful memories of her depression at diagnosis (initially of severe epilepsy, then further physical complications including gradual sight loss). Sarah:157ff "*I went from being cared for – my husband was on the verge of having to give up work because I was really not at all well and I went from, from being cared for, to, to, I suppose being in the caring role and looking after the husband and house again, which is where I had been. I'd been working full time prior to diagnosis.*"

This paragraph contains much: the sense of loss and devastation at diagnosis from holding one identity as a full time independent working person to the identity of total dependency being cared for. Then there is a sense of the painfully slow shift back to where she had been, a strong sense of independence and autonomy, working life and the carer role as mother in the family.

It is clear that life now for Sarah as a working mother gives her great satisfaction and fulfilment (which emerges in the theme of *modelling and encouraging independence in child* and *secure sense of self and family unit within wider community*). The aspiration and determination to be employed and achieve her ambitions concurrent with her educational achievements is also expressed by Ayesha. However, she is aware of the barriers and potential discrimination she faces on two fronts: not just as

a person with caring responsibilities looking for flexible work but as a visually impaired person, Ayesha:463 "*Employers don't have the best attitude towards visually impaired people. They are one of the highest percentages to be out of work out of all disabilities. So, you know – but it might take time but I'll get there eventually.*"

Ayesha and Sarah are unusual amongst the participants in the strength of desire expressed in their wish to be employed. Most of the mothers deflect in their responses to the open question inviting them to consider what the future might hold, and fall more into the *advocating carpe diem* theme. However, their implicit fears around the future were perceptible in discussion of their experience of the support groups, to which they were directed at diagnosis. The experience was overwhelmingly described as one of feeling out of place: Caitlin:548ff "*Because first when I lost sight they got me in touch with these clubs for the blind, like social kind of clubs. Where you'd go to a – like once a month or once every fortnight or whatever. And I felt like, it was so miserable there. It was full of old ladies in 70s and 80s complaining " oh I can't see anymore, can somebody pass me a fork because I don't know where it is", and "oh my god I'm not going to go out on this ramble walk, because what if I trip". And I'm like, what am I doing here, I'm everybody's granddaughter*".

Similarly, Sharon:304: "*You know they say 'oh come to this support group and stuff' but generally they are all old and they say oh we'll go on this outing and they go on a bus.... It would be nice if they did something outdoors that was active and you know what I mean that you don't normally get the chance to do instead of hanging around with a load of old folk*".

What emerges is that as a minority group within the visually impaired community, (experiencing sight loss as a young or middle aged adult), the mothers find themselves propelled towards services aimed at those far older than their years or interests. The psychological impact appears rather than being supportive, to increase a sense of isolation and anxiety about their visual impairment.

(4) (iv) Centrality of mother's role to own identity and sense of purpose

This final theme, under the fourth meta-theme of *the changed relationship with time*, relates to how motherhood itself appears central to the new depth and purpose with which the participants' experience life. It is identified in six of the nine mothers interviewed. For some, it was a journey of years from an initial depressed state of dependency on their partner or family to reach a place where they feel engaged and valuable within the world (for example, as described by Sarah above), and others remain on that journey (Sharon). Transcript data and researcher observational interview notes suggest that coming to recognise their importance as a mother to themselves and the wider world appears central to that process. Claudia:538 "*I can't imagine life without them – I think it would be totally pointless.*"

For others, reflecting on the benefit of their experience of a secure and supportive childhood themselves, motherhood was a key milestone in contributing overall to a happy and secure life with their partner. For Ayesha, registered blind from two years old, having children was central to her life plan and brings great happiness and fulfilment: Ayesha:149 "*I mean I just – I've always wanted children and I've had two children. And they're happy, healthy, very clever, intelligent – so I couldn't ask for more really. I would have been devastated if I couldn't have children – ... I would have done anything to have children... No idea, I don't think so, I don't think anybody in my family would, would go to such lengths to have children. ...I think I'm just determined. If I think if I want something, I'll just somehow try and get it.*"

Thus the children are seen both as a source of motivation (the theme of "*I just have to get on with things*"), plus a huge sense of pride and celebration of the role of motherhood and what it brings to life, Penny:328ff "*But I think being like um, you know, being a mum now and being registered blind, which I am now, I don't – I feel really proud. You know I feel like really proud of like where I've come and that and, and how far we've come.... Yeah, yeah. Yeah, they're um, yeah; they're my world.*"

In the section on meta-theme one, I commented on the theme *of loss of previous freedoms, knowledge and skills*, and the fact that this referred primarily to the mothers who had lost their sight in adulthood. Those mothers whose visual impairment stems from early childhood spoke about the sighted world as something

other and mysterious which had always been closed off to them. This quotation is from one such mother, Priyanka:605 speaking about what the concept of being able to see meant to her before she had her daughter, "*It was this marvellous most wonderful thing that everybody else could do and it was brilliant and if I could do it I would be a better person in the world.*"

This demonstrates the feeling of being like a second class citizen expressed in the themes "*self as secondary to others' needs*" and "*defensive, withdrawn and feeling secondary to others*" (which underlie the second meta-theme: *visibility and the impact of the others' gaze*).

However, I was very moved by Priyanka's introspection on the life-changing difference giving birth to and bringing up her daughter (who is sighted) has had to her own life and perception of the world. In a tone of voice with wonder and excitement, she describes how the world is opening up to her in a way she had not anticipated, through her daughter's verbalisation of what *she* can see, Priyanka:610ff "*I mean – but the other thing I've realised is that – Jasmine was about two, we were walking round the supermarket and she was telling us all the pictures and all the cans and all the packets round the supermarket. And I hadn't realised – I know it's fairly obvious but I'd never thought about it – that there were pictures on cans and, and packets and stuff. So I said 'Tom, why's she talking about – there's lots of cans in the supermarket', and he said 'yeah but she's looking at the pictures'. And I hadn't actually seen sight as this potentially so marvellous thing.... You know Jasmine takes her life – actually everything, everything – she, she is observing everything, she doesn't miss anything. ...I just find it amazing that this little tiny child is able to see so much, and then verbalise what she perceives, and actually give me a small part of what I've never had, which is what the world looks like.*"

Here, indirect knowledge about the world obtained interpersonally, through her relationship with her daughter, has prompted an intrapsychic shift, a re-evaluation of her understanding of the world. In her voice, it is possible to hear both the joy of what her daughter experiences as a person operating with sight in the world and that she can convey some of that to her mother, and the sadness that she personally will only have indirect experience, dependent on her daughter.

Discussion

Overview

Through the analysis and verbatim quotations detailed above, the voices of the nine mothers interviewed can be heard in strength, (in the co-constructed piece with myself as the interpretative researcher). For the purposes of this report, I have focused on connections between the interviews at the theme and meta-theme level. However, I am keen to emphasise the original richness, depth and breadth of the material, honouring each mother's perception and experience. The tone, character, and uniqueness of each mother comes through in the recording and translating through to transcript and coding.

Of the four meta-themes, the first two, (1) struggles around independence; and (2) visibility and the impact of the others' gaze, stand out in terms of frequency of theme and metaphor. These two meta-themes each contain a paradox at the centre of the mothers' lived experience. Each mother expresses her meaning-making of her experience and response to that paradox (whether concerned with independence or visibility) in an individual way. The richness of the themes underlying these two meta-themes suggest a wide range of emotional response. Thus these themes and meta-themes around independence, marginalisation and stigma provide a useful evidential base for a therapist to hold in mind when working with a client from this group.

It is in the final two meta-themes (3) "*life can sometimes be more complicated*" and, (4) the changed relationship with time, that courage, a sense of joy, identity as a mother and celebration of life with their children emerge. The mothers identify motherhood and its purpose as central to their life. Through an existential lens, many describe their experience of motherhood as almost possessing a heightened quality through the added complexity (and anxiety) sight loss brings. Related to this is an exploration of the idea that visual impairment and its consequences has given them as a mother a better appreciation of engaging fully with life, than sighted others.

Smith talks about the value of the "*gem*" in experiential qualitative psychology – that piece that "*stands out when you're reading a transcript...the extract that demands attention and prompts further analytic work*" (2011, p.7). All four of the meta-themes stem from initial pieces of text that commanded my attention in this way.

To use Smith's own categorisation of gems, from the "*shining*" (which possesses an immediacy in clarity of meaning to both participant and researcher), e.g. "*I just felt like I was like one person ... in the middle of nowhere on my own*" (Penny:73), to the "*suggestive*" (where the phenomenon is partially suggestive but some further work required), "*Yes, I've got my guide dog as well, (chuckle). Quite an entourage when I go out*" (Ayesha:445), and finally the "*secret*" (where there is a chink of meaning on the surface, but much more analytics is required) "*We (husband and I) do deal with a lot of things with humour because otherwise we'd just cry*" (Sarah:408). Recognising and working with such gems, a key part of the iterative coding process, helped to give definition to building up the themes, then finally meta-themes. Gems offer "*analytic leverage, they shine light on the phenomenon, on the transcript and on the corpus as a whole*" (Smith 2011, p.7).

Structured around a discussion of salient points from these four meta-themes, this discussion section has five main functions: it (1) highlights some implications arising from the findings and makes recommendations for those counselling psychologists and psychotherapists working directly with this client group, (2) outlines the main ways this piece of research contributes to previous research and helps raise awareness of the issues generally around parenting with visual impairment, (3) presents a reflective learning piece on my experience as a research-practitioner conducting this study, (4) examines some of the limitations of this investigation and (5) aims to highlight areas for future research.

A new depth and the possibility of working towards a new conceptual model

One of the key drivers behind this contribution to counselling psychology and psychotherapeutic practice was to explore the mothers' experience, with the hope of accessing an openness and authenticity to see what emerged. From this interpretative phenomenological analytical approach with its granular level of detail, I

believe a level of depth in examining that experience has been achieved not previously seen in a study of this size. Thus, in a similar vein to the written account give by the father who lost his sight, John Hull (1997), the findings across the four meta-themes acknowledge both something of the struggles experienced by the mothers and the aspects where their lives have been enhanced in becoming a parent.

As outlined earlier, previous psychological literature regarding experiences of disability have tended to fall, in a polarised fashion, largely within the medical or social model.   As an integrative psychotherapist, my instinct is to look for areas of coherence and integration, rather than the divisiveness inherent in a polarised model. Certainly, I hold it is desirable for those looking to offer psychological support to people with visual impairment to question and remain curious about possible new models.

As well as experiences common amongst the mothers, e.g. frustration around others' thoughtlessness, the findings highlighted many differences within their phenomenology. I argued one interpretation of these differences is to view them along a spectrum, e.g. the attitudes and feelings towards independence and using others for support. Reflecting on how the findings fit into existing theoretical models in the field, I am drawn to seek alternative possible model from the polarisation of the social and medical outlined above.

One such attempt to seek an alternative is the embodied ontology model proposed by Shakespeare & Watson (2002). They argue that while the social model has been useful in political terms, it has become a bit of a "*sacred cow*" by those in the disability movement.   They hold that the social model has developed its own limitations through the rigidity of issues such as its preoccupation in trying to break the definitional link between impairment and disability.

On the basis that this model, so rooted in its 1970s origins, has failed to move on sufficiently, they propose a paradigm shift away from the medical and social model, through the adoption of an embodied ontology. This model takes as its basic assumption that there is no qualitative difference between disabled people and non-

disabled people because we are all impaired (i.e. everyone has limitations, e.g. carrying recessive genes that cause impairment or disease in some way, and at root level, just simply the ag3ing process in general).

The basic universality of Shakespeare & Watson's (2002) argument appeals to me. Nevertheless, I hold their argument to be weakened by their assertion that it is difficult to achieve a core definition of "*disabled people*" because it is ambiguous as to who is disabled or not precisely because we are all placed on some kind of continuum of impairment and embodiment. Additionally, looking to the findings of this investigation as my evidential base, I do not believe that this model sufficiently honours the detail and difference in the experience.

Instead, I would like to come at the issue from the perspective of the essential experience of the person with the disability, taking into account the ontological reality of their impairment, within the context of the "*interhuman*" space (Hycner 1993, p.4). This tentative possibility of a new integrative conceptual model which takes greater account of the complexity of the experience as reported by those parenting with disability, is an approach similar to the detailed approach taken by Lutz & Bowers (2005).

In such a model, the challenges and positive aspects are acknowledged from that individual's perspective, rather than the focus being purely on their impairment (i.e. as something to cure or rehabilitate) or on the barriers within society that militate against their full participation within it. A more integrative approach concedes value in both the medical and social emphasis. However, its main focus is a bottom-up approach, integrating the phenomenology of the person, in this case the mother with visual impairment, with the relationship between what is co-created between that experience and the other.

The findings in this study can therefore be interpreted as offering one possible example for such integration, emanating as they do from the phenomenology of the participants. The benefit of such a granular phenomenological approach is that it helps highlight the nuances of the participant's experience. It attempts to show the psychologist or psychotherapist looking to work with someone who is visually

impaired something of the internal struggle often behind the integration process either at the intra-individual or inter-personal level.

Supple (2005 p.421) comments, "*Overwhelmingly, the assumption seems to be that disability is a physical problem, affected by an individual's thoughts and behaviours. The research rarely considered any social or contextual issues that may contribute to the experience of being disabled. Furthermore the research seemed to treat disabled people as a homogenous group, sharing traits and experiences, with little or no consideration given to how such a category is defined or what diversity may exist within it*". It has been important for me as researcher in this exploration of the experiences of women who are all mothers with visual impairment, to remain vigilant of Supple's call to highlight the heterogeneity in the field. Thus, I have been at pains to allow for a spectrum of responses from the participants. In the analysis I have sought both similarities and differences in the experiences presented.

