The Way We See It – A Qualitative Exploration of Life With Visual Impairment

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Abstract

Living with visual impairment is associated with numerous psychological challenges, including experiencing negative emotions, difficulty with social interaction, disclosing impairment to others, and the struggles of being confronted with a new identity. If visual impairment occurs during childhood, these same psychological challenges are also extended to the child's family, particularly parents. In considering support systems for visually impaired children experiencing psychosocial challenges, qualified teachers for visually impaired children (QTVIs) are often the primary source of expertise in this regard. Building on prior empirical research, this thesis aims to generate an in-depth understanding of the complexity of living with a visual impairment, through three qualitative studies, each focusing on a specific aspect of visual impairment. Within the first study, a focused exploration of psychological wellbeing in visually impaired adults following diagnosis of sight-loss was undertaken. Findings yielded themes relating to emotional response to diagnosis, social interaction, identity perceptions, and re-building life after sight-loss. The second study was concerned with how childhood visual impairment was psychologically experienced by mothers, where findings revealed issues during the diagnosis process, impacted relationships with the child and other family members, as well as social interactions and support beyond the family system. The third study investigated the psychological experiences of QTVIs working with visually impaired children. Findings highlighted the importance of maintaining positive and supportive relationships with the child, their family, and classroom teachers. Promoting wellbeing and social development was stressed, along with rewards and challenges to the QTVI service provision. Findings from all three studies are discussed in relation to prior literature, and their implications for medical, social, and educational practise.

Declarations

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed [redacted] ....

Date 16.06.2023

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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The University's ethical procedures have been followed and, where appropriate, that ethical approval has been granted.

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Contents

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Finally, to my parents; thank you for always believing in me.

Tables

Table 1

Study 1 Participant Demographics

Participant number	Pseudonym	Gender	Age	Diagnosis	CVI registration
1	Kate	Female	57	Optic atrophy	Sight impaired
2	Debbie	Female	49	Bardot-Biedl syndrome	Severely sight impaired
3	Adam	Male	64	Diabetic maculopathy	Severely sight impaired
4	Mary	Female	89	Vitelliform macular degeneration	Sight impaired
5	Angela	Female	78	Age-related macular degeneration (AMD)	Sight impaired
6	John	Male	72	Retinal dystrophy	Sight impaired
7	James	Male	66	Usher's syndrome	Severely sight impaired
8	Betty	Female	95	AMD	Sight impaired
9	Sarah	Female	72	Glaucoma/ AMD	Severely sight impaired
10	Nadine	Female	59	Usher's Syndrome	Severely sight impaired

Table 2 – Study 1 Emergent Themes

Superordinate Theme	Theme	Sub-theme
Response to crisis	Receiving the diagnosis	Lack of information – feeling “in the dark”
		Denial – “this isn’t happening to me”
Long-term losses and fears	Experience of Loss	Wish versus reality “as much as I like to think I could, I can’t”
		Loss of meaningful activity
		Fear of further sight-loss
	Effort and exhaustion	Physical and psychological experiences – “you just shut down”
		Extra mental effort; “I have to stop and think”
Social impact of sight-loss	The struggles of social interaction	Fear of social awkwardness/rejection; “I don’t want to offend people”
		Desire to connect with other visually impaired individuals versus feeling “segregated”
	Frustration of receipt of social support	Having to rely on others – “you kind of fit in around everybody else”
	Disclosing visual impairment	Being “well known” versus “private”.
	Reaction of family and friends to sight-loss	Loss of friendships; “they hide away”
		Others reluctance to accept sight-loss – “they didn’t want to talk about it”
Sight-loss and identity	Unpacking “disability identity”	“Illness” identity versus “disability” identity
		‘Disability’ is a label; “it’s the term we use”
	The visibility visual impairment	The ‘invisible disability’; “nobody sees you”
		Cane as a ‘symbol’ of visual impairment.
Rebuilding life after sight-loss	The road to acceptance	Attempting to gain meaning-“why have I had it?”
		What is acceptance? – Objective or subjective?
	Enlightenment through adversity	Increased empathy; “I have a more enlightened view”
		Advocating for visual impairment – “it made me more focussed on visual impairment rights and support”

Table 3 – Study 2 Participants Demographics

Participant number	Pseudonym	Participant age	Age of child	Gender of child	Child's VI registration	Child's eye condition
1	Kate	41	13	Female	Severely sight impaired	Marfan Syndrome
2	Tess	42	11	Male	Severely sight impaired	Norrie Disease
3	Susan	41	10	Male	Severely sight impaired	Not specified
4	Helen	35	6	Female	Severely sight impaired	Undiagnosed
5	Pam	39	14	Female	Severely sight impaired	Retinopathy of Prematurity (ROP)
6	Pennie	40	9	Male	Severely sight impaired	Nystagmus
7	Emily	39	15	Female	Sight impaired	Complications resulting from a brain tumour
8	Mel	32	5	Female	Sight impaired	ROP
9	Laura	29	3	Male	Severely sight impaired	Autosomal-Dominant Congenital Cataracts with Microphthalmia
10	Samantha	46	9	Male	Severely sight impaired	Midline brain defect
11	Rosie	36	11	Female	Severely sight impaired	Micropthalmia and coloboma
12	Sinead	42	19 months	Female	Severely sight impaired	Micropthalmia and coloboma
13	Daisy	40	13	Male	Sight impaired	Cerebral visual impairment (CVI)
14	Emma	27	5 months	Male	Severely sight impaired	Microphthalmia
15	Jess	25	3	Male	Sight impaired	Albinism

Table 4 Study 2 Emergent Themes

Superordinate Theme	Theme	Sub-theme
Living with VI as a family	The impact of diagnosis	Guilt – “I made my baby wrong.”
		Distress at diagnosis
		“There’s no fix for this”
	Facing the unknown	The child’s experience – “what can they see?”
		Comparison to other children- “is that normal?”
		The need for planning – “you are constantly having to think ahead”
Roles and relationships	Roles: beyond being a parent	The advocate – “the constant fight.”
		“Carer” versus “mum”
	Parent-child relationship	Managing expectations – “you don’t want to be the bearer of bad news”
		Protectiveness – “there is more vigilance” versus unwrapping the cotton wool – “we are on this independence path now”
		Nurturing identity – “I want her to be …confident and happy with herself”
	Relationships with siblings	Parental guilt; “I don’t want my other son to resent that”
		Fear of sibling comparison; “why can’t I do that? Why am I not doing that?”
Thinking about the future	Future concerns	Anticipated outcomes – “what if?” and “what’s next?”
		“When I am not around”
	Cautious optimism versus futility	Proving society wrong – “he is perfectly capable”
Beyond the family	Dealing with difference	Breaking the news to others – “I couldn’t face anybody”
		Pity from others – “she’s not a pet, she’s human!”
		Feeling judged – “you have to explain to everybody …what the situation is”
	Outside support	Feeling alone – “who’s there on the other end of the phone? Who?”
		Increased connectedness

Table 5 Study 3 Participant Demographics

Participant number	Pseudonym	Age	QTVI Base Location
1	Rachel	44	mainstream peripatetic
2	Eleanor	51	mainstream and special school peripatetic
3	Christine	48	mainstream and special school peripatetic
4	Beth	42	fixed position at a single mainstream school
5	Katie	45	mainstream peripatetic
6	Sandra	56	mainstream and special school peripatetic
7	Lisa	36	mainstream peripatetic
8	Heather	49	mainstream peripatetic
9	Megan	53	mainstream peripatetic
10	Isabel	46	mainstream peripatetic