This study has been an attempt not merely to move as far as possible away from the historically pathologising view but, through the words of the participants, to demonstrate and promote an emphasis evidenced in the findings on the "*strengths and strategies*" of "*good enough*" parenting (Kirshbaum and Olkin, 2002, p.19).

Before discussing the findings at a more macro level in the light of this integrative approach, I would like to give one example to illustrate the complexity an integrative model affords. In doing so, I have focused on one individual, which fits in line with the ethos of this piece of work, giving equal weight to each mother's experience, while acknowledging her contribution to an overall picture and themes.

Penny lost her sight suddenly two years ago, and has since had a second daughter. The findings across all four meta-themes movingly illustrate the shift in her lived experience of her new life as a visually impaired mother. Her initial feeling is one of being devastated at this sudden loss of vision totally dominating her life, thrown into a state of bewilderment and panic as to how she can fulfil her role as a mother, given her new physical state. But she reports how this loss progresses to become far less figural, and her growing sense of self as mother embodying an empowered position of modelling independence, strength and determination to her daughters.

While there are similarities with the other mothers, e.g. her experience of the lack of counselling support offered and going through post-natal depression, there are also notable differences, e.g. the guilt she reports that she experiences because she once had sight, held towards other mothers who been blind since birth, and a sense of feeling lost somewhere in the middle.

Lutz & Bowers also noted this difference (2005, p.1044) "*Persons who were born with a disabling condition described how they knew no other way to live their lives, whereas those who acquired a disabling condition during their lifetime described their lives in terms of before and after acquisition of the disabling condition. For some the "after" was devastating whereas for others it was perceived as a new and different life experience...*". Penny explicitly and implicitly describes experiencing a wide range of emotions, from anger, loss, isolation, sadness, fear to the energised, empowered sense of celebration in her growing acceptance of this new way of being with her children and as a person.

With such complexity, a simple reduction through the medical or social model loses aspects which a more integrative approach rooted in the phenomenology of the experience of the "*interhuman*" (Hycner 1993, p.4) can better capture. Thus the first key recommendation from this study would be, *(A) both in training and beyond, for psychological practitioners and at a wider level, service providers, to consider this integrative phenomenological approach as a possible theoretical model for therapeutic practice with those with disabilities.*

The independence paradox

The next few recommendations centre largely around the two major meta-themes: (1) struggles around independence and (2) visibility and the impact of the other's gaze.

Issues of independence and mobility constitute a major theme in the existing literature on the experiences of parents with disabilities. Travel, transport and mobility and independent living skills were the top themes identified as problematic in

the VICTAR study (Douglas et al, 2006) and access to the environment is one of the top topics cited by participants as one for further research (Duckett and Pratt, 2001). Lack of spontaneity and the restrictions on freedom of having to use public transport have also been brought up as major issues (Conley-Jung and Olkin, 2001, Kirshbaum and Olkin, 2002).

This is unsurprising as travel is an integral part of the role of being a mother, from visiting the doctors, to playgroups or school every day, before the many after school activities that children take part in (scouts, sports clubs, etc). Here again the findings add weight to previous studies, though the mothers' expressed frustration, sadness and some shame evidenced through the theme of *restricted freedom* and the emotions around the in vivo theme of *feeling trapped into* "*having to rely on everybody else*".

Counselling psychologists looking to work with a visually impaired mother can hold in mind that one quarter of the top twenty themes by frequency that emerged from the mothers' accounts related to this meta-theme of *struggles around independence.* Therefore, as a practical basic it is important to establish and promote a practice with maximum possible ease of access, e.g. near public transport.

However, through the lens of an integrative approach it is possible to see that the picture that emerged from the participants' experience was again more complex than the notion of physical (e.g. poor public transport options) or attitudinal barriers preventing their freedom of movement (e.g. social services' pre-determined ideas around what it is that a mother with visual impairment might need in terms of help with transport).

The situation was different for each mother, with economic and geographical factors playing an important part in the options available. Rural isolation, with little or no support from family or friends, and partner out at work all day, understandably appeared to be a key contributory factor for PND.

The findings emphasise again the need for flexible transportation by providers who are trustworthy, respectful and willing to collaborate and communicate (Lutz &

Bowers 2005, p.1048). The second recommendation from this study would be *(B) to hold in mind within the therapeutic framework the possible emotional and physical aspects of such isolation and lack of freedom; and that service providers listen to and act on direct input from the mothers as to what provision would improve their and their family's quality of life.*

Thus, a spectrum of attitudes and emotions emerged from the mothers describing their experience around the struggle to attain, hold onto and demonstrate independence from the other: from those almost totally dependent on their partner to the "*fiercely independently almost to the point of being belligerent*" Sarah:123. Specifically in terms of the intergenerational dynamics and their relationship with their children, the study evidenced that several of the mothers were keen to impress upon and model a sense of independence upon their children (Bandura, 1977).

The findings discussed how this notion of autonomy came over particularly strongly in the case of domestic violence where the mother made the difficult and traumatic choice to stand up to a violent partner. For Bridget, carrying a self awareness of the intergenerational impact of the trauma of suffering domestic violence herself as a child, this choice was made all the more difficult by her internalised notion from her abusive partner of her incompetence and inadequacy as a mother should she think to leave him.

One interpretation of this is as an extreme example of the notion of "*internalised ablism*" Olkin (1999), discussed in the literature review. This links with the concept of the good enough mother discussed in the findings in meta-theme two: *visibility and the impact of the others' gaze*. There appears to be an assumption found in all but one of the mothers that they are in some way secondary and one-down compared to those mothers without a disability. Within this, in terms of independence, is the paradox that lies at the heart of the feelings expressed towards accepting relevant and helpful support if offered, which the findings demonstrate is implicitly held and common to all the mothers interviewed.

Bridget spoke about "*a big cover up*".   It was clear that there is a basic mistrust of the other resulting in the paradox: though a mother might require support, the fear in

asking for help is that by doing so she proves the unsaid assumption, held by many of the mothers, and explicitly expressed by some that she is in fact less competent than a sighted mother. The third recommendation would therefore be *(C) that psychologists and psychotherapists hold in mind the possible implicit fear, shame and paranoia when working with a mother with visual impairment, plus the importance of working towards a collaborative approach, emphasising a listening, open, non-judgmental position.* Being mindful of the nature of these feelings towards the therapist as the other, and their own counter-transference is a key part of the work for the therapist working with a client with visual impairment.

Interestingly, the one place in which the majority of participants felt they could relax and let down their guard (where fear and anxiety at the centre of this paradox is less figural) was on the website group set up by and for mothers with visual impairment. Here both major and minor accomplishments can be celebrated in an accepting atmosphere. This was the case as the mothers experienced and appreciated the implicit and sometimes overtly expressed sense of being understood, shown through the themes: *true self emerging through meeting similar* and *boost to confidence through vi group*.

The data also confirmed how the mothers use the "vi" group in a confirmatory way in terms of reflecting back the meaning in their life and the part played by their role as a mother. What came through here was that becoming a mother had given them (albeit in a different way for each individual) a renewed sense of purpose and meaning to their life (the theme of *centrality of mother's role to own identity and sense of purpose*). Though over half the mothers describe serious factors around PND that militate against reaching a such a state.

The positive impact of the peer support available on a daily basis through a website as a safety valve is clear, both for the frustrations of dealing both with the physical reality of visual impairment (i.e. not being able to drive) and those evoked by social interaction in the public realm. Here the importance of peer support (barely touched on in previous literature (except for Kent, 2002), emerged as a strong theme across eight out of the nine mothers, and was explored in a new dimension through the advancement through applications such as Facebook and Twitter.

The issue of independence is usually framed in the literature in terms of mobility and rehabilitation (Douglas et al, 2006, and Costanzo et al, 1997). Two significant factors within the mothers' experience as outlined in the findings added to the debate. The first, just mentioned above, is the new dimension afforded by online social networks. Previous studies (Rosenblum et al, 2009 and Pey et al, 2007) have touched on the need to address the increasingly important role new technologies can play (both those technological pieces specifically for people with visually impairment and generic technology pieces).

This study has stressed perhaps more than any previous research, the increasingly important role played by online social networks in the lives of mothers with visual impairment, especially given the high take up of mobile phones as a facilitator for lifestyle amongst this age group (84% of 18-49 year olds interviewed by Pey et al, 2007, with communication or email chat cited as the top reason for use by those with internet access on a PC).

Additionally, there is a freedom of choice (e.g. from where to shop to meeting on social network sites) available through technology and the Internet, which also can be seen in terms of the frame of reference of independence. The fourth recommendation is *(D) for specific research into how access to psychological services online can be improved, ensuring high quality psychological support to the widest possible audience of mothers and their support network.*

The second factor, confirmed by five mothers in the findings, are the reported benefits, emotional and practical, achieved by accessing the services of a guide dog (Rosenblum et al, 2009). As the mothers in this study shows, not everyone will welcome an animal into their daily life (having a guide dog is a major lifestyle commitment not suitable for all families, with take-up generally only from a small proportion of those people with visual impairment according to Pey et al, 2007).

However, within those families who had chosen to live with a guide dog, two of the mothers described the dog's arrival and integration into the family unit as a tipping point out of PND. The guide dog, and intervention of a human facilitator appeared to

act as a key source of stability and security for the mother, giving her the confidence to get out and about with her family (theme of: *guide dog as tipping point to gaining a sense of independence).* Certainly this effect is one it would be useful for health professionals to be aware of in signposting mothers without a guide dog to the possibility of this potentially life-changing service.

A further observation in this section on independence, is that only two of the nine mothers talked about the world of employment and the important role it played in their life in terms of giving them confidence in society (though two others mentioned volunteering on an ad hoc basis). This 22% is broadly in line with an employment rate (taking full time, part time and self employed together) of 28% of people registered blind aged under 60 and not retired. This contrasts with the overall employment rate for mothers of 67% (Office for National Statistics, March 2011), and for all working age people in the UK of 75% in 2004 (Pey et al, 2007).

This perhaps suggests that more work and greater emphasis is needed on the excellent work done so far by Morris (1991, 1996) and Morris and Wates (2006) to develop their feminist arguments towards greater working opportunities for mothers with disabilities. It links too with the idea above, also within the feminist tradition, that the mothers evidenced their working life as a key part of their role as a mother, embracing modelling autonomy and a sense of independence to their children.

The visibility paradox

The other major area that came out in the findings (also a key topic explored in the literature review) was the exposure of the oppressive impact of attitudes to difference. This cuts across many of the themes that emerged in the study, e.g. *frustrated that life has to be a series of battles; defensive, withdrawn and feeling secondary to others; being a target for others' assumptions about visual impairment.* In fact, eight out of the top twenty themes as identified by frequency relate to the visibility paradox.

Negative metaphors betray entrenched attitudes about physical impairment within UK society and culture, e.g. that people with visual impairment can sometimes be

seen as passive, incomplete – themselves the recipients of care rather than the providers of it Olsen and Clarke (2003). This point was felt keenly by Sarah in her discussion of the power dynamic between her and her husband within the context of carer and cared for (Sarah:157). Additional assumptions made about people with disabilities include that the person will have a negative self identity, or be reduced to their impairment, which is dehumanising and disempowering (Corker, 2008).

The VICTAR longitudinal study (Douglas et al, 2006, p.94) quoted several examples of this that chime with the findings of this study: a 29 year old employed registered blind woman's commented *"I think one thing I've found that is embarrassing, is the way people treat disabled people as if you're different – have an interpretation of what a visually impaired person needs, but don't ask you – make assumptions – like [my] mother-in-law who assumes [I] can't look after the house[…] It's general awareness really."* Such attitudes at the extreme have pathologised parents with physical impairments (Olsen and Clarke, 2003 and Kirshbaum and Olkin, 2002), stigmatising their children and even questioned their right to parent (Olkin, 1999, 2002).

One interpretation of the findings from this study, largely under the meta-theme *visibility and the impact of the others' gaze*, is that a tension around visibility and invisibility can exist in the mother's self identity, constructed through interactions with others. On the one hand, several of the mothers spoke about their sense of invisibility as a mother: in the school playground or at toddler group. They reported a sense of being ostracised or ignored by others who were, clearly and perceptibly to the mothers, nervous and uncomfortable around a visible difference and inability to make eye contact.

Two of the mothers, Caitlin and Sharon, spoke about their embarrassment around the visual stigma of their sight loss. They reported they would rather go without obvious mobility aids so as not to draw attention to themselves, and thus avoid another's stigmatising gaze. The very visibility of their impairment seems to trigger a social response different from that of an invisible or less obviously visible impairment (e.g. a mental health condition or hearing impairment), a distinction Goffman (1968) draws between "*discrediting*" and "*discreditable*" stigma.

The impact of others' stigmatising and marginalising reactions to the mother's visible difference contributed to a perceptible sense of isolation, active withdrawal, and invisibility, something not given prominence in previous studies relating to mothers with visual impairment. A sense of isolation has been reported in the minority of articles that exist generally on parenting with a disability, e.g. Feldman (1994), though not invisibility specifically.

Invisibility is discussed as a theme in Olsen & Clarke (2003) in related terms, citing the relative invisibility of mothers with disabilities, in comparison to the visibility of young carers, for example, in public and policy discourse. The next key recommendation therefore follows on from Olsen and Clarke's emphasis, *(E) for psychological practitioners, actively to consider the implicit and explicit in terms of visibility and power dynamics within the therapeutic relationship, when working with this client group.*

However, the findings themselves underline that such discourse is a delicate and sensitive matter. In addition to being ignored frequently on a daily basis, the majority of participants also felt their identity as a mother with visual impairment gave them a sense of unwanted visibility in public. Each mother displayed a different way of coping with others' reactions to her visibility as a mother with visual impairment, from sarcastic anger (Sarah) and active avoidance and withdrawal (Claudia and Caitlin) to Ayesha, the outlier of the group, who reported celebrating the visible difference of her family unit within her community.