Table 6 Study 3 Emergent Themes

Superordinate theme	Theme	Subtheme
Relationships	Relationships with children and families – a deeper relationship	The balance between being “distanced” versus “that person you can ring up at midnight”
		Emotionally supporting children; “I just let them talk …cos that’s what they need”
		Providing emotional support to families – engagement versus resistance; “I had to be strong because mum couldn’t be strong”
	Relationships with teaching staff; “education the educators”	Lack of VI awareness; “sometimes they forget”
		Walking on eggshells; “I don’t want you to feel like you are being watched or that you’re being checked up upon”
The rewards and challenges of being a QTVI	Expectations	Managing the child’s expectations – being “realistic”
		Expecting more from the child – “they have to try so much harder!”
		“Everybody expects us to know everything”
	“Championing” the children	Encouraging self-advocacy – for “when I am not there”
		The battle versus the excitement for greater VI awareness
Social development – observation and facilitation	Observed influences of social development	Family dynamics – being “wrapped up in cotton wool” versus “getting on with it”
		Feeling “alike” versus feeling “different”
	Facilitating social development	Managing anxiety around “making friends with children who don’t know my vision”
		Acceptance through familiarity; “they are all aware”

Abbreviations

AMD - Age-related Macular Degeneration

ASD - Autism Spectrum Disorder

CVI - Cerebral Visual Impairment

CVI - Certificate of Visual Impairment

ECLO - Eye Clinic Liaison Officer

IPA - Interpretative Phenomenological Analysis

MACS - Microphthalmia, Anophthalmia, and Coloboma Support

QTVI - Qualified Teacher for the Visually Impaired

RNIB - Royal National institute for the Blind

ROP - Retinitis of Prematurity

RP - Retinitis Pigmentosa

SI - Sight Impaired

SO - Superordinate

SSI - Severely Sight Impaired

VI - Visual Impairment

VICTA - Visually Impaired Children Taking Action

WHO - World Health Organisation

Chapter 1 - Introduction

1.1 Background

Visual impairment (VI) is defined as loss of vision - resulting from a functional deficit within the eyes or visual system, which causes significant limitations to visual functioning, and typically is not improved through use of refractive correction, visual aids, medication, or surgery (Sacks & Silberman, 1998; de Boer et al. 2004; Hayhoe, 2012). Visual impairment may occur as a result of congenital factors (Yazdani & Traboulsi, 2004; Oberacher-Velten, Segerer, and Helbig, 2012), hereditary disorders such as retinitis pigmentosa (Dryja, 2002), or acquired degenerative conditions such as Age-related Macular Degeneration (AMD) (Uribe & Buckley, 2013), glaucoma (Nickells et al. 2012), and diabetic retinopathy (Antonetti, Klein, and Gardner, 2012). The Royal National Institute for the Blind (RNIB) estimates that around 2 million individuals living in the UK are experiencing sight-loss, with 360,000 individuals being registered as sight impaired or severely sight impaired (RNIB, 2013). Estimations also indicate that the number of visually impaired individuals in the UK is likely to increase in tandem with the ageing population (Charles, 2007). However, it must be noted that these estimations are not exclusively based on the elderly, and it is important to be mindful of sight-loss, regardless of age (RNIB, 2013).

Throughout the thesis, a functional approach to visual impairment is adopted, which compliments past tendencies for research to view visual impairment from a more medical standpoint (Schinazi, 2008). This chapter presents an introduction to the psychosocial implications of sight-loss in adulthood, along with the psychological implications for visually impaired children, their families, and their education. This chapter concludes by highlighting a general scarcity of understanding within the context of visual impairment, both from an individual perspective, as well as from the perspectives of those providing support to visually impaired individuals.

Visual impairment poses a significant challenge to public health, due to its numerous (and often negative) physical and psychological effects, such as functional status decline, disability and suffering (US Department of Health and Human Services, 1983; Rubin et al., 2001; Court et al., 2014). Visually impaired individuals encounter the continuous challenge of psychological adjustment to their impairment. Psychological adjustment to disabilities such as visual impairment is defined as the complex process of responding to stresses and demands; involving cognitive, emotional, and behavioural alterations in order to reach an optimal experience of well-being (Tuttle, 1987; Livneh & Antonak, 1997). Due to the heterogeneous nature of visual impairment, along with the potential influence of additional factors such as education and family life, psychological adjustment to visual impairment is idiosyncratic – it depends on the individual and their experiences. Adjusting to a world that places emphasis on vision is a complex process. Researchers have attempted to address several issues, including the effects of acute or degenerative sight-loss, emotional impacts of sight-loss, along with the significance of social support from family, friends, and charities (Nyman et al., 2010; MarquèsBrocksopp, 2012; Popescu et al., 2012; Rebeiro et al., 2015).

1.2 Context and Terminology

Numerous discussions regarding terminology and social perceptions within the context of disability studies have arisen. In terms of disability-related labelling, many previously used terms are now viewed as offensive, since they often perpetuate negative social attitudes towards disabled individuals (Barnes & Mercer, 2001; Clark & Marsh, 2002). Whilst the term 'disability' has been frequently disputed, this term is universally recognised by disabled individuals (Clark & Marsh, 2002). This thesis will likewise employ the term 'disability', since this was the term most widely adopted by participants in the reported study. When examining visual impairment-related terminology, there is little consensus, with organisations such as visual impairment support charities use alternating terms. For instance, the Royal National Institute for the Blind (RNIB) uses a variety of terms, including visual impairment, sight-loss, partial sight, and blind (RNIB, 2012a). Recognising the potentially limiting and socially constructed implications of visual impairment terminology remains important. Nevertheless, the focus of this thesis is to acknowledge the terminology recognised by visually impaired individuals themselves; and, though some of these terms are debatable, participants in the present research used the terms 'visually impaired' or 'blind' to refer to themselves and society's perception of them.

When discussing visual impairment terminology and its implications, it is important to be cautious, since labels may actually "blind" an individual through definition (Schinazi, 2008). The term "blindness" is often a generic and inexact concept, since approximately 75% of individuals classified as blind still possess some remaining vision (Moore et al., 1997). Huebner (2000) noted that severely sight-impaired individuals are often labelled as “blind”, even though the presence of light perception may be useful for orientation and navigation. Society’s categorisation of individuals based on physical characteristics may impact on both personal and social identity (Corn & Koenig, 1996a). For example, individuals with some remaining functional vision who are continually categorised as “blind”, may subsequently doubt the usefulness of their residual vision, acting and believing that they have no sight (Schinazi, 2008). Lowenfeld (1963) highlighted the fact that ophthalmologists often did not offer encouragement regarding residual vision use. However, there is now much more focus on optimising functional vision, where restricting its use is considered detrimental (Ashcroft, 1966). It should be noted that reliance on one’s remaining sight is unique to the individual, since some depend heavily on their remaining vision, whereas others may develop strategies to use alternative sensory modalities.

Through the concept of ocularcentrism; a social framework which emphasises the importance of vision, attitudes and beliefs about visual impairment and blindness are shaped. ‘Seeing’ is synonymous with ‘knowledge’, and so those labelled as “blind” are viewed with associated negative connotations (Bolt, 2005, 2013; Verhaeghe et al., 2016). For instance, Bolt (2014, p. 31) noted the way in which media advertisements depicting ‘blind people’ may simultaneously show progress with regards to inclusivity, whilst perpetuating stereotypes and ocularcentrism by equating positive experiences through use of excessive visual language. When considering the term “blind”, there may be several negative connotations and stereotypes that spring to mind, for example: the implication of darkness, mobility aids including a guide dog or white cane, and the inability to recognise faces, all of which imply a sense of helplessness (Southwell, 2012; Aziz, 2017). These connotations are present both socially, and within the world of work, where they may account for the high unemployment levels among visually impaired individuals (Douglas, Corcoran, & Pavey, 2006). It is therefore not surprising that fear of sight-loss is the most frequently occurring fear relating to sensory loss (Baker & Winyard, 1998; De Leo et al., 1999). Diagnosis of a visual impairment is commonly accompanied by uncertainty and anxiety about the future (Norowzian, 2006;

Stephens, 2007; Thurston, Thurston and McCleod, 2010). Worry, stigma, and pity related to visual impairment exist to a degree within all of us, at least until we realise that they are correctable subconscious stereotypes (Zaborowski, 1997; Southwell, 2012). Therefore, when an individual loses their sight in later life, having never imagined themselves in this situation, or having had any contact with a visually impaired person, they may apply these pre-conceived assumptions to themselves (Southwell, 2012).

Visually impaired individuals often feel a need to appear as “normal”, commonly characterised by behaving in ways that hide any noticeable disability (Southwell, 2012). The sudden onset of sight-loss may threaten an individual in a society that values “normality” (Fourie, 2007). This sociological phenomenon is termed “passing” (Kusisto, 1998; Southwell, 2012). Passing as a sighted individual may appear a beneficial strategy, particularly in situations where presuppositions and preconceptions may have serious socioeconomic consequences for the visually impaired individual, such as in the workplace (Douglas et al., 2006). Anecdotally, Schinazi (2008) described the case of a young man who decided to ‘pass’ as sighted following repeated rejection when he tried to gain employment. Subsequently, he was able to secure several job interviews. However, at the point of being offered work, it became apparent that being able to drive was part of the job description. He was therefore forced to admit his inability to drive or travel independently, resulting in him being turned down. Whilst it is unclear as to whether passing as sighted helped to secure the interviews, it is apparent that the experience of being seen as sighted was equated with greater surety of securing a job.

The concept of passing can also have reverse outcomes, as is shown in “Looking Blind: A Revelation of Culture’s Eye”, in which Titchkosky (2005) described her experience of being a sighted individual passing as visually impaired, and thereby being mistaken as such. Her husband (who was visually impaired), was working late and became concerned about his guide dog becoming tired, so he asked his wife to take the guide dog home early. Whilst walking home with her husband’s guide dog, Titchkosky was physically guided to the train station by a passer-by, despite her own protestations that she did not need help. She wrote: “Despite this stranger’s impositional power, performed through his own status as a ‘helpful sighted person,’ he failed to see that I was sighted” (p. 221), but he also failed to see her as being simultaneously independent, competent, and visually impaired. In this in-between state of passing as visually impaired, Titchkosky highlighted how interaction constructed “blindness” as an identity. While passing as an everyday concept is likely not to be as extreme as the two above illustrations, both examples serve to epitomise how society may react to disabilities such as visual impairment with underestimation and protectiveness. Nevertheless, both examples also highlight the need for further understanding of meaningful interactions between visually impaired and sighted individuals, with the potential for such interactions to be experienced as respectful and reciprocal.

Another important factor in considering psychological adjustment to visual impairment is time. Since individuals with congenital disabilities have not encountered any loss of functioning, it stands to reason that their adjustment process (and subsequent psychological distress levels) would differ from those with acquired disability. Indeed, the scarcity of research into psychological adjustment among congenitally disabled individuals, implies an unspoken supposition that these individuals encounter less psychological challenges. Studies that include samples of congenital or acquired disabilities, indicate an association between congenital disability and better adaptation, although congenital disability has rarely been directly compared to acquired disability. For example, there are significantly higher levels of psychopathology among people who acquire facial paralysis compared to those for whom this is a congenital condition (VanSwearingen et al., 1999). However, research examining Moebius Syndrome, (involving congenital facial paralysis), did not report elevated negative emotional responses (Bogart & Matsumoto, 2010; Briegel, 2012). The few existing studies directly comparing adjustment to acquired versus congenital disabilities reported that individuals with congenital disabilities described lower psychopathology compared with those who had acquired disabilities (Li & Moore, 1998; Bogart, Tickle-Degnen, & Ambady, 2012).

Much of the literature surrounding psychological adjustment to disability focuses on the idea that people acquiring a disability are grieving over loss of functioning (Devins et al., 1983; Wright, 1983). Therefore, ‘adjustment’ occurs when the individual is no longer psychologically distressed by their functional loss. The term ‘adjustment’ is an interesting concept, since it implies both functional and psychological alterations in order to reach emotional reconciliation with a disability.

Arguably, individuals with congenital disabilities do not ‘adjust’ to their situation, or only do so after realising they are ‘different’ from their peers. Rather, they actually describe lower levels of psychological distress, incorrectly labelled as ‘adjustment’.

Within the context of psychologically adjusting to visual impairment, the age of visual impairment onset may significantly impact on an individual’s emotional development (Rosa, 1993). Visual impairment literature repeatedly takes the view that being visually impaired since birth results in an easier (or non-existent) psychological adjustment process (Warren, 1984; Tuttle & Tuttle, 2004; Pinquart & Pfeiffer, 2011). This is because congenital visual impairments require an almost automatic acceptance, whereas impairments acquired later in life typically involve surprise and negative emotional responses followed by an adjustment period (Pinquart & Pfeiffer, 2011). Whilst the studies in this thesis do not make direct comparisons between the psychological impact of congenital versus acquired visual impairments, it is still worth noting that these differences exist.

1.3 Psychological Impact of Sight Loss

Sight-loss is typically experienced with several negative psychosocial consequences. These include increased dependence on others, loss of participation in valued activities such as reading or driving (Nyman et al., 2012), dislocated social relationships, and impaired mobility and employment opportunities (Nyman et al., 2012). As previously noted, the impact of visual impairment is unique to the individual, depending on factors such as the age of onset, severity of sight-loss, utilisation of coping strategies, as well as the accessibility of good social support (Percival & Hanson, 2007; Reinhardt, Boerner, and Horowitz, 2009; Brown & Barrett, 2011). Individuals may experience stress relating to issues with navigation and mobility (Turano et al., 1999), social and environmental awareness, increased mental effort, and self-perception of skills (Turano, Geruschat, & Stahl, 1998). Coping with sight-loss is multifaceted, involving adaptation to the physical, emotional, and social consequences of visual impairment (Hodge et al., 2013). When adjusting to the life-changing event of losing their sight, individuals often experience negative emotions including frustration, anger, and denial (Scott et al., 2001; Percival & Hanson, 2007; Hodge et al., 2013). Moreover, visual impairment has the potential to severely hinder the individual’s psychological well-being (Zayfert et al., 2002;

Horowitz, 2004; Hassell et al., 2006; Mitchell & Bradley, 2006; Brown & Barrett, 2011). Reactions such as grief and shock are common among individuals experiencing sight-loss (Evans, 1983; Baus, 1999), and such responses are present regardless of age (Emerson, 1981). Additionally, certain eye conditions such as Retenitis Pigmentosa (RP) involve day-to-day fluctuations in vision, creating further elements of uncertainty (Heckenlively et al., 1988).

The experience of sight-loss has been strongly and consistently associated with both depression and poor quality of life (Horowitz, Reinhart and Kennedy, 2005; Mitchell & Bradley, 2006). While much of this research has tended to focus on older individuals, evidence has linked even higher negative emotional responses such as depression and anxiety among middle-aged individuals (Boerner, 2004; Cimarolli, 2006; Horowitz & Reinhart, 2006). This may have reflected the onset of an untimely disability which significantly hindered the pursuit of life goals, including careers or supporting family (Nurmi, 1992). This goal interference results in interruptions to daily tasks and routines (Popivker, Wang, & Boerner, 2010), with ensuing emotional distress (Wheeler, Munz, & Jain, 1990).