It is interesting that Ayesha reported very positive experiences in her dealings with others throughout her life, as a person registered blind from birth, living initially in India and then the UK (from her supportive parents and husband to the wider community). This sense of security and family support clearly contributed to a high level of confidence and aspiration for herself and her children: her frustrations in daily life are less around others' attitudes towards her and more practically-based – largely based around her restricted independence through lack of driving ability.

The majority's sense of unwanted visibility was reported as a feeling of exposure, for them and their family unit: treated as an object of others' judgments and even shaming. It was clear from the examples given (particularly those highlighted under the meta-theme *visibility and the impact of the other's gaze*) that the other and their opinion(s) can play a large part in contributing to the mothers' sense of self, and, as reported by some, a sense of failing or being judged to have failed in some important aspects of care as a mother.

As shown by the theme: *defensive, withdrawn and feeling secondary to others*, held by eight of the mothers, the belief that others devalue them as human beings because of the disability is still sadly prevalent (Lutz and Bowers 2005, p.1045). Certainly one of the main emotions around interpersonal relationships in public generally was anger, brought out explicitly by frustration at self and others. The findings under the in vivo theme: "*they seem to think they have a right to, to, to comment on or pass judgement on your – the things that you do in your life*" and *being a target for others' assumptions about visual impairment*, I believe add weight to Olkin's (1999) idea that the constant exposure to others' negative attitudes can lead to a state of "*internalised ablism*".

Two of the mothers were particularly vocal in their anger towards the particular type of visibility that they feel is thoughtlessly promulgated by mainstream media, which can feed such pathologising attitudes, (citing a recent Channel 4 television documentary that represented a family with parents who were both visually impaired as incompetent and neglectful of their children).

In this sense, the mothers' feelings around this aspect of their public visibility and the reactions their presence often evokes in others agree with the previous research. It is possible to interpret the findings as giving depth and detail to the picture given in previous literature by illustrating three main reactions to the feeling often expressed by the mothers of being in a one down position: an angry drive to prove themselves as a mother by going 110% (seen in Conley-Jung and Olkin, 2002); detachment or withdrawal from others; and active reflection on others attitudes but a security in her sense of identity and self in the wider community.

Sadly, however, evidence presented from several of the mothers in this study (e.g. Sarah's reporting of the CAMHs worker's assumptions around her daughter's referral, Caitlin's experience of her GP and antenatal care from a hospital doctor) suggest that poor experiences with professionals are still prevalent. Therefore, a further key recommendation would follow Rosenblum's et al (2009) call for the medical community to be better advised on the abilities of parents with visual impairment; *(F) as part of the annual review for professionals in public services, e.g. NHS, educational systems, etc, to incorporate an awareness of recent research and actively challenge their attitudes and assumptions around mothers with visual impairment.*

Such oppression as some of the mothers reported experiencing within the NHS or school system is shaming. Shame occurs specifically in relation to parenting in the mothers' accounts, through two major themes in this study: *shame and anger at others' perception of self as unfit parent*; and the in vivo theme "*almost to prove a point that we are just as good parents as anybody else*".

For some of the mothers (e.g. Claudia and Penny), this sense of shame and feeling of being judged was evident not just in the public sphere, but held also within the domestic sphere through shaming reactions within the attachment configuration from members of their close family (mother, sister, etc). Uncomfortable with and unable to understand the emotional needs and position of the mother in each case, the family members' shaming stance appear to reinforce much of the negative attitudes which the mother can experience in her wider community. The mother with visual impairment therefore face "*battles*" at home and in public, an experience reported as being exhausting, frustrating and isolating.

There is a clear contrast with the mothers who benefit from a good deal of support from home, e.g. Ayesha detailed as a example above, Caitlin and Sarah (supportive partner, parents, family and friends). This indicates that the informal support acts as an important buffer mitigating and helping to reduce the impact of the feelings, for example, of frustration, anger and isolation, which can arise. For example, Caitlin looks to her partner and family for support and to express her frustration over the

shaming experience of being reported on as using her son inappropriately as a guide and helper.

Shame is a social emotion increasingly linked to mental health problems such as anxiety, depression and low self-esteem (Fennel 1997 and Gilbert 2000). Seven out of the nine mothers interviewed reported experiencing one or more of these mental health problems, during their time as a mother, and four of the nine reported experiencing severe post natal depression.

Exploratory questions around the type of emotional support the mothers were able to access found that of those who lost their sight in adulthood, none were offered the chance to talk through any emotional difficulties around their sight loss. This supports previous literature that dedicated counselling services for visually impaired people remain scarce (Nicholls, 2004), and access often difficult (Thurston and McLeod, 2010).

However, eight out of the nine mothers interviewed said they would have liked the chance to have had access to some form of emotional support (in addition to friends and family) on giving birth. As Penny mentions repeatedly during her interview, she would have appreciated the chance to focus on the emotions she was going through post-diagnosis, at the same time as supporting the transition to this new life with her daughter. She talks about how this would have given her a much needed opportunity to acknowledge and mourn the loss of her previous life with full visual capacity, rather than suppressing those feelings in the necessity of getting on with life as a parent.

Additionally, two mothers spoke about partners still waiting on counselling lists as a result of their own issues coping with their partner's sight loss. Thus two key recommendations would be *(G) acknowledgement of and provision made within the NHS for increased counselling opportunities at diagnosis, specifically with the needs of 18-49 year olds in mind*, and *(H) further research into the needs of partners supporting a mother with visual impairment.*

The positive message from the findings was that a respectful trusting collaborative intervention can make a significant difference to a mother with visual impairment feeling vulnerable and with low confidence: one professional stepped in to provide emotional support (and a practical solution – access to a guide dog) for Claudia at a key time when she was suffering from severe PND. That individual's sensitive intervention proved to be the tipping point for Claudia and the beginning of a reduction in her sense of isolation and vulnerability in depression.

Life as a series of battles: tears and laughter

One of the key themes that came up through the data, frequently in expressive language and metaphor, was the sense in which, for a mother with visual impairment, daily life entails the frustrations of fighting battles. This is a phenomenon reported in the grey literature around being a mother with visual impairment: personal blogs, and articles in magazines or newspapers (as opposed to formal research studies).

On the whole, such battles were seen and accepted by the mothers as minor irritations, arising sometimes from the extra time and effort involved to accomplish daily tasks (e.g. Sarah reports having to grope around trying to find something that had been there just before, but has subsequently been moved by someone). A further interpretation could be how the extra time a task takes due to the visual impairment helps in the natural bonding and attachment process between mother and child, e.g. Priyanka reading her "*learning journeys*" with her five-year old daughter, or Caitlin going food shopping with her son, (a point on the bonding process made too by Conley-Jung and Olkin, 2001) .

However, on occasion, battles were reported as feeling more significant. Such battles were largely created by others' thoughtlessness or attitudes and actions rooted in stigma (appearing under the meta-theme "*life can sometime be more complicated*"). This included the times reported by the mothers where they felt frustrated, expressing opinions about service provision but left with a feeling of not being heard or ignored, e.g. Caitlin on the support she needs to get out and about, and Bridget on feeling discriminated and excluded by the third sector service offering

in her community because, in their family provision, they target mothers of children with visual impairment, and do not extend services to mothers with visual impairment.

A point well made by Shakespeare (1994) is that part of the psychological origins of hostility to people with disabilities may lie in the tendency of people without disability to deny their vulnerability, frailty and mortality. They then project these uncomfortable issues onto people visibly different from themselves, who they can subsequently oppress, exclude and ignore. What emerged, both in the findings and the general process of interviewing, was one of the main ways the mothers responded to such battles and the experience of being at the end of such projections from others was the use of humour.

This section of the discussion looks at some of the interesting ways that humour came up in the interviews and process. I believe it is worth exploring on the theoretical and pragmatic levels the important part humour plays psychologically in the mothers' experience. I discuss possibilities for what it represented for the mothers in the "*interhuman*" space (Hycner, 1993, p.4), and some thoughts about implications for the relational work with a therapist (sighted or visually impaired). The use and experience of humour in the interviews can be seen as a good example of how a more integrative conceptual model can explore and hold the tensions that exist at the boundaries in the complex dialectic of biological, psychological, cultural and socio-political factors in the mothers' experience.

Humour generally appeared to play an important part in the mothers' experience. As a first example, sharing a joke often played part of the interview process, and I was interested to consider what might be going on in the process between us when it did. Did it act as a distancing mechanism, or further strengthen the working alliance between us as researcher and interviewee? (Again, this is an interesting question to be curious about within a therapeutic setting).

My known status as a mother (as well as researcher) often elicited a kind of humour through a sharing of the commonality of experience of life with a toddler for example,

from the challenges faced through their ability to climb over everything and a shared fascination and revelling in their innate curiosity that entails such a life on the go.

Other ways humour is used in the piece (self deprecatingly, to deflect pain, sarcastically, to express sheer joy, black humour, and so on) are explored in the section above under the in vivo meta-theme "*Life can sometimes be more complicated*".

In his fascinating article *Disability Humour: what's in a joke?* Albrecht (1999) argues that disability humour is powerful both for the strong emotions it can elicit (anger and fear) and reactions against the instigator of such jokes. The mothers' sense of anger towards others, who target them and make judgments on their parenting skills purely on the basis of their visible disability is made clear through themes such as: *being a target for others' assumptions about visual impairment; frustration and anger at self and others* and *shame around internalised assumption of stigma of visual impairment*, as three examples.

Here, humour serves as a method by which to process, either explicitly or implicitly, the sense of division between the mothers and the sighted world. Some of the mothers' anger is towards others' thoughtlessness and lack of empathy that often result in "*silly little things*" occurring, e.g. Claudia's 376ff dry risibility towards the committee of mothers who, as she perceives it, so easily dismiss the added complications she faces in life as a mother with sight loss.

The occasional sense of shame and embarrassment is palpable when the mothers report experiences such as, due to a lack of effective communication, sending their child to school in clothing different from everyone else because it is a non-uniform day (Sarah); not being able easily to see or check on your child's behaviour at toddler group (Caitlin) or as Bridget:31-33 comments: "*Occasionally a chair isn't a chair and I end up on the floor, or a cat isn't a cat and it's a clump of grass or whatever, you know, things like that really, or paper on the floor is not sunshine and daft things like that.*" Humour here is employed to deflect the pain and embarrassment felt by the mother of demonstrating to herself (and others) the minor

disconnect she momentarily experiences between her intentional grasp of the world and her actual perception of the world, due to poor sight.

Such experiences are discussed and shared on the website for mothers with visual impairment. These web groups, run for and by the participants, appear to be an outlet which demonstrates the other side of Albrecht's (1999) argument, where disability humour can be emancipating. Here, laughing at oneself amongst similar others helps to redefine the experience (Berger, 1997) in a way that can promote self-confidence and lifts the sense of isolation. One interpretation of sharing the humour in this way is that it helps to put the experience in a context that eases the difficulties mothers can face in daily life (Gill, 1991).

Stronach & Allan's (1999) work on the construction of the self and disability humour offers another perspective for me in analysing and reflecting on this conversational data. Their work has been criticised (Robillard, 1999) over validity for its reliance on literary research as opposed to recorded naturally occurring situated phenomena. However, I believe their approach, based on Goffman's (1963) dramaturgical perspective in the construction of self through relations with others, offers a useful lens through which to view the recorded interactions collated in this study.

Albrecht's (1999) analogy with the theatre is also useful here in drawing a distinction between the disability as experienced by the person who lives it (the actor) and; by those in their social life (their partner or friends), or the general public who do not have exposure to such conditions (the audience). Albrecht also distinguishes a third group, those with similar experiences to the protagonist but either co-actors or occasional audience members (for example, the peer support group). What is humorous and acceptable within the context of the peer support group, such as the website group for mothers with visual impairment, may not be understood by the people in the outside world (Morris, 1996). I consider Albrecht's distinction to be a thoughtful and useful one for the psychologist or psychotherapist working with this client group, to help consider where they sit and how this informs the work and its process.

As a researcher-outsider, I am a member of the audience, and during the interview process, elicit a range of humour responses as described above. One possible example, might be Caitlin's:16 "*If I walk into something, I just laugh*", a self-deprecating comment, early on in our interviews (with an audible laugh from Caitlin on the recording). Painfully aware of how walking into something must look to others, as members of the sighted audience, including me, Caitlin's unconscious intent could be interpreted as an attempt to reclaim the embarrassing event for farce rather than tragedy (Stronach and Allan, 1999).

She thus rescues herself from humiliation in the other's eyes by laughing at herself and attracting laughter. Caitlin permits the audience to laugh directly at them, erasing a taboo, an act usually strongly prohibited. Though Stronach and Allan (1999) point out, jokes about people with disabilities are very much a part of societal attitudes within the subculture. What was initially negative – a desire to shrink from such exposure and centre stage visibility through her visual impairment, back into the peripheral – thus becomes more positive. Caitlin can be interpreted as making a transformation from passive to active.

However, fundamentally, I agree with Stronach & Allan (1999, p.34-5) in their assessment of the power dynamics within this transformation move. An ambivalence remains in this unconscious striving in the space between actor and audience to preserve "*the vulnerable surfaces of "normality"*" in that "*disability – the unwelcome ghost at the banquet is erased. But it is not to be denied*".

I have tried to show that through an interpretation based on a dramaturgical perspective, it is possible to see the humour displayed and experienced by the mothers in these interviews as a microcosm of the interplay between the comic and tragic forces in their lives. This is one possible interpretation of the natural polarity that emerges in the top themes (by frequency) Appendix 9: with the fragility, and perhaps potential tragedy, of life emphasised in *anxiety with living with the unknown*, and *advocating a carpe diem* philosophy in life, set against the energy and power expressed through *celebrating self as proud mum*, and *centrality of mother's role to own identity and sense of purpose*.

Tragedy here is most obviously and poignantly expressed in the interviews by the mothers' sense of loss. For example, the loss of seeing her daughter's changing beauty as she grows up, instead relying indirectly on others' descriptions of the visual element of her daughter (Sarah), or her son scoring the winning goal at a football match (Sharon). What is also interesting is the imperative, seemingly closely tied up with that sense of loss: the necessity of having "*to get on with it*" when you are a parent (which can entail for some of the mother's a sense of lack of opportunity to process what is going on for them, an experience reported by Caitlin and Penny).

For me, this interplay between the tragic and comic is succinctly summed up by Sarah's comment on her experience of sharing the parenting role with her husband: Sarah:408 "*We do deal with a lot of things with humour, because otherwise we'd just cry*". This precarious sense of somehow not knowing whether to laugh or cry perhaps demonstrates that frequently both forces operate at the same time. Transformation is possible from one to the other (Stronach and Allan, 1999) and, I would argue from the findings, an essential part of the mothers' experience. An integrative perspective and model of the mothers' experience as posited at the beginning of this discussion would, I believe, go a long way to allow for this delicate balance.

Reflections on my position within the research

Leading on from the discussion above, framed in terms of actor and audience, I now reflect on my experience as researcher in this piece of work. In various ways (journal, recorded pieces on my iPhone, sketches, observational notes) I have recorded my reflections during the years of this research piece. What follows is a summary piece of my observations.

From the beginning of my relationship with this piece of research, and the nine mothers involved, I considered what sparked my initial interest in the field (my family history, combined with clinical experience of a client with vision problems while working for a counselling charity in Hampshire). I quickly became conscious of the important difference between me and a number of other researchers in this field, namely that I am not visually impaired. In this respect, my research inherently lacks

the insider perspective afforded of the absorbing material offered by Dale (2008) or Thurston & McCleod (2010).

After speaking with practitioners in the field (both sighted and visually impaired), I resolved to disclose my interest (namely my family history of eye conditions, and the fact that I am also a mother of young children), for two reasons: firstly, I was advised by those practitioners, that participants were more likely to take part if they felt the researcher had personal knowledge of some of the issues; and secondly, that it might help, as I believe it did, to build an effective working alliance in the interviews.

I recognised the importance of an effective alliance fostering openness in the interview, from research by Supple (2002, 2003) that explored how people speak about themselves and their experiences of disability. This found that although the participants (all with a physical disability) felt able to discuss their physical impairment, they often felt unable to speak about their experiences of disability.

Thus, I began this project, not as an insider, but not a total outsider either – a counselling psychologist and psychotherapist in a liminal position, a sighted mother of young children. I observed during the interviews, that this position evoked a degree of transference that either served to strengthen the working bond or to alienate. On occasions, I experienced passive aggressive swipes from the participant, for whom I represented something of the sighted mothers who have caused so much distress and alienation (this is clearest in points in the interview with Claudia).

Other times, it felt like it was hard for me to get a word in during the interview. I wondered about this experience in terms of a parallel process over visibility and being heard in the interview process and generally in the project.

I have found this research process a transformatory process in several ways. The first as a learning curve professionally: finding my doctoral voice, and gaining the authority and confidence to speak out. This is a process that in many ways mirrors what is under exploration: a project that hopes to raise awareness and give authentic

voice to the mothers, (as opposed to the stigmatisation and media portrayal that so angers them).

This process includes experiences contacting NHS and third sector organisations to help me with recruitment, being interviewed on Insight Radio, presenting my research progress at the VINCE (Visual Impairment Network for Counselling and Emotional Support) conference in March 2011, putting in a submission for an individual paper at the DCoP conference in July 2012 and seeing where this research could contribute.

Early on in the planning I gained confidence through active consideration of my roles: both as a researcher and clinical practitioner: as Singer (2005) points out both qualitative research and therapy are iterative processes, where the researcher or therapist builds up meaning and improves understanding in a generative manner.

Picking up on my own anxious excitement about beginning my doctoral study, I was also aware of a palpable sense of wanting to get it right somehow, to ensure that I did a thorough job on behalf of the mothers who I had already spoken to in lining up interviews. I wonder about a parallel process there, linking with what emerged from the mothers' experiences about wanting to get it right, and to prove myself as good enough.

Helpful in this was an experiential group research session on my course. I reflected here with colleagues that through my training as a clinician, I already possessed the listening empathy skills required for building a good working alliance with my interviewee, putting them at their ease and helping them to open up.

The data and the therapeutic conversation are similar too in pointing to several ways to go in terms of meaning and outcome, different possible interpretations (Singer, 2005). There is no single way to interpret the interview data or what emerges from a therapeutic session, only "*more or less useful ways of expressing what the data reveals*" (Patton, 1980, p.322).

I was also careful to consider the power dynamics around this investigation. Within the research relationship it felt very important not to emulate the power dynamics of a doctor-patient relationship (a point raised by Duckett & Pratt's (2001) study into the views of people with visual impairment on the use of participation in research). A key benefit of interviewing by telephone the basic equalising element – without the benefit of sight in a face to face interview, we were able to connect on an equal sensory basis.

In carrying out the interviews, I experienced feelings of anger, protectiveness and sadness, in hearing the descriptions of the mothers' experiences around domestic violence or discrimination or neglectful behaviour from others. I was careful to manage my own process around this, following an interview, or period of intense analysis or coding with the material.

This was made more complex and personal as, post-interviews, just before I had begun the main coding cycles, I was in a serious car accident. While my children sustained no lasting injuries, one of the physical injuries I developed was problems with my vision, which have remained, as a result of the air bags that hit me in the head-on collision.

While I remain able to drive, it has been an anxious journey to reach a steady state of acceptance of my changed visual field. Plus my anxiety over further sight decline remains as a result of the accident. In Shakespeare & Watson's (1997) embodied ontology terms, my decline in vision fits with their idea that as human beings we are all impaired in some form and, through life experience (by nature or by accident), impairment increasingly forms an essential part of who we are.

This project, combined with my personal experience, has certainly made my awareness of my own use of sensory capacity and, particularly, the visual sense, more acute. For example, in working on the analysis and cross-analysis for the themes, it was important to my thought and mood process to create diagrams, shift around post-it notes, and physically place themes in different places in the room across the extent of my visual field. I feel that I have been conscious of how fully and effectively I have used all my senses to collect and analyse the data. This point

Janesick (2001, 2004) emphasised as one of the strengths of a qualitative researcher, including that intuitive sense of "*seeing*" or following up on a hunch.

Despite never having met the mothers face-to-face I have a clear idea of the character of each of the nine, dancing around my head during coding, analysis and write up. At times, I feel that I have been successful in truly inhabiting their experience and process, which I hope comes through in the detailed findings section.

Finally, I note that much of the literature review has a cultural bias towards research produced from the USA. This is partly down to the fact that there are some research institutes there doing excellent critical appraisal and fostering debate on societal attitudes towards disability, e.g. Through The Looking Glass foundation in California. There is also a personal piece, as I was born in Toronto, Canada, and hold dual Canadian and British citizenship. As such I have a natural tendency to look towards North America as a touch stone for my own thinking and attitudes, both as an individual and professionally as a counselling psychologist and psychotherapist.

Limitations of the research

Finally, before concluding, I would like to cover what I believe to be some of the limitations within this study.

Firstly, within the depth of experience proffered in the findings section, I am also aware of the visibility of each mother as an individual. Given the constraints of word limit, it has not been possible to give as full an account of each mother as the material collated would have permitted. The question of visibility within the research between each mother and me as the researcher, and then each mother and you as the reader, has been an interesting parallel process in itself.

Secondly, it has not been the aim of this research either to seek out the single experience of being a mother with visual impairment, or a solution in terms of support: the participant group itself demonstrates the heterogeneity within it, as within any parent group. Different themes might well have been found with a

different set of participants. Instead the aim has been to create a space for the mothers' voices to be heard, and active debate generated. As Smith (1999, p.413) has argued, in judging IPA research, we should look as to how illuminating it is of the particular cases studied, while the "*micro-theorising should be richly informative of those particular individuals and may well be fairly modest in its claims to generalisation*".

This study has identified key times when a mother with visual impairment might be more likely to reach for support from psychological services. These include: ante- and immediate post-natal care, from when the baby becomes mobile and becoming a toddler, plus the transition from pre-school life to full time education when their child first starts primary school.

The research could have gone into greater depth by interviewing participants, not just once, but a second time, perhaps going back with a the list of themes in mind generated from the first round of interviews. The benefit of this would have been to explore the themes generated by the mothers in further detail.

A further possible limitation is my own selective vision as the primary researcher. While I have attempted to stay as a close as possible to the data, and the mothers' own description of their experiences, there has been a necessary filtering and reduction in the analysis process. As this is naturally an interpretative process, the research is inherently limited in its scope through the very methodological design.

Conclusion and future directions

In conclusion, I hope this research has gone some way to addressing the views held of research by those who are visually impaired, as highlighted by Duckett & Pratt (2001). Certainly, central to my ethos in carrying out this investigation, has been transparency, authenticity, inclusiveness aimed towards immediate and practical benefit to those interested in the field.

The framework under consideration here makes no claims to generalisability, being grounded in the detailed exploration of the nine mothers' accounts. However, in using IPA, this study presented its aims as being beyond simple description and categorisation of salient themes (Rizq & Target 2009). I would argue that the findings have led to discussion of the possibility of a new conceptual and integrative model as a philosophical approach to how we view disability, consistent with and rooted in the subjective phenomenology of the mothers' experiences.

Supported by the verbatim quotations highlighting these experiences, eight key recommendations emanated from the findings as discussion points for counselling psychologists and psychotherapists, and areas for immediate practical action. These were:

(A) both in training and beyond, for psychological practitioners and at a wider level, service providers, to consider this integrative phenomenological approach as a possible theoretical model for therapeutic practice with those with disabilities.

(B) to hold in mind within the therapeutic framework the possible emotional and physical aspects of such isolation and lack of freedom; and that service providers listen to and act on direct input from the mothers as to what provision would improve their and their family's quality of life.

(C) that psychologists and psychotherapists hold in mind the possible implicit fear, shame and paranoia when working with a mother with visual impairment, plus the importance of working towards a collaborative approach, emphasising a listening, open, non-judgmental position.

(D) for specific research into how access to psychological services online can be improved, ensuring high quality psychological support to the widest possible audience of mothers and their support networks.

(E) for psychological practitioners, actively to consider the implicit and explicit in terms of visibility and power dynamics within the therapeutic relationship, when working with this client group.

(F) as part of the annual review for professionals in public services, e.g. NHS, educational systems, etc, to incorporate an awareness of recent research and actively challenge their attitudes and assumptions around mothers with visual impairment.

(G) acknowledgement of and provision made within the NHS for increased counselling opportunities at diagnosis, specifically with the needs of 18-49 year olds in mind.

(H) further research into the needs of partners supporting a mother with visual impairment.

I have found the journey of planning, carrying out and writing up this research a great privilege and totally absorbing. My final hope is that this piece of work has gone some way to reducing the "*gulf*" that Claudia reports as being at the heart of her daily experiences of otherness between her as a mother with visual impairment and those with sight in the world.

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Appendices

Appendix 1

Participant statistics

no. of participants   9

	Priyanka	Claudia	Bridget	Ayesha	Gail	Sharon	Sarah	Caitlin	Penny	Total
age	38	32	47	35	44	32	40	33	35	
age when first experienced sight loss	0	1	0	2	0	17	20	25	30	
number of children	1	2	3	2	1	2	2	2	2	
geographical area	Central England	Central England	Scotland	South East	Central England	South East	South East	Wales	North England	
ethnicity	Asian/British	White/British	White/British	Asian/British	White/British	White/British	White/British	White/British	White/British	
living without a partner	0	0	0	0	0	0	0	0	1	1
married/long term partner - sighted	1	1	0	1	1	1	1	1	0	7
married/long term partner - visually impaired	0	0	1	0	0	0	0	0	0	1
in paid employment post children	0	0	1	0	0	0	1	0	0	2
in voluntary work post children	0	1	1	0	0	0	0	0	0	2
mother working in the home post children	1	1	1	1	1	1	1	1	1	9
educational level - to A'Level	1	1	1	1	1	1	1	1	1	9
educational level - to postgrad	0	1	0	1	1	0	1	0	0	4
guide dog in the home	0	1	0	1	1	0	1	0	0	4

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A phenomenological investigation into the impact of being a parent on mothers with sight loss in the UK

A psychological research study to capture, in their own voice, the experience of mothers with visual impairment

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to consider the following information carefully and discuss it with others if you wish. Please ask if anything is not clear or where you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study aims to give an accurate picture of life as a

mother with visual impairment with young children in the UK today. As part of the DCPsych programme at Middlesex University in conjunction with the Metanoia Institute, it is hoped that this research will help inform psychological services and eye departments. By volunteering to take part you will help to guide and improve knowledge for such services in the future.

Why have I been chosen?

You have been invited to take part through your involvement with your local visual impairment services. The aim is to recruit at least ten mothers with visual impairment, each with children aged seven or under.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, and given a copy. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I decide to take part?