When considering the literature linking visual impairment and negative emotional responses, it is important to note the connection to visual functioning, as opposed to measures of visual impairment. Visual functioning is the extent to which a visually impaired individual is able to complete tasks of daily living. Nyman et al. (2010) reported a stronger association between visual function and emotional wellbeing compared to visual acuity (which measures remaining visual ability among individuals with sight-loss). However, this study only proposed an association between these two factors, where the causal relationship between visual functioning and negative mood states such as depression was not established. A prospective study of older individuals with recent-onset age-related macular degeneration found heightened levels of depressive symptoms were associated with decreased reports of visual functioning over time, regardless of measured visual acuity (Rovner, Casten and Tasman, 2002). Therefore, studies such as that of Rovner et al. imply a potential bi-directional association between vision function and depression, whereby poor visual function was linked to higher depression levels and vice versa. However, this link between visual acuity, visual functioning and depression may be present at other levels than those described above. Bookwala and Lawson, (2011); reported that depressive symptoms were predicted by self-reports of poor vision, rather than poor visual function. Therefore, subjective appraisal of visual functioning and visual acuity does not exclusively correlate with objectively measured impairment. Likewise, Zimdars et al. (2012) noted that only one third of participants reporting having a visual impairment were medically classified as being severely sight impaired. Subsequently, appraisals resulting from negative mood have the ability to influence subjective experience, which is discrepant to objective measures of that experience.

In addition to being considered as a personal experience, visual impairment and blindness can be viewed within a social context (Michalko, 2010). Disabilities including visual impairment exist as a result of social and cultural norms, where society may ‘disable’ and limit the visually impaired individual’s prospects for meaningful engagement (Simson et al., 2005; Michalko, 2010). Visually impaired individuals encounter significantly less engagement in valued activities and higher levels of social isolation compared to sighted individuals (Crudden et al., 2005; Bambara et al., 2009; Joseph, 2010; Berger et al., 2013). There is substantial evidence that people with visual impairment experience loneliness and lack of social support (Barron et al., 1992; Davis et al., 1995; Percival, 2003; Bruce et al., 2007). Research has shown higher levels of visual impairment to be associated with poorer or fewer social relationships (Carabellese et al., 1993). Considering these apparent limited opportunities for social participation, it is unsurprising that visually impaired individuals have reported reductions in quality of life (Harada et al., 2008; Rudman & Durdle, 2009).

1.4 Visual Impairment and the Family

Psychological adjustment to visual impairment often involves the social context of family and friends (Travis et al., 2003; Orr & Rogers, 2006). The role of immediate family members is particularly intimate and crucial, since they often live with the visually impaired individual. They therefore have first-hand experience of how the visually impaired individual has reacted to their sight loss and can be seen as the true experts on what living with visual impairment means for their loved one. This enables family members to provide tailored practical and emotional support, in addition to being the active point of communication and liaison with visual impairment-related services (Travis et al., 2004). Hence families are a source of both physical and emotional support (Palmer & Glass, 2003). Diagnosis of visual impairment has direct and long-lasting consequences for the family, and, while family members often differ in their responses, the initial diagnosis may result in significant psychological distress (Tuttle, 1986). Individuals with disabilities and their families exist as a complex system, since disabilities including visual impairment present unique challenges to pre-existing relationships, whereby family members are forced to adopt a new role and identity (Glass & Maddox, 1992). Thus, contextualising visual impairment within the family system enables a more rounded understanding of the psychological response to visual impairment (Silverstone, 2000).

Childhood visual impairment has life-long implications for both the child and their family, impacting on development and education, along with the care and support provided by families and professionals. Visual impairment acquired in childhood also shapes the future adult the child will transition into, posing challenges for aspects including socialisation and employment (Rahi & Cable, 2003). Although childhood visual impairment is less prevalent compared to sight-loss during adulthood (Charles, 2007), the lifetime duration of ‘blind years’ experienced by visually impaired children remains a significant consideration (Gilbert & Foster, 2001). Therefore, the on-going requirements of visually impaired children and their families need to be regarded within a lifetime context (Fielder et al., 2010).

Since visual impairment is a disability, it remains crucial to consider the unique nature and impact of childhood disability on family functioning, particularly in relation to parenting. Caring for a disabled child requires life-long commitment from the family, in addition to large amounts of time and resources. Parenting a child with a disability is often a challenging process, but one that can be simultaneously rewarding. Families need to learn how to adapt and cope with daily tasks requiring physical, psychological, social, and financial resources which are often unavailable. Additionally, parents are required to coordinate regular medical appointments and treatments, whilst trying to balance the needs of other members of the family. Empirical research has described the heightened psychological strain and stress resulting from parenting a disabled child (Dellve et al., 2006; Mackey and Goddard, 2006; Ryan and Runswick-Cole, 2008), with levels of stress and depression being higher when the child exhibits behavioural problems (King et al. 1999).

In addition to emphasising parental stress, research has indicated that there is a perceived need for parents of disabled children to act as advocates for their child (Ryan and Runswick-Cole, 2008). In particular, mothers are regarded by their children as allies due to their mediation on the child's behalf, in addition to being an "expert" on the child's condition (Lutenbacher et al., 2005). One universal issue repeatedly raised by families of disabled children is a perceived scarcity of physical, psychological, and social support, whereby families often direct their frustration towards a lack of communication between various service providers (Lutenbacher et al., 2005), and feeling like they are "on their own" (Mackey & Goddard, 2006).

Anxiety about their child's future represents an additional parental concern, in that parents consistently report worrying about their child's social abilities and independence (Vickers & Parris, 2005; Little & Clark, 2006). Such concerns become especially pertinent at the point of the child transitioning to adulthood, which is a period of significant change involving a perceived 'gap' in service availability and provision. This often results in a need for increased parental support (MacDonald & Callery, 2008). Whilst much of the existing empirical literature centres around the negative aspects of childhood disability on the family, some research has recognised the joys and positive elements of parenting. In particular, parents highlight feelings of strength and enrichment resulting from their new role as a parent of a disabled child, with self-focus being replaced with increased empathy (Scorgie & Sobsey 2000).

1.5 Visual Impairment and Education

Visually impaired children and their families often face the challenge of making decisions regarding the child's education. Parents may be worried about the best course of action for their child's educational requirements. What is the most suitable educational placement for their child, and how would their child "fit in" to a particular education setting (Roe, 2008; Ravenscroft, 2009)? As visual impairment (particularly severe visual impairment and blindness) is a low-incidence disability, the term "blind" again becomes misleading because many visually impaired children do possess some vision. Therefore, the "blind" child is often a seeing child, and it is imperative that those providing educational support, including classroom teachers and qualified teachers for the visually impaired (QTVIs), are able to utilise the child's remaining vision and support them as a "seeing child".

The conceptualisation of pupils with disabilities in the UK has undergone significant change during the past 40 years, with increasing focus being placed on identifying special educational needs, along with provision of the appropriate support in order to meet such needs (Vlachou, 1997). The 1981 Education Act places emphasis on pupils being educated in a mainstream setting wherever possible (HMSO, 1981), although specialist units, schools and colleges continue to be an option where educational needs cannot be met in mainstream (Thomas & Vaughan, 2004). Two ideological positions exist regarding the debate on special educational needs: inclusivity versus educational effectiveness. In promoting inclusivity within education, one argument proposes that a system of ‘special educational needs’ is not fully inclusive, since pupils may become isolated or segregated through emphasis on their medical diagnosis (Hall, 1997; Kenworthy & Whittaker, 2000; Thomas & Loxley, 2001). Supporters of the approach to inclusive education view inclusivity as an issue of civil rights, where segregation of pupils (i.e. placement in specialist schools) may be potentially damaging to the pupils potential, along with the unity of wider society (Christensen & Rizvi, 1996). On the other hand, those taking a position of educational effectiveness advocate for the right of the individual to receive an educational placement that is effective in catering for their disability (Hegarty, 1987; Lui, 1995). Therefore, placement in a mainstream setting that is not fully equipped to meet the pupil’s needs is counterproductive to both the individual and the educational system long term.