If you decide to take part, your details will be given to a research interviewer. She will then be in touch to arrange a suitable time for a one-off interview. This interview will last approximately one hour and half and will be at a time convenient to you. We ask that you also make provision for someone to look after your children for this time, even if the interview is carried out in your home, to give you the time

and space for the interview. You will be asked questions about your life since pregnancy and motherhood and asked to report your experience of this time. The interview will be recorded.

Following the interview there will be an opportunity to find out more how the research, or receive further information on services in the field of visual impairment counselling.

What are the possible disadvantages and risks of taking part?

It is possible that the interview brings back memories and feelings from a period of your life that you have not thought about for a while. Should you experience feelings that you wish to explore following the interview, the research team will be able to put you in touch with someone within the counselling field for a debrief session.

What are the possible benefits of taking part?

We hope that participating in this study will help you. However this cannot be guaranteed. The information we get from this study may help future mothers with visual impairment gain better services in the psychological therapies. It is hoped that the research will give a voice to mothers with visual impairment, to inform psychological and support services in the future.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course

of the research will be kept strictly confidential. Any information from you which is used will have your name and address removed so that you cannot be recognised from it.

All data will be treated with full confidentiality, collected and stored in accordance with the Data Protection Act 1998. If excerpts from your interview were to be published, this would be done in such a way that you could not be identified.

What will happen to the results of the research study?

It is intended that this research be published as part of a postgraduate dissertation, with copies held at Metanoia Institute and Middlesex University. The findings will also be made available to the Visual Impairment Centre for Teaching and Research (VICTAR) and the Visual Impairment Counselling network (VINCE).

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Appendix 3

Q&A Prompt Grid: semi-structured interview

Notes for research interviewer:

Flexible data collection instrument preferred (Smith 2003) to help researcher analyse in detail how participants perceive and make sense of things which are happening to them

Stay close to the participant's experience, with an open mind and genuine curiosity; Wish is to as far as possible enter the psychological and social world of the respondent. The respondent can therefore share more closely in the direction the interview takes, perhaps introducing an issue the researcher had not thought about. Respondent = experiential expert on the subject and therefore should be allowed maximum opportunity to tell their own story.

How is participant constructing the meaning of her existence and her issues?

Interview schedule: participant's experience of the impact of being a mother with sight impairment
plus use technique of funnelling
check for medical model assumptions!

A. Sight impairment (10 mins)
(1) Could you please describe the nature of your sight impairment and when it first began?
(2) Could you please give me a brief history of sight loss in your family – current and past?
(3) If you had to describe in your own words what your sight impairment means to you, what would you say?
(4) How would you describe yourself as a person before having children (Prompt: happy, moody, confident, shy ...)
B History of counselling (5 mins)

(1) Have you ever visited a counsellor, psychologist or psychiatrist before? (if, yes, please describe your experiences)
C Becoming a mother: identity (40 mins)
(1) How and when did you make the decision to become a mother?
(2) Can you describe to me your feelings at that time?
(3) Has being a mother made a difference to how you feel about yourself (prompt: physically, emotionally, mentally)? (if so, how would you say you have changed?)
(4) How much do you think your visual impairment has impacted on your experience of motherhood?
(5) What are your thoughts about the way that people perceive and consider you?
(6) Do you think much about the future?
(7) Could you describe to me in your own words your relationship with your children and what it means to you?
D Practicalities of being a mother with sight impairment (30 mins)
(1) What if anything do you feel would have made your experience as an expectant mother easier?
(2) On a day to day basis, how do you feel you deal with the practicalities of being a mother? Is there anything you feel could make your life easier?
(3) Do you know many other mothers with visual impairment?
(4) Could you please describe to me the role of your partner (and/or wider family)?

Raw data sample 153-337

153 R: Yeah, so and, and, and how do you feel you coped in those early years when this was going on, and, and Matthew was kind of like well nought to two I guess?

154 M7: Well I was a little bit depressed, but you know

155 R: How did you recognize that you were a bit depressed?

156 M7: Because I wasn't in the mood for doing – I normally read a lot;

157 I couldn't be bothered to open a book.

158 I couldn't be bothered to dress up nicely – you know

159 R: And you'd normally do, do those things?

160 M7: And I went through this – you know OCD, Obsessive Compulsive Disorder.

161 I cleaned obsessively

162 R: Oh right, ok

163 M7: I still do now and then, but you have to!

164 *Chuckle*

165 R: So you felt that that had got out of control

166 M7: Yeah

167 R: Ok. And what did you do about, about feeling that, those, those feelings?

168 M7: Nothing much to be honest - I didn't want to take anti depressants or nothing

169 R: *Pause*. And so what happened, did you just kind of come out of that?

170 M7: I did go to a Doctor but she tried to give me anti depressants and sleeping pills.

171 That was just soon after my ex left

172 R: Right

173 M7: And basically I said how do you expect me to take a sleeping pill with a two year old next door who's *muffled* call me?

174 R: Yeah, yeah

175 M7: So I shoved the pills down the toilet and that was it

176 R: I mean did you, when you say, you, you I mean you said at the beginning the best thing is friends. Did you, did you get support from, from your friends, or -?

177 M7: Oh yes, yes

178 R: Yeah. And, and from family, are they -?

179 M7: Well the family's is all over the water so -

180 R: Ok

181 M7: Over the phone yeah, but not really personal d'you know?

182 R: Yeah. Sure. So, so you didn't take any drugs, you just sort of got better over the – what -how long would you say before you felt yourself again?

183 M7: About three months

184 R: Ok. And that was after he'd gone

185 M7: Yeah

186 R: Sort of thing, then you felt better. And how would you say that during the first, you know couple of years with Matthew – or when - it was a lot longer than that wasn't it, about, well about four years when it was just you and Matthew I guess before Erin, Erin came along, or -

187 M7: No. Well Matthew was born March 2004.

188 My ex left July 06.

189 And I got with my partner September 07

190 R: Right. *Pause*. And what's your partner's name?

191 M7: Owen

192 R: Owen. *Pause*

193 M7: I dragged him to Wales from Ireland you know?

194 R: Right. And basically what, what – so you, so things got a bit better?

195 M7: Oh yeah

196 R: Yeah. And that was – I'm just trying to think about – this is after?
197 M7: I started going home
198 R: You started going home
199 M7: I started going home.
200 I'd fly to Ireland twice a month with Matthew
201 R: Right
202 M7: And it was keeping me going like.
203 You know, I was, I was never here, never there, you couldn't catch with me
204 R: Yeah. So you found that that was kind of really helpful and supportive for you to go back and see your family
205 M7: Purse straining, but ok
206 R: Yeah, yeah. But it was kind of worth it in the –
207 M7: Well, Matthew was happy but he was getting on all these airplanes and going here and there
208 R: Yeah. So and how was the traveling with him when he was small?
209 M7: To be honest no problem.
210 Because these airlines are so good with assistance.
211 They'd give me assistance right from the checkout point, through security, on airplane and there'd be somebody to collect me and find the luggage
212 R: Oh right, oh that's excellent
213 M7: They're really, really good. Much better than rail or buses
214 R: So that was actually quite a – a really positive thing to do and, and helped you out
215 M7: It was good. It was never a challenge; there was always somebody there for you
216 R: That's excellent. And I should have asked you this before, but do, do you have a guide dog?

217 M7: No
218 R: No
219 M7: No. Never been an animal person
220 R: No
221 M7: I wouldn't know to look after one
222 R: Yeah. Oh I think no, yes we did, we chatted about that – yeah, yeah, not an animal person, yeah
223 M7: No
224 R: And then you had – so when was Erin born?
225 M7: November 08
226 R: November 08. And was that a decision that you made? You wanted to have another child?

227 M7: I did yes. It was probably a little bit rash.
228 But because I had a miscarriage in 2006 – I wanted - I know the baby can't replace the baby right.
229 But in a way you can, d'you know what I mean?
230 R: Yeah
231 M7: And well me and my partner were only together like what four months.
232 And I'm like - I wanted one and he wanted one- he's much younger than me.
233 R: Ok
234 M7: And I thought 'Oh my god is that right' but then when I said, "Look a kid's on the way, what we going to do about it?"
235 "Well we're going to have it".
236 So I said well I wanted to live in Ireland but the problem was access to Matthew for his Dad

237 R: Right
238 M7: So I said, "what you're going to do". Muffled sticks and move to Wales".
239 Well if he's prepared to do that, then fine, fair enough
240 R: So he was prepared to come all the way back to Rhyll to, to, to –
241 M7: Yeah. He fell out with all his family because of it
242 R: Right, oh gosh, ok

243 M7: He's still not talking to them.
244 But he's got Erin and Matthew so he's happy
245 *Background talking*
246 R: So you'd say that you're -
247 M7: He says his family's a pack of screwballs
248 R: Ok
249 *Laughter*
250 M7: And they are
251 R: Fair do's. Ok, so you are all happy now the four of you
252 M7: Oh yeah
253 R: Yeah
254 M7: No problem, you know, he's so good.
255 It's no problem.
256 I can hold onto him in town or whatever. Any post comes; I don't have to say "will you read that post for me?"
257 He'll automatically pick it up, open and say, "this come for you, that come for you."
258 There's no secrets here like - do you know what I mean?
259 R: Yeah. So you, obviously you trust each other and you have that really close relationship and look after each other
260 M7: Yeah, yeah
261 R: Yeah, yeah. That sounds really good
262 M7: He's dyslexic right.
263 So you should see us on the computer, right.
264 He'll go on the Internet "what do you want me to find?" - this and that – "ok I'll find it", but he has to spell every word. Laughter
265 *Background talking*
266 R: What's he say?
267 M7: He's good at DIY
268 *Laughter*
269 R: He's good at DIY *muffled*. Well, good, hang on to him then I'd say
270 M7: Yeah I know
271 R: - if he's good at DIY. So what are your thoughts about the way that people perceive and consider you, you know if you are out and about?
272 M7: I don't really care
273 R: You don't care
274 M7: Because I can't see them looking at me
275 R: Yeah. Good point, yeah
276 M7: The only thing annoys me when somebody says " Oh I see you in town - I waved at yer".

277 I said - what's the good of that I couldn't see - "You ignorant pig – you didn't answer me – I see you in town and I waved at yer".
278 I said what's the good of that, either shout my name or beep the horn and I'll react
279 R: *Laughter*. Yes, yes. So it's um, it's not a problem. You don't feel that other's opinions or anything like that – it doesn't trouble you – I don't know, school or toddler group or anything like that –
280 M7: Ah the mothers can be terrible in playgroups.
281 They completely isolate you.
282 They, they treat you like the proverbial nigger, do you know what I mean?
283 R: Yeah ok
284 M7: I'm not racist or anything – it's just an expression
285 R: Yeah, yeah. So tell me a bit more about that
286 M7: Well when I used to go to a mother and toddler group with Matthew, there was a couple of mums who were really nice but we tended like – all the local welsh clique tended to stick together.
287 And there was me, there was a German mum, there was a Thai mum and there was another Irish mum.

288 And we were a clique then.
289 R: Because you are all outsiders
290 The sort of non-welsh lot
291 M7: Yeah
292 R: Yeah, ok. So you didn't find them particularly friendly, the welsh lot
293 M7: No. They talked to you - "Oh good morning", you know "how is Matthew today?"
294 That's all
295 R: So what was your reaction to that?
296 M7: I don't know, it's a little bit narrow minded.
297 Because in these playgroups you have to look after your own child, there's no teacher.
298 And, and for a person like me it's awful difficult.
299 And some mum would come - "Your son just nicked a toy off of from my daughter!"
300 And I said, "I'm sorry for that, I didn't see him do that". Obviously, do you know what I mean?"

301 R: Yeah, yeah
302 M7: But they wouldn't say, " Oh my daughter just snatched a toy off your son", would they?
303 R: Yeah. So it sounds like you felt there was um, well, a lack of, a lack of help and a lack of understanding really
304 M7: Oh yeah, oh yeah
305 R: Yeah. Yeah. So what would you, what would you have said to them if, if you could sort of let them know how you were feeling?
306 M7: Well -
307 R: Or perhaps you did say to them, I don't know
308 M7: I did. I said if I have another child, I'm not bringing him to a playgroup, because rather than having a good time without stress – oh it's terrible.
309 Like, you know when they sat on a table and, and they had a little biscuit and things, I, I couldn't serve Matthew like because I didn't want to knock anything over.
310 Or when there would have been pictures or something visual, there was nobody there to help him
311 R: So he was sort of left on his own?
312 M7: Yeah
313 R: Oh god
314 M7: Well the friendly mums would but sometimes you know it wasn't obligatory you know.
315 Sometimes they weren't there or whatever.
316 I'd, I'd phone the night before "Are you coming – if you're not going, I'm not going"
317 Do you know what I mean?
318 R: Yeah. Sort of check out to make sure you had a bit of support
319 M7: Yeah, yeah. Otherwise I wouldn't go
319 M7: Yeah, yeah. Otherwise I wouldn't go
320 R: Yeah. And is there any other things that you felt sort of limited your experience as it were, because, because of people's reactions to things. Any other settings I suppose
321 M7: No, it's just the playgroup I found the trouble with
322 R: Just the playgroup. So school's been pretty good so far
323 M7: School's ok because he's bigger.
324 So if there's anything to read Owen will do it now, anyway.
325 Although he goes to Welsh school, so at the beginning that was difficult but now he's absolutely fluent at reading that's ok
326 R: Oh yes you said he reads, yeah that's brilliant
327 M7: He reads
328 R: Yeah, that's amazing. And, and so, and they've got – do they have, any, and aids for you to help him with his reading? Or did they, did they have that at the –
329 M7: Absolutely not
330 R: No
331 M7: Absolutely nothing
332 R: Would that have felt – would you have -?

333 M7: They didn't offer like a letter in large print or letter in Braille or email or – or no nothing like that.
334 Absolutely unprepared
335 R: Right
336 M7: But then I never asked to be honest because I've got Owen.
337   Better than a guide dog, in' it

139 R: So you stayed together because of Matthew

140 M7: For two years yeah, But then I, I - Matthew was getting to the age where he was two plus and he was watching this, this stuff

child witnessing → " "
d. v.

141 R: Ok yeah. So he's watching his Dad, you know, be abusive to his mum essentially. And what did you feel about that?

142 M7: Well I chucked him out – my ex I did, not Matthew

motivated to get   standing up for
rid of partner   needs of self & child

143 R: Yeah, sure, and that was, that was for your sake, but also do you feel you were kind of motivated really to do something because of Matthew

144 M7: That's it. Yeah, yeah

145 R: So Matthew got to that age, two plus, and you felt that he, he needed to have, what a better –

needs of child as   " "
primary motivating   →
factor to exit
violent relationship

146 M7: I didn't want him turning out like that.

147 Thinking it's normal and acceptable.

fears for son's   *fears over son*
future   *modelling violence*
"thinking its   *in future.*
normal & acceptable"   *fear over son*
                            internalizing
                            violence as normal

148 Mind you, he's very good to the child, he's never do nothing nasty to him or anything and you know I never stop him being a Dad, just because he can't be a husband to me.

149 It doesn't stop the fact that he's Matthew's Dad.

maintaining link
with partner as   →   " "
father

150 If he's prepared to act in a family manner then fair enough

151 R: So, so things have been better recently sort of as time's gone on

152 M7: Well yeah

153 R: Yeah, so and, and, and how do you feel you coped in those early years when this was going on, and, and Matthew was kind of like well nought to two I guess?

154 M7: Well I was a little bit depressed, but you know

PND   "   "

155 R: How did you recognize that you were a bit depressed?

156 M7: Because I wasn't in the mood for doing – I normally read a lot;

157 I couldn't be bothered to open a book.

mood & behaviour   →   "   "
change as indicator
of depression

158 I couldn't be bothered to dress up nicely – you know

159 R: And you'd normally do, do those things?

160 M7: And I went through this – you know OCD, Obsessive Compulsive Disorder.

161 I cleaned obsessively

162 R: Oh right, ok

163 M7: I still do now and then, but you have to!

164 *Chuckle*

165 R: So you felt that that had got out of control

166 M7: Yeah

167 R: Ok. And what did you do about, about feeling that, those, those feelings?

168 M7: Nothing much to be honest - I didn't want to take anti depressants or nothing

169 R: *Pause* . And so what happened, did you just kind of come out of that?

170 M7: I did go to a Doctor but she tried to give me anti depressants and sleeping pills.

171 That was just soon after my ex left

172 R: Right

173 M7: And basically I said how do you expect me to take a sleeping pill with a two year old next door who's *muffled* call me?

174 R: Yeah, yeah

175 M7: So I shoved the pills down the toilet and that was it

176 R: I mean did you, when you say, you, you I mean you said at the beginning the best thing is friends. Did you, did you get support from, from your friends, or -?

177 M7: Oh yes, yes

178 R: Yeah. And, and from family, are they -?

179 M7: Well the family's is all over the water so -

180 R: Ok

181 M7: Over the phone yeah, but not really personal d'you know?

182 R: Yeah. Sure. So, so you didn't take any drugs, you just sort of got better over the – what -how long would you say before you felt yourself again?

183 M7: About three months

184 R: Ok. And that was after he'd gone

185 M7: Yeah

Handwritten margin notes:

jargon aware — *cleaning to feel in control*

rejected meds for FND — *fear avd taking meds for depression*

rejected GP advice → *" "*

lack of understanding from GP — *GP not understanding or mtg needs*

threw meds away — *violent rejection of meds*

no near family support — *Lack of family support*

186 R: Sort of thing, then you felt better. And how would you say that during the first, you know couple of years with Matthew – or when - it was a lot longer than that wasn't it, about, well about four years when it was just you and Matthew I guess before Erin, Erin came along, or -

187 M7: No. Well Matthew was born March 2004.

188 My ex left July 06.

189 And I got with my partner September 07

190 R: Right. *Pause*. And what's your partner's name?

191 M7: Owen

192 R: Owen. *Pause*

193 M7: I dragged him to Wales from Ireland you know?

194 R: Right. And basically what, what – so you, so things got a bit better?

195 M7: Oh yeah

196 R: Yeah. And that was – I'm just trying to think about – this is after?

197 M7: I started going home

198 R: You started going home

199 M7: I started going home.

200 I'd fly to Ireland twice a month with Matthew

201 R: Right

202 M7: And it was keeping me going like.

203 You know, I was, I was never here, never there, you couldn't catch with me

204 R: Yeah. So you found that that was kind of really helpful and supportive for you to go back and see your family

205 M7: Purse straining, but ok

206 R: Yeah, yeah. But it was kind of worth it in the –

207 M7: Well, Matthew was happy but he was getting on all these airplanes and going here and there

208 R: Yeah. So and how was the traveling with him when he was small?

209 M7: To be honest no problem.

210 Because these airlines are so good with assistance.

[Handwritten margin notes:]

returning to family helped shift in mood.

shift in mood triggered by increase in family support

"keeping me going" → "

self assessment finding own way through depression.

financial drain

travelling by plane → " "
good experience

211 They'd give me assistance right from the checkout point, through security, on airplane and there'd be somebody to collect me and find the luggage

supportive experience

experiencing others as helpful

212 R: Oh right, oh that's excellent
213 M7: They're really, really good. Much better than rail or buses

difference in supportiveness of public transport

214 R: So that was actually quite a – a really positive thing to do and, and helped you out
215 M7: It was good. It was never a challenge; there was always somebody there for you

it was never a challenge

there was always somebody there for you

others helping to reduce the challenge

feeling secure with some there always

216 R: That's excellent. And I should have asked you this before, but do, do you have a guide dog?
217 M7: No
218 R: No
219 M7: No. Never been an animal person

220 R: No
221 M7: I wouldn't know to look after one

outside field of expertise

self as inexpert.

222 R: Yeah. Oh I think no, yes we did, we chatted about that – yeah, yeah, not an animal person, yeah
223 M7: No
224 R: And then you had – so when was Erin born?
225 M7: November 08
226 R: November 08. And was that a decision that you made? You wanted to have another child?
227 M7: I did yes. It was probably a little bit rash.

loss of miscarriage

desperate for another baby.

sadness & desperation @ loss of baby in miscarriage

looking to replace loss

228 But because I had a miscarriage in 2006 – I wanted - I know the baby can't replace the baby right.
229 But in a way you can, d'you know what I mean?
230 R: Yeah
231 M7: And well me and my partner were only together like what four months.

232 And I'm like - I wanted one and he wanted one- he's much younger than me.
233 R: Ok
234 M7: And I thought 'Oh my god is that right' but then when I said, "Look a kid's on the way, what we going to do about it?"

speedy pregnancy

decisiveness & speed in wanting a child to replace loss

235 "Well we're going to have it".

clear decision.

236 So I said well I wanted to live in Ireland but the problem was access to Matthew for his Dad

237 R: Right

238 M7: So I said, "what you're going to do". Muffled sticks and move to Wales".

239 Well if he's prepared to do that, then fine, fair enough

240 R: So he was prepared to come all the way back to Rhyll to, to, to –

241 M7: Yeah. He fell out with all his family because of it

242 R: Right, oh gosh, ok

243 M7: He's still not talking to them.

244 But he's got Erin and Matthew so he's happy

245 *Background talking*

246 R: So you'd say that you're -

247 M7: He says his family's a pack of screwballs

248 R: Ok

249 *Laughter*

250 M7: And they are

251 R: Fair do's. Ok, so you are all happy now the four of you

252 M7: Oh yeah

253 R: Yeah

254 M7: No problem, you know, he's so good.

255 It's no problem.

256 I can hold onto him in town or whatever. Any post comes; I don't have to say "will you read that post for me?"

257 He'll automatically pick it up, open and say, "this come for you, that come for you."

258 There's no secrets here like - do you know what I mean?

259 R: Yeah. So you, obviously you trust each other and you have that really close relationship and look after each other

260 M7: Yeah, yeah

261 R: Yeah, yeah. That sounds really good

262 M7: He's dyslexic right.

263 So you should see us on the computer, right.

264 He'll go on the Internet "what do you want me to find?" - this and that – "ok I'll find it", but he has to spell every word. Laughter

265 *Background talking*

Handwritten margin notes:

access difficulties for first child

difficulties in balancing own needs with child's

partner sacrificed family relationship for M7.

self boosted by partner's decision to choose her over his family.

partner & M7 together

closeness with supportive partner.

"he's so good
It's no problem"

"I can hold onto him " . . .

very supportive partner held by

there's no secrets here do you know what I mean?

aware of possible damage of unsaid. are you getting me?

dir. appeal to interviewer

partner's impairment

equality with partner thro' impairment on some level.

balancing each other out

266 R: What's he say?

267 M7: He's good at DIY

268 *Laughter*

269 R: He's good at DIY *muffled* . Well, good, hang on to him then I'd say

270 M7: Yeah I know

271 R: - if he's good at DIY. So what are your thoughts about the way that people perceive and consider you, you know if you are out and about?

272 M7: I don't really care

273 R: You don't care

274 M7: Because I can't see them looking at me

275 R: Yeah. Good point, yeah

276 M7: The only thing annoys me when somebody says " Oh I see you in town - I waved at yer".

277 I said - what's the good of that I couldn't see - "You ignorant pig – you didn't answer me – I see you in town and I waved at yer".

278 I said what's the good of that, either shout my name or beep the horn and I'll react

279 R: *Laughter* . Yes, yes. So it's um, it's not a problem. You don't feel that other's opinions or anything like that – it doesn't trouble you – I don't know, school or toddler group or anything like that –

280 M7: Ah the mothers can be terrible in playgroups.

281 They completely isolate you.

282 They, they treat you like the proverbial nigger, do you know what I mean?

283 R: Yeah ok

284 M7: I'm not racist or anything – it's just an expression

285 R: Yeah, yeah. So tell me a bit more about that

286 M7: Well when I used to go to a mother and toddler group with Matthew, there was a couple of mums who were really nice but we tended like – all the local welsh clique tended to stick together.

287 And there was me, there was a German mum, there was a Thai mum and there was another Irish mum.

288 And we were a clique then.

289 Because you are all outsiders

290 R: The sort of non-welsh lot

Margin annotations:

interchange b/w interviewer M7 + partner

playful comfortableness

playful and comfortable with picture

rejection of others → " "

what I can't see doesn't bother me

literally what I have no access to doesn't bother m

defensive

angry @ others not getting me

angry @ others not adapting how best to communicate .

other mothers behaviour

"they completely isolate you"

negative experience of other mothers' behaviour

"they completely isolate you"

defensive

confirmatory why?

sticking together with mums who are the same cultural backgrd .

outsider status

clique

gaining confidence by being with mums of same outsider status – cultural

minority politically

291 M7: Yeah

292 R: Yeah, ok. So you didn't find them particularly friendly, the welsh lot

293 M7: No. They talked to you - "Oh good morning", you know "how is Matthew today?"

294 That's all

295 R: So what was your reaction to that?

296 M7: I don't know, it's a little bit narrow minded.

297 Because in these playgroups you have to look after your own child, there's no teacher.

298 And, and for a person like me it's awful difficult.

299 And some mum would come - "Your son just nicked a toy off of from my daughter!"

300 And I said, "I'm sorry for that, I didn't see him do that". Obviously, do you know what I mean?"

301 R: Yeah, yeah

302 M7: But they wouldn't say, " Oh my daughter just snatched a toy off your son", would they?

303 R: Yeah. So it sounds like you felt there was um, well, a lack of, a lack of help and a lack of understanding really

304 M7: Oh yeah, oh yeah

305 R: Yeah. Yeah. So what would you, what would you have said to them if, if you could sort of let them know how you were feeling?

306 M7: Well -

307 R: Or perhaps you did say to them, I don't know

308 M7: I did. I said if I have another child, I'm not bringing him to a playgroup, because rather than having a good time without stress – oh it's terrible.

309 Like, you know when they sat on a table and, and they had a little biscuit and things, I, I couldn't serve Matthew like because I didn't want to knock anything over.

310 Or when there would have been pictures or something visual, there was nobody there to help him

311 R: So he was sort of left on his own?

312 M7: Yeah

313 R: Oh god

[Handwritten annotations, left-center column:]
minimal contact from some mums – majority.

narrow minded

no professional help available

Son & mother victim of hostile attack →

defensively apologising →

no help for M7 benefit

standing up for herself →
rejecting playgr scenario + how it felt →

fear of causing accident/ looking stupid

nobody there to help him →

[Handwritten annotations, right column:]
felt ostracized into minimal contact by majority of mums

annoyed @ others' majority narrowminded attitude.

lack of professional help in playgr environment

" "

" "
angry +

no look out for M7 or her son from others

" "

" "

fear of looking stupid or causing problem in front of others

" "

[Handwritten annotations, left margin near 300-303:]
+ look @ derivatives of words used e.g. obviously eh + hes

314 M7: Well the friendly mums would but sometimes you know it wasn't obligatory you know.

315 Sometimes they weren't there or whatever.

316 I'd, I'd phone the night before "Are you coming – if you're not going, I'm not going"

317 Do you know what I mean?

318 R: Yeah. Sort of check out to make sure you had a bit of support

319 M7: Yeah, yeah. Otherwise I wouldn't go

320 R: Yeah. And is there any other things that you felt sort of limited your experience as it were, because, because of people's reactions to things. Any other settings I suppose

321 M7: No, it's just the playgroup I found the trouble with

322 R: Just the playgroup. So school's been pretty good so far

323 M7: School's ok because he's bigger.

324 So if there's anything to read Owen will do it now, anyway.

325 Although he goes to Welsh school, so at the beginning that was difficult but now he's absolutely fluent at reading that's ok

326 R: Oh yes you said he reads, yeah that's brilliant

327 M7: He reads

328 R: Yeah, that's amazing. And, and so, and they've got – do they have, any, and aids for you to help him with his reading? Or did they, did they have that at the –

329 M7: Absolutely not

330 R: No

331 M7: Absolutely nothing

332 R: Would that have felt – would you have -?

333 M7: They didn't offer like a letter in large print or letter in Braille or email or – or no nothing like that.

334 Absolutely unprepared

335 R: Right

336 M7: But then I never asked to be honest because I've got Owen.

337 Better than a guide dog, in' it

338 R: Yeah

339 *Laughter*

340 M7: It's an intelligent one

help sometimes there but occasional

help not always reliable

are you coming...

needing support to fully participate.

avoiding playgroup.

self as avoidant

school better than playgroup

different experience of educational institutions

over confirmatory...