Though the concepts of special educational needs and inclusivity are universal to pupils with disabilities, visual impairments, as a low-incidence disability, may present particular educational challenges and demands (Smith et al., 2001; Keil & Crews, 2008). Pupils with visual impairments require adaptations to ensure successful orientation and mobility within their physical environment, including sufficient lighting levels and tactile guidance (Pavey et al., 2002). Teaching visually impaired pupils also presents its own challenges, especially when using visual tools such as PowerPoints or visual diagrams. Inclusivity is only possible through the use of assistive aids and accessible formats such as Braille or speech and magnification software (Hutchinson et al., 1998). Moreover, certain eye conditions including cataracts and RP may require varying adjustments, particularly when considering aspects such as lighting levels and print size. For example, pupils with cataracts may be sensitive to lighting, and require larger print, whereas those with Retenitis Pigmentosa might use standard size print, but require stronger lighting due to night blindness (Corn & Koenig, 1996).

Given the needs of visually impaired pupils, it is evident that the nature of support required for inclusive education needs to be extremely specialised. James and Biesta (2007) have proposed that achievement is highly dependent on developing a relationship in which the teacher is able to appreciate the pupil's educational needs. The low-incidence high-impact nature of visual impairment poses a challenge to teacher-pupil relationships, particularly when the teacher has limited awareness of visual impairment-related requirements for an appropriate learning environment. One of the most important elements when considering inclusive education is that the visually impaired child is able to participate as a full member of their class, and that they are recognised as equal to their peers (Gale, Kelley & d' Apice, 1998). This is possible when the classroom teacher is able to act as a positive role model, encouraging the child's peers to accept them despite their visual impairment. However, the classroom teacher may need some support in order for them to in support their visually impaired pupil.

The most central source of support comes from qualified teachers for visually impaired children (QTVIs), who are agents of awareness-raising and empowerment through their collaboration with classroom teachers, as well as the child's peers and family. However, the QTVI must go beyond merely raising awareness, since this could be considered as a one-way progression that does not emphasise the recipient's empowerment to take a more active role in gaining knowledge about visual impairment. It has been suggested that teachers often dramatically alter their practices after interacting with others who share their own "community of practice" (Coburn, 2001; Printy, 2008). Therefore, the role of QTVIs is integral for establishing a two-way relationship that empowers mainstream teachers to optimise accessibility for visually impaired children within their teaching practices. However, the QTVI should not hold full responsibility for promoting behaviour change, since teachers taking an active position in engaging with their own learning is vital for continuous improvement of instructional practice (Stein and Nelson, 2003).

1.6 Aims of the Current Research

Much of the existing literature on the psychological impact of visual impairment is weighted towards a quantitative research approach, using standardised instruments to measure emotional responses, coping, and social functioning. Such an approach is limiting in terms of providing a rounded representation of this experience. Qualitative studies comprising interviews with visually impaired individuals appear scarce. Moreover, aspects of the psychological impact of sight-loss (such as emotional responses, social interaction, and fatigue) are often explored separately, with little or no parallels being drawn between them. Some researchers are conscious of the differing nature of varying types of visual impairment, as well as the divergent influences of congenital versus acquired impairments. However, when observing psychological outcomes of visual impairment, conclusions are typically drawn following comparing visually impaired versus sighted individuals. Since much of the existing visual impairment-based research is longitudinal, consideration of the individual within the context of their environment and society becomes blurred. Therefore, focusing on particular psychosocial aspects of visual impairment requires a real-time exploration, that both identifies each single issue of relevance, and how these issues interrelate. The first study in this thesis therefore aims to investigate the psychological impact of sight-loss, through supplementation of quantitative research with qualitative data. This study will give voice to the experiences of adults with sight-loss, with specific focus on the immediate versus long-term response to sight-loss, and its impact on social interactions and identity perceptions.

The second study changes emphasis, exploring the psychological experience of living with visual impairment as a family. Much of the empirical literature relating to the impact of visual impairment on family functioning has focused primarily on family members providing care and support for adults with sight-loss in older adults who have acquired their impairment in later life. Thus, family members are adapting to the prospect of caring for someone who was previously able to conduct activities which are now no longer possible for them. In contrast, parents of visually impaired children face a completely different set of challenges in adapting to their child’s condition, that will likely have life-long consequences. Little research exists in relation to the unique psychological experiences of parents of children with visual impairment, with reference to specific psychological processes, such as emotional responses, alterations to family dynamics and relationships, and experiencing support from sources external to the family. It is therefore the aim of the second study within this thesis to address these research gaps, by providing a holistic exploration of parents' psychological experiences relating to their child's visual impairment, focusing on the journey through diagnosis, impacts on parental roles and relationships, and perceptions of external responses and support for the family. Understanding such experiences has significant implications for gauging (and promoting) wellbeing among family members of visually impaired children.

The third study steps away from these 'traditional' foci to consider on the experiences of specialist, QTVI and teachers involved in the education of children with visual impairment. The literature surrounding childhood visual impairment within an educational context has tended to focus on the logistical and conceptualisation issues of educating visually impaired children, with little or no consideration of the psychological experiences of those providing support to these children. The role of the QTVI warrants particular attention, since they are often perceived within the literature as go-betweens for the child, classroom teacher, and the family. Hence, there may be numerous psychological factors that the QTVI encounters, that could positively or negatively influence providing optimum support. Accordingly, how QTVIs perceive their role, along with managing the multitude of relationships they are required to maintain, is an important area of research. The final study therefore offers a unique insight into the psychological experiences of QTVIs working with visually impaired children, with a focused examination of teacher-pupil relationships within the context of visual impairment, teacher's perceptions of their role in the visually impaired student's interaction with education and socialisation, along with exploration of both positive features and barriers to service provision. This study therefore represents an extension to study 2, since it offers an extra dimension to the experience of childhood visual impairment, through the eyes of service providers who are heavily involved with the visually impaired child in addition to the family.

Chapter 2 – Methodological Context

2.1 Introduction

The primary focus of this chapter will be an in-depth examination of the methodological considerations relevant to the present research. The importance of methodological considerations within the context of disability and visual impairment is outlined, along with justifications for the utilisation of a qualitative, interpretative phenomenological approach (IPA). The IPA approach is defined and appraised, with particular reference to issues surrounding reliability and validity, since these present challenges within qualitative research due to its idiosyncratic nature (Elliott, Fiascher, & Rennie, 1999). This chapter also acknowledges a reflective bearing as part of the research process, recognising the role of the researcher in being involved in the construction of the final narrative (Smith, 1996; Elliott et al., 1999).

2.2 Research within the Context of Disability

2.2.1 Changing Perceptions – The Need for Individual Experience

Research into disability has previously been criticised for not fully contributing to the social emancipation of disabled individuals (Davis, 2000). This has led to discussions regarding the political and social connotations of disability research (Hunt, 1981; Hahn, 1993; Barnes, 1996; Barnes & Mercer, 1997), where researchers are making increasing adaptations to their epistemological and methodological focus, to address the reality of disability (Hammersley & Atkinson, 1983). There is also increased recognition that disabled individuals are the true experts on disability (Zarb 1992); and, as such, disabled individuals are increasingly voicing their criticism regarding potential exclusion of their participation in disability research management, design, and evaluation (Minkes et al., 1995; McConkey, 1998).

Several disabled individuals within the academic field such as Oliver (1992), have been critical of the omission of individuals with disabilities from disability-related discourse, calling for disability research to be more emancipatory (changing society in a positive way) and empowering (creating positive change via participation). It is argued that disability research does not represent the experiences and knowledge of disabled individuals, due to the fact that much of the existing research has been carried out by non-disabled researchers (Kitchin, 2000). It is contended that only individuals with disabilities can offer a full appreciation of what it is like to be disabled, and therefore only they can offer true interpretation and presentation of disability research (Kitchin, 2000). Supporting this, Hunt (1981) has described the experience of living as a resident of Le Court Cheshire Home, where he felt disheartened by participation in research that ignored the participants' views and primarily followed the researcher's own agenda. Subsequently, this has created the argument that a lack of understanding by non-disabled researchers has created dissatisfaction among disabled research populations, where disability organisations and activists have concluded that present disability research reflects exploitation and inequality, as opposed to liberation (Barnes & Mercer, 1997b). This point is particularly relevant for the current thesis, since the researcher is herself visually impaired, and therefore may have more life experience with the phenomenon under investigation than a non-disabled researcher. An argument is presented for destabilising relationships between the researcher and researched, along with a reformulation of research agendas utilising traditional research methods (i.e., no participation without representation) (Finkelstein, 1985, cited in Barnes & Mercer, 1997b).