" absolutely nothing "

shocked at lack of support

school unprepared

partner better than a guide dog

equating partner with guide dog.

victim – rescuer

Appendix 6 - full coding example
Caitlin

Raw data	Preliminary Code	Final Code	Themes
153 R: Yeah, so and, and, and how do you feel you coped in those early years when this was going on, and, and Matthew was kind of like well nought to two I guess?			
154 M7: Well I was a little bit depressed, but you know	experiencing PND	coping with PND	difficulties of living with severe PND
155 R: How did you recognize that you were a bit depressed?			
156 M7: Because I wasn't in the mood for doing – I normally read a lot;	mood and behaviour change as indication of depression	self reflective of mood change as indictor for PND	difficulties of living with severe PND
157 I couldn't be bothered to open a book.	"I couldn't be bothered"	"I couldn't be bothered"	difficulties of living with severe PND
158 I couldn't be bothered to dress up nicely – you know			
159 R: And you'd normally do, do those things?			
160 M7: And I went through this – you know OCD, Obsessive Compulsive Disorder.	psychologically aware	feeling the need to be in control	rejecting out of control and dependent self
161 I cleaned obsessively			
162 R: Oh right, ok			
163 M7: I still do now and then, but you have to!			
164 *Chuckle*			
165 R: So you felt that that had got out of control			
166 M7: Yeah			
167 R: Ok. And what did you do about, about feeling that, those, those feelings?			
168 M7: Nothing much to be honest - I didn't want to take anti depressants or nothing	rejected medication for PND	fears around taking medication for depression	rejecting out of control and dependent self
169 R: *Pause*. And so what happened, did you just kind of come out of that?			
170 M7: I did go to a Doctor but she tried to give me anti depressants and sleeping pills.	rejected medical advice	angry at medical experts' incompetence and helplessness	angry at others for lack of support
171 That was just soon after my ex left			
172 R: Right			
173 M7: And basically I said how do you expect me to take a sleeping pill with a two year old next door who's *muffled* call me?	lack of understanding from GP	angry at medical experts' incompetence and helplessness	angry at others for lack of support
174 R: Yeah, yeah			
175 M7: So I shoved the pills down the toilet and that was it	threw meds away	total rejection of anti-depressants	rejecting out of control and dependent self
176 R: I mean did you, when you say, you, you I mean you said at the beginning the best thing is friends. Did you, did you get support from, from your friends, or -?			
177 M7: Oh yes, yes			
178 R: Yeah. And, and from family, are they -?			

179 M7: Well the family's is all over the water so -	no family support nearby	self without family support nearby	loss of previous life and support network
180 R: Ok			
181 M7: Over the phone yeah, but not really personal d'you know?			
182 R: Yeah. Sure. So, so you didn't take any drugs, you just sort of got better over the – what -how long would you say before you felt yourself again?			
183 M7: About three months			
184 R: Ok. And that was after he'd gone			
185 M7: Yeah			
186 R: Sort of thing, then you felt better. And how would you say that during the first, you know couple of years with Matthew – or when - it was a lot longer than that wasn't it, about, well about four years when it was just you and Matthew I guess before Erin, Erin came along, or -			
187 M7: No. Well Matthew was born March 2004.			
188 My ex left July 06.			
189 And I got with my partner September 07			
190 R: Right. *Pause*. And what's your partner's name?			
191 M7: Owen			
192 R: Owen. *Pause*			
193 M7: I dragged him to Wales from Ireland you know?			
194 R: Right. And basically what, what – so you, so things got a bit better?			
195 M7: Oh yeah			
196 R: Yeah. And that was – I'm just trying to think about – this is after?			
197 M7: I started going home	returning home restored mood and lifted depression	shift in mood away from depression through support from family	accepting and appreciating others' support
198 R: You started going home			
199 M7: I started going home.			
200 I'd fly to Ireland twice a month with Matthew			
201 R: Right			
202 M7: And it was keeping me going like.	keeping me going	shift in mood away from depression through support from family	accepting and appreciating others' support
203 You know, I was, I was never here, never there, you couldn't catch with me		self as resourceful finding own way through depression	feeling in control, resourceful and independent
204 R: Yeah. So you found that that was kind of really helpful and supportive for you to go back and see your family			
205 M7: Purse straining, but ok			
206 R: Yeah, yeah. But it was kind of worth it in the –			
207 M7: Well, Matthew was happy but he was getting on all these airplanes and going here and there			

208 R: Yeah. So and how was the traveling with him when he was small?			
209 M7: To be honest no problem.			
210 Because these airlines are so good with assistance.	travelling by plane as a good experience	supported by airline staff when travelling by plane	accepting and appreciating others' support
211 They'd give me assistance right from the checkout point, through security, on airplane and there'd be somebody to collect me and find the luggage	supportive experience	experiencing others as helpful	accepting and appreciating others' support
212 R: Oh right, oh that's excellent			
213 M7: They're really, really good. Much better than rail or buses			
214 R: So that was actually quite a – a really positive thing to do and, and helped you out			
215 M7: It was good. It was never a challenge; there was always somebody there for you	it was never a challenge	life seen as a series of challenges	frustrated that life has to be a series of battles
215 M7: It was good. It was never a challenge; there was always somebody there for you	always somebody there fore you	gaining security through dependence on others	accepting and appreciating others' support
216 R: That's excellent. And I should have asked you this before, but do, do you have a guide dog?			
217 M7: No			
218 R: No			
219 M7: No. Never been an animal person			
220 R: No			
221 M7: I wouldn't know to look after one	outside field of experience	rejecting need for guide dog	rejecting out of control and dependent self
222 R: Yeah. Oh I think no, yes we did, we chatted about that – yeah, yeah, not an animal person, yeah			
223 M7: No			
224 R: And then you had – so when was Erin born?			
225 M7: November 08			
226 R: November 08. And was that a decision that you made? You wanted to have another child?			
227 M7: I did yes. It was probably a little bit rash.			
228 But because I had a miscarriage in 2006 – I wanted - I know the baby can't replace the baby right.	loss of miscarriage; keen for another baby as possible replacement	trauma and loss of miscarriage	centrality of mother's role to own identity and sense of purpose
228 But because I had a miscarriage in 2006 – I wanted - I know the baby can't replace the baby right.	wanting to replace	keen to become a mother again	centrality of mother's role to own identity and sense of purpose
229 But in a way you can, d'you know what I mean?			
230 R: Yeah			
231 M7: And well me and my partner were only together like what four months.			
232 And I'm like - I wanted one and he wanted one- he's much younger than me.			
233 R: Ok			

234	M7: And I thought 'Oh my god is that right' but then when I said, "Look a kid's on the way, what we going to do about it?"	speedy conception	keen to become a mother again	centrality of mother's role to own identity and sense of purpose
235	"Well we're going to have it".			
236	So I said well I wanted to live in Ireland but the problem was access to Matthew for his Dad	access difficulties with first child	difficulties balancing own needs with those of child's	wanting to prove self as good mother to self and others
237	R: Right			
238	M7: So I said, "what you're going to do". Muffled sticks and move to Wales".			
239	Well if he's prepared to do that, then fine, fair enough			
240	R: So he was prepared to come all the way back to Rhyll to, to, to –			
241	M7: Yeah. He fell out with all his family because of it	partner sacrificed family relationship for M7	feeling of security from partner's sacrifice for their relationship	security gained from reliance on supportive partner
242	R: Right, oh gosh, ok			
243	M7: He's still not talking to them.			
244	But he's got Erin and Matthew so he's happy			
245	Background talking			
246	R: So you'd say that you're -			
247	M7: He says his family's a pack of screwballs			
248	R: Ok			
249	Laughter			
250	M7: And they are			
251	R: Fair do's. Ok, so you are all happy now the four of you			
252	M7: Oh yeah			
253	R: Yeah			
254	M7: No problem, you know, he's so good.	he's so good	self given confidence and security by supportive partner	security gained from reliance on supportive partner
255	It's no problem.			
256	I can hold onto him in town or whatever. Any post comes; I don't have to say "will you read that post for me?"	I can hold onto him	self given confidence and security by supportive partner	security gained from reliance on supportive partner
257	He'll automatically pick it up, open and say, "this come for you, that come for you."			
258	There's no secrets here like - do you know what I mean?	no secrets - unlike previous relationship	difference between self then and self now in positive relationship	reflecting on many changes within self
259	R: Yeah. So you, obviously you trust each other and you have that really close relationship and look after each other			
260	M7: Yeah, yeah			
261	R: Yeah, yeah. That sounds really good			
262	M7: He's dyslexic right.	partner's not perfect - he too has impairment -	sense of equality at some level in relationship with impairments	security gained from reliance on supportive partner
263	So you should see us on the computer, right.			
264	He'll go on the Internet "what do you want me to find?" - this and that – "ok I'll find it", but he has to spell every word. Laughter	playful, comfortable with partner	self given confidence and security by supportive partner	security gained from reliance on supportive partner
265	Background talking			
266	R: What's he say?			

267 M7: He's good at DIY			
268 *Laughter*			
269 R: He's good at DIY *muffled*. Well, good, hang on to him then I'd say			
270 M7: Yeah I know			
271 R: - if he's good at DIY. So what are your thoughts about the way that people perceive and consider you, you know if you are out and about?			
272 M7: I don't really care	outright rejection of others	outright rejection of others	self as detached and not understood by others
273 R: You don't care			
274 M7: Because I can't see them looking at me	what I can't see doesn't bother me	self as detached from others	self as detached and not understood by others
275 R: Yeah. Good point, yeah			
276 M7: The only thing annoys me when somebody says " Oh I see you in town - I waved at yer".	annoys me	angry at others' thoughtlessness	frustration and anger at self and others
277 I said - what's the good of that I couldn't see - "You ignorant pig – you didn't answer me – I see you in town and I waved at yer".			
278 I said what's the good of that, either shout my name or beep the horn and I'll react	others need to change their behaviour	angry at others' thoughtlessness	frustration and anger at self and others
279 R: *Laughter*. Yes, yes. So it's um, it's not a problem. You don't feel that other's opinions or anything like that – it doesn't trouble you – I don't know, school or toddler group or anything like that –			
280 M7: Ah the mothers can be terrible in playgroups.			
281 They completely isolate you.	"they completely isolate you"	"they completely isolate you"	self as vulnerable and isolated when a new mum
282 They, they treat you like the proverbial nigger, do you know what I mean?			
283 R: Yeah ok			
284 M7: I'm not racist or anything – it's just an expression	defensive	self as defensive	defensive, withdrawn and feeling secondary to others
285 R: Yeah, yeah. So tell me a bit more about that			
286 M7: Well when I used to go to a mother and toddler group with Matthew, there was a couple of mums who were really nice but we tended like – all the local welsh clique tended to stick together.	sticking together - outsiders against clique	self feeling part of outsider minority group	defensive, withdrawn and feeling secondary to others
287 And there was me, there was a German mum, there was a Thai mum and there was another Irish mum.	difference through cultural background	self feeling part of outsider minority group	defensive, withdrawn and feeling secondary to others
288 And we were a clique then.			
289 R: Because you are all outsiders			
290 The sort of non-welsh lot			
291 M7: Yeah			

292 R: Yeah, ok. So you didn't find them particularly friendly, the welsh lot			
293 M7: No. They talked to you - "Oh good morning", you know "how is Matthew today?"	minimal contact from majority	feeling ostracised with minimal contact from majority	defensive, withdrawn and feeling secondary to others
294 That's all			
295 R: So what was your reaction to that?			
296 M7: I don't know, it's a little bit narrow minded.	narrow minded	"they completely isolate you"	self as vulnerable and isolated when a new mum
297 Because in these playgroups you have to look after your own child, there's no teacher.	no professional support	lack of support	angry at others for lack of support
298 And, and for a person like me it's awful difficult.	difficulty over lack of support	lack of support	angry at others for lack of support
299 And some mum would come - "Your son just nicked a toy off of from my daughter!"	son and mother as victim of others' hostility	son and mother as victim of others' hostility	defensive, withdrawn and feeling secondary to others
300 And I said, "I'm sorry for that, I didn't see him do that". Obviously, do you know what I mean?"	defensive, apologetic	self as defensive	defensive, withdrawn and feeling secondary to others
301 R: Yeah, yeah			
302 M7: But they wouldn't say, " Oh my daughter just snatched a toy off your son", would they?	angry and defensive	self as angry and defensive	defensive, withdrawn and feeling secondary to others
303 R: Yeah. So it sounds like you felt there was um, well, a lack of, a lack of help and a lack of understanding really			
304 M7: Oh yeah, oh yeah			
305 R: Yeah. Yeah. So what would you, what would you have said to them if, if you could sort of let them know how you were feeling?			
306 M7: Well -			
307 R: Or perhaps you did say to them, I don't know			
308 M7: I did. I said if I have another child, I'm not bringing him to a playgroup, because rather than having a good time without stress – oh it's terrible.	standing up for herself	standing up for self and needs of child	feeling in control, resourceful and independent
309 Like, you know when they sat on a table and, and they had a little biscuit and things, I, I couldn't serve Matthew like because I didn't want to knock anything over.	anxiety, shame and difficulties around lack of support	shame and anxiety over lack of support	shame and anger at others' perception of self as unfit parent
310 Or when there would have been pictures or something visual, there was nobody there to help him	son missing out	son missing out through lack of support	fear of self or children missing out
311 R: So he was sort of left on his own?			
312 M7: Yeah			
313 R: Oh god			
314 M7: Well the friendly mums would but sometimes you know it wasn't obligatory you know.	help there sometimes but not always reliable	occasional support	angry at others for lack of support
315 Sometimes they weren't there or whatever.			

Line	Transcript			
316	I'd, I'd phone the night before "Are you coming – if you're not going, I'm not going"	anxiety over possible lack of support	shame and anxiety over lack of support	life feels more difficult and complicated than for others
317	Do you know what I mean?			
318	R: Yeah. Sort of check out to make sure you had a bit of support			
319	M7: Yeah, yeah. Otherwise I wouldn't go	avoiding playgroup	self as avoidant	defensive, withdrawn and feeling secondary to others
319	M7: Yeah, yeah. Otherwise I wouldn't go	missing out	son missing out through lack of support	fear of self or children missing out
320	R: Yeah. And is there any other things that you felt sort of limited your experience as it were, because, because of people's reactions to things. Any other settings I suppose			
321	M7: No, it's just the playgroup I found the trouble with			
322	R: Just the playgroup. So school's been pretty good so far			
323	M7: School's ok because he's bigger.	school better than playgroup	different experience in different educational settings	life feels more difficult and complicated than for others
324	So if there's anything to read Owen will do it now, anyway.			
325	Although he goes to Welsh school, so at the beginning that was difficult but now he's absolutely fluent at reading that's ok			
326	R: Oh yes you said he reads, yeah that's brilliant			
327	M7: He reads			
328	R: Yeah, that's amazing. And, and so, and they've got – do they have, any, and aids for you to help him with his reading? Or did they, did they have that at the –			
329	M7: Absolutely not	indignant	lack of support	angry at others for lack of support
330	R: No			
331	M7: Absolutely nothing	"absolutely nothing"	"absolutely nothing"	angry at others for lack of support
332	R: Would that have felt – would you have -?			
333	M7: They didn't offer like a letter in large print or letter in Braille or email or – or no nothing like that.	school unprepared	others as unprepared	angry at others for lack of support
334	Absolutely unprepared			
335	R: Right			
336	M7: But then I never asked to be honest because I've got Owen.	close attachment with partner	closely dependent on partner	security gained from reliance on supportive partner
337	Better than a guide dog, in' it	partner better than a guide dog	equating partner with guide dog	security gained from reliance on supportive partner

Appendix 7
Caitlin pivot

Row Labels	Count of Initial theme list
"you just sort of get on with it"	2
advocating carpe diem attitude	3
angry at others for lack of support	7
centrality of mother's role to own identity and sense of purpose	1
feeling in control, resourceful and independent	2
frustration and anger at self and others	6
rejecting out of control and dependent self	1
self as detached and not understood by others	4
self as unique and challenging to others	2
self as victim of violence	8
shock at sudden atrophy & sight loss	6
using humour as a way to deflect pain	1
Grand Total	**43**

Appendix 8

Summary table of themes & frequency	Priyanka	Claudia	Bridget	Ayesha	Sharon	Gail	Caitlin	Sarah	Penny	Total
"almost to prove a point that we are just as good parents as anybody else"	0	0	0	0	0	0	0	1	0	1
"I didn't feel like I was me anymore"	0	0	0	0	0	0	0	0	1	1
"I have to get on with it"	0	0	0	0	0	0	0	1	1	2
"I just felt like I was like one person ...in the middle of nowhere on my own"	0	0	0	0	0	0	0	0	1	1
"I just have to get on with things"	0	0	1	0	1	0	0	0	0	2
"it's having the kids makes you hang in on in there"	0	1	0	0	0	0	0	0	1	2
"like any mum"	0	1	1	0	0	1	0	0	0	3
"they seem to think they have a right to, to, to comment on or pass judgement on your – the things that you do in your life."	0	0	0	0	0	0	0	1	0	1
"you just sort of get on with it"	0	0	0	0	0	1	1	0	0	2
accepting and appreciating others' support	1	1	1	1	1	1	1	0	1	8
advocating carpe diem	1	0	1	0	0	0	0	1	0	3
angry at others for lack of support	1	1	1	1	1	1	1	1	1	9
angry in rejection of professional support	1	0	1	0	0	0	1	0	0	3
anxiety living with the unknown	1	1	1	1	1	1	0	1	1	8
awareness of self within context of intergenerational vi	0	0	1	0	0	0	0	1	1	3
becoming a mother central to reducing anxiety around others' perceptions	0	1	0	0	0	0	0	0	0	1
being a target for others' assumptions about visual impairment	0	1	1	1	1	0	1	0	1	6
boost to confidence through vi group	1	1	0	0	0	0	1	1	1	5
celebrating positive birth experience second time around	0	1	0	0	0	0	0	0	0	1
celebrating self as proud mum	1	0	1	1	0	0	0	1	1	5
centrality of mother's role to own identity and sense of purpose	0	1	0	1	0	1	1	1	1	6
children as important helpers	1	0	1	1	1	0	1	0	0	5
children protective and defensive of their mother	0	0	0	0	0	0	1	1	1	3
conscious rejection of attachment history with own family	0	1	0	0	0	0	0	0	0	1
defensive, withdrawn and feeling secondary to others	1	1	1	0	1	1	1	1	1	8
difficulties of living with severe PND	1	1	1	0	0	0	1	0	0	4
enjoying shocking others	0	0	0	0	1	0	0	1	0	2
envy at differences within family	0	0	0	0	0	1	0	0	0	1
excited and investing in the future through child	0	0	0	0	0	1	0	0	0	1
extra effort and time required	1	0	0	0	1	1	0	1	0	4
fear of self or children missing out	1	1	1	1	1	0	1	1	1	8
feeling hopeless about the future	0	0	0	0	0	0	0	0	1	1
feeling in control, resourceful and independent	1	1	1	1	0	1	1	1	0	7
feeling invisible in mother role	1	0	0	0	0	0	0	1	0	2
feeling part of isolated minority	0	0	0	0	0	0	0	1	0	1
feeling responsible and guilty as a vi mother	1	0	0	0	0	0	0	0	0	1
feeling trapped into having "to rely on everybody else"	0	1	0	0	1	0	0	0	0	2
frustrated that life has to be a series of battles	1	1	1	1	0	1	1	1	1	8
frustration and anger at self and others	1	1	1	1	0	1	1	1	1	8
growing in confidence through motherhood experience	1	0	1	0	0	0	0	0	0	2
guide dog as tipping point to gaining a sense of independence	1	1	0	0	0	0	0	1	0	3
increased use and awareness of senses	0	0	0	0	1	0	0	0	0	1
insecurity in sense of self within wider society	1	0	1	0	1	0	1	0	1	5
internal struggle in accepting help	0	0	0	0	0	0	0	1	0	1
isolation and envy at differences within family	0	1	0	0	1	0	0	1	0	3
less time for self	1	0	0	0	0	1	0	0	0	2
life feels more difficult and complicated than for others	1	1	1	1	0	1	1	1	1	8
living with the difficulties of gradual sight loss	0	0	0	0	1	0	0	1	1	3
loss of previous freedoms, knowledge and skills	0	0	0	0	1	0	1	1	1	4
loss of previous life and support network	0	1	0	0	0	0	1	0	0	2

modelling and encouraging independence in child	1	0	1	0	0	0	0	0	0	2
motherhood entails responsibility and curiosity about own embodied state for next generation	0	1	0	0	0	0	1	0	0	2
needing space for self as a mother	1	0	0	1	0	0	0	0	0	2
pregancy as shock	0	0	0	0	0	1	0	0	0	1
pregnancy as time of heightened anxiety with self in flux	0	1	0	0	0	0	0	1	1	3
prior to becoming a mother, self full of anxiety around life's purpose	0	1	0	0	0	0	0	0	0	1
reflecting on many changes within self	1	0	1	1	0	0	1	1	1	6
reflecting on self as constant	0	0	0	1	1	0	0	0	0	2
reflecting on self as happy and confident	0	1	0	1	1	0	0	0	0	3
rejecting dependent self	0	0	1	1	0	0	0	0	1	3
rejecting out of control and dependent self	0	1	1	0	0	1	1	1	0	5
resigned acceptance	1	0	1	1	0	1	0	0	0	4
resistance to inversion of parent - child caring role	0	0	0	1	1	0	0	0	1	3
restricted freedom	0	0	1	1	1	1	1	1	0	6
secure sense of self and family unit within wider community	0	0	1	1	0	0	0	1	1	4
security gained from reliance on supportive partner	1	0	1	1	0	0	1	1	0	5
self as dependent and fearful of experts' power	0	0	0	0	0	1	0	0	0	1
self as detached and not understood by others	1	1	1	0	0	0	1	0	1	5
self as distrustful and wary of others' motives	0	1	0	0	0	0	0	0	0	1
self as secondary to others' needs	0	0	0	0	0	1	0	0	0	1
self as source of pain to family	0	0	0	0	0	0	0	1	1	2
self as strong and determined	0	0	1	1	0	0	0	1	1	4
self as unique and challenging to others	0	1	1	1	0	0	1	1	0	5
self as victim of violence	0	0	1	0	0	0	1	0	1	3
self as vulnerable and isolated when a new mum	1	1	1	0	0	0	1	0	1	5
self gaining identity through working	0	1	0	1	0	0	0	0	0	2
self in mother's role as giving unconditional love and support	0	0	0	0	0	1	0	0	0	1
self included by other mums	0	0	0	0	0	1	0	0	0	1
self seen as victim by others	0	0	0	0	0	0	0	1	1	2
sensitive to difference within family	1	0	1	0	0	0	0	0	0	2
shame and anger at others' perception of self as unfit parent	1	1	1	0	1	0	1	1	0	6
shame around internalised assumption of stigma of visual impairment	0	0	1	0	1	0	1	1	0	4
shame at loss of job and sense of identity within community	0	0	0	0	0	1	0	0	0	1
shock at sudden atrophy & sight loss	0	1	0	0	0	0	1	0	1	3
sight loss accepted as biological "given"	1	0	0	1	0	0	0	0	0	2
struggle of living with pain and chronic poor health	0	0	1	1	0	0	0	1	0	3
survivor through cumulative loss and trauma	0	0	0	0	0	0	0	1	1	2
taking responsibility for own anger & frustration	0	0	1	0	0	0	0	0	0	1
true self emerging through meeting similar other	0	1	1	0	1	0	0	0	0	3
using humour as a way to deflect pain	1	1	1	0	1	0	1	1	0	6
using knowledge as a means of feeling in control	1	0	0	1	1	0	1	0	0	4
viewing self identity within mainstream experience	0	0	0	1	0	0	0	0	0	1
wanting to please and get it right	0	0	1	0	0	1	0	1	0	3
wanting to prove independence to self and others	0	0	1	1	1	0	1	1	0	5
wanting to prove self as good mother to self and others	0	1	1	1	0	1	1	0	1	6
	34	37	43	31	27	25	35	42	37	

Appendix 9

Summary table of top 20 themes by frequency

	Priyanka	Claudia	Bridget	Ayesha	Sharon	Gail	Caitlin	Sarah	Penny	Total
angry at others for lack of support	1	1	1	1	1	1	1	1	1	9
accepting and appreciating others' support	1	1	1	1	1	1	1	0	1	8
defensive, withdrawn and feeling secondary to others	1	1	1	0	1	1	1	1	1	8
fear of self or children missing out	1	1	1	1	1	0	1	1	1	8
frustrated that life has to be a series of battles	1	1	1	1	0	1	1	1	1	8
frustration and anger at self and others	1	1	1	1	1	0	1	1	1	8
life feels more difficult and complicated than for others	1	1	1	1	0	1	1	1	1	8
feeling in control, resourceful and independent	1	1	1	1	0	1	1	1	0	7
wanting to prove self as good mother to self and others	0	1	1	1	0	1	1	0	1	6
anxiety living with the unknown	1	1	1	1	1	1	0	1	1	8
being a target for others' assumptions about visual impairment	0	1	1	1	1	0	1	0	1	6
centrality of mother's role to own identity and sense of purpose	0	1	0	1	0	1	1	1	1	6
restricted freedom	0	0	1	1	1	1	1	1	0	6
shame and anger at others' perception of self as unfit parent	1	1	1	0	1	0	1	1	0	6
using humour as a way to deflect pain	1	1	1	0	1	0	1	1	0	6
advocating carpe diem attitude	0	0	0	0	0	0	0	0	0	0
boost to confidence through vi group	1	1	0	0	0	0	1	1	1	5
celebrating self as proud mum	1	0	1	1	0	0	0	1	1	5
children as important helpers	1	0	1	1	1	0	1	0	0	5
insecurity in sense of self within wider society	1	0	1	0	1	0	1	0	1	5
	15	15	17	14	12	10	17	14	14	