The social model of disability has signalled the importance of emancipation within disability research, arguing for reconsideration of the relevance of traditional research methods (Duckett & Fryer, 1998; Moore et al., 1998). This model places focus on the societal barriers that 'disable' individuals, in contrast to the medical model of disability, which solely equates disability with physical impairment. Traditionally, disability research has been viewed as limited (Wirz, 1996), with much of the focus being on quantitative approaches (Mitchell, 1999). The documented quantitative research is primarily focused on the prevalence of a particular impairment, medical factors, as well as intervention efficacy (Finkelflugel, 1998). This makes disability research problematic, since the predominance of impairment-related studies often do not account for the psychosocial aspects of disability. Ironically, similar parallels exist between quantitative and qualitative research methodologies, as for the social versus medical model of disability. Conventionally, the medical model is allied with quantitative approaches, and may therefore lose meaning when relating to situations that emphasise complex and subjective perceptions. Such perceptions are better represented qualitatively, although both methodologies are necessary for a complete picture of disability, as are all disability models. Quantitative methods also encounter practical issues when applied to disability. For instance, the low incidence and heterogeneity of disabilities such as visual impairment; pose challenges for making statistical inferences, and controlling for variance (Kariuki, Ani, & McGregor, 2001; Wirz et al., 2001).

Traditionally, disability research has been dominated by the quantitative approach (Mitchell, 1999), with the quantifiable underpinnings of bio-medical needs, or medical intervention efficacy (Finkelflugel, 1998). Since the traditionalist research paradigm has often resulted in the perpetuation of viewing disability as a primarily individual issue, this has inhibited the position of individuals with disabilities, and in fact may have compounded the challenges they face (Oliver, 1990). Previous disability research has been criticised for being non-inclusive, and often depreciative to participants with regards to research design, procedure, data analysis, and distribution (Barnes, 1992; Oliver, 1992; Beazley et al., 1997; Mercer, 2002). Specifically, quantitative research may not capture ‘life full’ narratives (Kothari & Hulme, 2003). It may lack the ability to offer an in-depth understanding of disability as it is experienced by individuals, along with its effect on the lives of those around them (Mehrotra, 2004). Contrary to this, the qualitative approach may offer more empowerment to disabled individuals through providing them with a voice. The concept of empowerment is essential within disability research as argued by Swain et al. (2003), since research is unable to be emancipatory in the absence of empowerment. When considering the existing narratives regarding disabled individuals, there is a tendency for these narratives to come from the perspectives of professionals, rather than from the individuals themselves (Biklen & Duchan, 1994; Bogdan & Taylor, 1994; Kliewer & Biklen, 1996). There is a scarcity of qualitative research portraying the voice of the disabled individual, with the main focus of research often being the voices of professionals or caregivers (Lloyd, Gatherer & Kalsey, 2006; Carlsson et al., 2007). The current research places emphasis on highlighting the voices of the disabled individuals (specifically individuals with visual impairment), with the additional inclusion of the voices of parents of visually impaired children, and specialist teachers working with these children, in order to gain a more holistic insight into visual impairment. This research reflects the value of inclusion for individuals who may be marginalised, and whose voices are often overlooked (McCallum, Hargreaves, & Gipps, 2000; Whyte, 2005).

2.2.2 Visual Impairment Research – From The Insights of the Individual

It is vital to ensure that visual impairment research is heavily informed by visually impaired individuals themselves. As discussed above, much of the visual impairment research designed to support the individual, is centred on an approach that emphasises the impairment itself, and therefore overlooks active involvement of the individuals that would benefit from the research. Consequently, several researchers have attempted to avoid focus on ‘fixing’ the impairment, instead recognising that the ‘impairment’ reflects societal influences and marginalization of visually impaired individuals (Duckett & Pratt, 2001; Shakespeare & Watson, 2001; Foley & Ferri, 2012; Shakespeare, 2013). Given that visually impaired individuals are the experts on their own unique experiences (Oliver et al., 2001; Caron-Flinterman, Broerse, & Bunders, 2005), and are the most likely benefiters of visual impairment research, they therefore possess the right to be involved in any decision-making regarding their impairment (Goodare & Smith, 1995; Popay & Williams, 1996).

2.3 Choosing a Methodological Strategy and Research Design

2.3.1 Recapping the Aims and Research Questions of the Present Research

Using a qualitative IPA approach, the present research aimed to expand the understanding of individuals living with sight-loss, families living with visual impairment, and teachers for the visually impaired working with visually impaired children, in order to better inform appropriate strategies for alleviating any psychological issues these individuals face. This research was exploratory in nature, reflecting a knowledge gap in the phenomena under examination. Denscombe (2010) described exploratory research as the process of gathering data regarding how things are, rather than how things may be explained or evaluated. In addition to being exploratory, the present research reflects emancipation of the individuals involved, since they were given the opportunity to describe their experiences in their own words.

Research questions were deliberately broad, in keeping with the research epistemological framework, and the purpose of describing individual experiences of visual impairment. Following a review and identification of the gaps in existing visual impairment literature, the following research questions were derived:

Study 1: What are the psychological experiences of individuals living with sight-loss?

Study 2: What are the psychological experiences of parents of visually impaired children?

Study 3: What are the psychological experiences of qualified teachers for the visually impaired (QTVIs) working with visually impaired children?

As mentioned above, the shortcomings of quantitative approaches within disability research, has prompted a move towards a qualitative methodology in order to reflect the current research aims. Following deliberation, IPA was selected as an appropriate analysis approach for the research. This was due to the use of a small sample size, along with the aim of maintaining idiographic focus, in contrast to other qualitative methods such as Thematic Analysis, which focuses on patterned meaning throughout a larger data set (Braun & Clarke, 2006). Interpretative Phenomenological Analysis (IPA) was conducted throughout the three studies, obtained through semi-structured interviews with 10 adults experiencing sight-loss, 18 parents of visually impaired children, and 10 qualified teachers for the visually impaired (QTVIs).

2.3.2 Claims of Knowledge - Considering Ontological and Epistemological Positions

The philosophical positions of research are underpinned by arguments regarding the central nature of knowledge or being (ontology) and the constitution of valid knowledge (epistemology). An appreciation of such debates is important for the clarification of a qualitative research design choice. The following section discusses the debate relating to ontology, epistemology and outlines the ontological and epistemological positions adopted by the present research, leading to the chosen methodology.

Ontology. Willig (2008) described ontology as being concerned with the world's nature, with the fundamental question of "what is there to know" (p.13). Ontological positions are present on a continuum of realist-relativist. Realist positioning relates to the world being made up of objects and structures, which in turn have a strong and dependable relationship of cause and effect with each other. Therefore, the concept of reality is independent of human thought, and is present in the outside world. Conversely, relativist ontological positions contest the existence of reality in a consistent external world. Instead, relativism emphasises the variety of interpretations that can arise concerning the external world, where these interpretations are intertwined with how individuals make meaning of their life experiences. In terms of ontological positioning, the present study exists between relativism and realism, and therefore can be seen to draw on critical realist ontological assumptions. Critical realism represents a post-modern ontological position described by Bhaskar (2008). In critical realism, central features are independent in the world, but the individual's exploration and examination of these features is dependent on sociocultural influences. Accounting for this ontological position, the present research methodology is placed within a framework of phenomenology. Phenomenology relates to the experience of interpretation, that what we know is derived from our understanding of individual experience. Phenomenological research is based on work by Husserl, who proposed that phenomena are understood through exploration of individual meaning making, rooted in the context of language, relationships, culture, and politics (Moran & Cohen, 2012). Taking a stance of critical realism provides a fundamental ontological and epistemological basis required in phenomenological research including IPA, due to its acknowledgment of the world as both the real and the perceived phenomena (Mertens, 2010). By investigating individual experience, the researcher makes the assumption that there are experiences or phenomena to be produced (ontological realism), and that these experiences can be interpreted in numerous ways (epistemological relativism).

Epistemology. Epistemology is described as "the branch of philosophy concerned with the theory of knowledge" (Willig, 2008, p. 2). Epistemology is concerned with how we can know. Debate has arisen relating to two positions of epistemology. The positivist approach epistemologically maintains that research should aim to determine objective knowledge, accomplished by conducting empirical research following an experimental, hypothesis-driven approach. Kirk & Miller (1986). noted that positivist epistemological stances assume that "the external world itself determines absolutely the one and only correct view that can be taken of it, independent of the process or circumstances of viewing” (p. 14). However, critique of utilising positivist epistemology began to emerge, with a shift in approach towards the assumption that researchers are unable to place themselves externally to the research subject matter, due to them having some prior relationship or experience to the phenomenon under exploration (Haraway, 1988).

Constructivism represents an alternate epistemological stance to positivism. Taking a constructivist perspective, “individuals seek understanding of the world in which they live and work. They develop subjective meaning of their experiences” (Creswell, 2012, p. 24). Rather than beginning with a testable hypothesis, constructivist researchers are inductive in their use of information, in order to discover meaning, patterns and intricacies. Within constructivism, there is acknowledgment that realities are both time and socially dependent (Willig, 2008). Researchers are concerned with exploring the experiential meaning made by individuals, recognising that their world view is rooted within the contexts of their lives and work, and acknowledging the fact that the researcher makes interpretations shaped by their own perspective. As a psychology researcher, it is important to understand that one event may be interpreted in numerous ways, influenced by several factors including culture and language. It is therefore difficult to be completely objective when viewing a situation, since personal experiences and assumptions would also be involved. As such, social constructivism echoes the researcher’s own epistemological standpoint. After establishing a philosophical outline, a methodology supportive of this epistemological stance was pursued, enabling an acknowledgment and exploration of individual experience as a complex phenomenon.

2.3.3 Design of the Research – Qualitative Research

An appraisal of qualitative research characteristics led to the adoption of this research design for the present research. Qualitative research is an overarching terminology for several non-statistical research methods, which are concerned with understanding and representing phenomena as they are experienced by the individual (Denzin and Lincoln, 1994). Despite the existence of numerous qualitative methodologies, all qualitative research seeks to develop and review understanding, as opposed to simply confirming prior theory (Murphy et al., 1998; Elliott, Fiascher, & Rennie, 1999). The characteristics of qualitative research were congruent with the primary aim of the present research, i.e., to investigate the experience of visual impairment, whilst avoiding potential impositions of explicit or a priori bases.

Qualitative research seeks to obtain textual significance through participant accounts, rather than numerical significance as in the case with quantitative research. Emergent themes are able to identify commonalities of the participant's experiences. Bryman, (1988) described qualitative research as the study of actions, events, values and norms from the individual's perspective. Subsequently, qualitative research is appropriate when a study aims to present an in-depth understanding of a phenomenon, as opposed to obtaining facts, as with quantitative research. Qualitative research lends itself to answering questions including "what", "why", "how" and "who", and therefore may tap into unexplored assumptions (Coyle, 2006). These features of qualitative research are well-suited to the aim of the present research, i.e., asking "how" individuals make sense of their experiences of visual impairment, and "what" meaning they attribute to their experiences.

2.3.4 Choosing a Methodology - IPA

The following section describes the philosophical position of Interpretative Phenomenological Analysis (IPA) and justifies its use within the present research. The phenomenological methodology of IPA concerns itself with "exploring experience in its own terms" (Smith, Flowers & Larkin, 2009, p. 2). In IPA, the researcher engages in active listening in order to obtain an insider's perspective from the participant's reported experiences. The researcher then interprets participant's shared experiences to gain an increased understanding of what these experiences might mean for the individual (Reid, Flowers & Larkin, 2005). In order to meet this objective, IPA research is characterised by small, purposive samples ranging from single case studies to 5-10 individuals, with a smaller number of studies presenting larger sample sizes (Reid et al., 2005). It is argued that there is no 'correct' sample size, rather the research quality is dependent on alternative factors such as the level of commitment to the idiographic analysis, the richness of data obtained from each individual, and how each case is compared and contrasted (Smith & Eatough, 2006). Therefore, small sample sizes allow more time and opportunity for the researcher to conduct an in-depth, full analysis of each participant account, as opposed to collecting a larger sample, resulting in a more superficial analysis (Smith and Eatough, 2006; Smith, 2003). Since the present research aimed to explore experiences obtained from a small sample of individuals, the intentions of IPA were compatible with the research objective. In demonstrating the congruity of IPA with the present research, an examination of the main philosophical considerations of the approach was undertaken.

Phenomenology is a position of philosophy initially described by Edmund Husserl (1981), and relates to individual experience of the world. Husserl noted that, although individual experience is shaped by pre-existing understanding, we are nevertheless valid in our description of such experiences (Smith et al., 2009). Phenomenology relates to the experiences of individuals within particular contexts, as opposed to simply making generalised statements about the world (Willig, 2008). Moustakas (1994) acknowledges that, in taking a phenomenological position, “self and world are inseparable components of meaning” (p. 28). If perception is entwined with experience, and not with interpretations of experience, this might explain how one event might be perceived in several ways.

Interpretative Phenomenological Analysis (IPA) - encompasses features of descriptive phenomenology and interpretative phenomenology. The researcher strives to emulate the view of the participant as much as possible through delicate, open-ended questioning which maintains an inductive approach. As such, the phenomenon is able to reveal itself as it is. However, IPA recognises the impossibility of gaining direct insight into participant experiences, since the analysis always reflects the researcher’s interpretation of the participant’s own interpretation of their experiences. Within this framework, the final interpretation can be viewed as a combination of participant and researcher, who are both attempting to translate the experiences of the participant (Larkin, Watts, & Clifton, 2006; Smith, 2004).

In recognising the importance of the researcher’s own conceptions in understanding the meaning of a phenomenon for participants, it should also be noted that these attempts may be potentially contentious (Smith, 1996). Therefore, it is vital for the IPA researcher to closely represent the participant’s experiences, and free the analysis as much as possible from potential needless and altering preconceptions. In achieving this, the researcher should adopt a “phenomenological attitude” (Willig, 2008), meaning that the researcher needs to attempt to “bracket” their own pre-existing conceptions (Moran & Cohen, 2012). This contemplation phase is known as epoche, where the researcher suspends any assumptions, in order to view what is before them (Moustakas, 1994). It is impossible to completely “bracket out” pre-existing knowledge, but this may be facilitated throughout the interview process, in placing focus on the account of the participant, who is not preoccupied by existing knowledge.

Hermeneutics represents a philosophical position concerned with the interpretation of discourse, text, or events. IPA is shaped by Heidegger’s (1962) hermeneutic version of phenomenology. Within IPA, there is an interpretative process, where the researcher explores a particular phenomenon (Smith, Flowers & Larkin, 2009). This process of interpretation involves a double hermeneutic, which assumes that “the researcher is making sense of the participant, who is making sense of x” (Smith, Flowers & Larkin, 2009, p. 35). Therefore, the researcher has a dual role in that they need to comprehend both the participant’s account of their experience, and their own perception of that experience. This is described as first and second order meaning making (Smith, Flowers & Larkin, 2009). The significance of hermeneutics within IPA is based on the acknowledgment that the research process is influenced by the pre-existing experiences and assumptions of the researcher. It is suggested by Smith, Flowers & Larkin (2009) that the researcher “adopts a 'spirit of openness’” (p. 27), whereby reflexivity on the part of the researcher is integrated into the research process.

Interpretative Phenomenological Analysis (IPA) is idiographic in its methodological nature, where in-depth involvement with individual cases produce insights into how a phenomenon is experienced by the individual. Although the initial analysis focuses on individual cases, studies of more than one participant are able to offer exploration of comparisons and contrasts between participants. Smith (1994) proposes that the idiographic approach within IPA recommends it as a suitable methodology within health psychology, since both health psychology and IPA are based on the paradigm of cognition, which in turn assumes that “people think about their bodies and what they say about their bodies is in some way related to their thoughts” (Smith, 1994, p. 264). This assumption stems from the argument that IPA’s affinity with “mentation” and “sense making” is comparable to social and cognitive psychology (Smith, 1994). This argument has been opposed by the notion that IPA is not wholly compatible with a focus on cognition, since capturing individual experience cannot be entirely achieved through involving “non-propositional thoughts that maybe unmediated and unfocused” (Willig, 2008 p. 68). In response to this critique, Smith (2004) makes a parallel between IPA and meaning making as proposed by Bruner, as opposed to more traditional conceptions of cognitive psychology as being concerned with information processing. Despite the contention surrounding the term “cognition” within IPA, cognition is nevertheless an important aspect in attempting to comprehend participant’s “hot cognitions” i.e., primary and present issues, versus “cool cognitions” i.e., participant’s more enduring reflections (Smith and Eatough, 2006, p. 327).

IPA is positioned between approaches of social cognition and discourse analysis, placing emphasis on analysing language content as opposed to the use of language. The researcher takes an empathetic stance in order to gain an ‘insider’s’ perspective, whilst simultaneously questioning what the participant says in order to reveal underlying meaning. This is known as an “etic” approach, which creates a more enriched, insightful analysis (Reid et al., 2005; Larkin et al., 2006; Smith, 2003). Smith, (1994) noted that, although IPA theory accounts for how participants describe their experiences, it also recognises that responses may be contrived.

2.3.5 IPA Limitations

Whilst the use of IPA within psychological research has allowed non-philosophical researchers access to phenomenological research methods, it is nevertheless essential to be mindful of potential conceptual and practical limitations (Willig, 2008). One such critique of IPA is centred around the role of language, which is the primary form of participant communication of their experiences with the researcher. IPA researchers therefore make the assumption that language represents a valid form of communicating experience. Critics of this approach, influenced by philosophical positions of Wittgenstein and Foucault, propose that communicating “what is in your mind” cannot be reliably achieved through language (Gergen, 1989). Since there are several ways of describing an experience, the choice of language by the participant heightens the meaning within their social context (Willig, 2008). For instance, participants may use alternative words to describe an experience based on the researcher’s gender or professional role. This implicates the importance of reflexivity in recognising the potential influence of the researcher-participant relationship, in determining how the participant chooses to use language. Therefore, good qualitative research should involve consideration of the role of the researcher (Willig, 2008). It is suggested by Willig (2008) that participants may be limited by their linguistic and communicative capacity to convey their experiences, which may be further constrained by researchers. As such, the availability of language to participants precedes their capability for conceptualising and describing their experiences. Tuffour (2017) viewed this argument as potentially elitist, proposing that IPA should be exclusively available to eloquent participants.

Further evaluation of IPA relates to its descriptive nature, which may prohibit more in-depth theorising and interpretation. Tuffour (2017) argues that, while IPA produces full data regarding subjective experience, the analysis may not allow for the theorising of events, and in the absence of a more explanatory stance, may not provide adequate understanding of a phenomenon. In spite of the criticisms of IPA, it nevertheless offers an inductive research methodology within psychology, allowing for the development and furthering of knowledge regarding psychological phenomena, previously explored using positivist approaches.

2.3.6 Issues of Reliability and Validity

The terminology of reliability and validity are well established within both qualitative and quantitative research. In qualitative research, the aim is specificity as opposed to generalisation, where meaning is indexical and subject to alteration depending on time or social context (Smith, 1984; Banister et al., 1994). Such characteristics mean that comparing qualitative research against quantitative-related concepts of reliability and validity is problematic. Two theoretical positions exist in relation to evaluating reliability and validity in qualitative research. The first position is that if we accept the existence of numerous interpretations of reality, then we cannot accept one superior interpretation. Therefore, issues relating to reliability and validity are irrelevant (Smith, 1984). Similarly, Barbour, (2001) argues "that a relativist perspective renders internal validity checks redundant" (p.1117). This position is a logical outcome of a fundamentalist idealist stance but presents a dilemma for psychologists and other qualitative researchers who want to produce knowledge that others can be reasonably confident about (Murphy et al. 1998).

Alternatively, it has been proposed that there should be criteria for establishing reliability and validity within qualitative research, which should acknowledge the uniqueness of the qualitative approach (Henwood and Pidgeon, 1992; Elliott et al., 1999; Yardley, 2000). Taking this position, qualitative research needs to be evaluated through recognition of its credibility and ability of findings to address research questions (Elliott et al., 1999). Developing specific criteria also encompasses the importance of being reflexive, comprehensive, and transparent in presenting analysis samples, offering examples of data to demonstrate the process of analysis, along with monitoring credibility through triangulation and reporting findings in a way that resonates with the reader (Elliott et al., 1999). Reviewers such as Elliott et al. (1999) have advocated for the utilisation of specific criteria when appraising qualitative research. Likewise, Smith (1996) proposed distinctive evaluation of IPA research, following recognition of multiple interpretations; "The aim of validity checks on qualitative data is to ensure that the particular account presented is a sound one warrantable from the data, not to prescribe the singular true account of the material" (p. 69). This stance is relevant to the ontological and epistemological position adopted by the present research. Criticism of qualitative research evaluation is addressed through the advocation of clear acknowledgement of the relativeness of any interpretation, whilst also establishing the validity of the account. Specifically, triangulation and independent validation checks during data analysis are proposed by Osborn and Smith (1998), along with establishing whether the research argument corresponds with the data, and sufficient data presentation to enable interpretation examination by the reader.

2.3.7 Rationale for the Use of IPA

Following exploration of the philosophical basis of IPA, along with data collection and analysis processes, it was concluded that IPA was suitable to the present research purpose, aims and questions. The emphasis on examining subjective experiences, followed by tentative generalisations, would enable in-depth and accurate exploration of research questions. Reid, Flowers & Larkin (2005) argue that IPA is “particularly well-suited to researching in “unexplored territory”” (p. 23).

When conducting research into a relatively novel concept, the inductive nature of IPA creates an approach of interactionism. Rather than acquiring data based on a priori hypotheses, IPA allows for the progressive identification of themes (Smith et al., 2009). The capacity for utilising the double hermeneutic was an important consideration as an 'insider researcher', since it enabled a reflexive appraisal of the research process. Moreover, IPA places value on ethical integrity, involving a “dynamic process requiring frequent monitoring throughout the data collection and analysis” (Smith et al., 2009, p. 53).

2.4 Research Procedure and Data Analysis

This section offers an outline of the research procedure adopted throughout the present research.

2.4.1 Sampling Strategy

The present research adopted a strategy of purposeful sampling. Purposeful sampling involves participants being sampled deliberately based on their specific characteristics, as opposed to them being randomly selected, as in probability sampling. Purposeful sampling was chosen due to its appropriateness for the study aims, i.e., an in-depth report of participant’s experiences of visual impairment (Smith & Osborn, 2003). The researcher is therefore able to select participants on the basis of gaining the optimal level of useful data. In order to obtain this level of productivity, participants were selected on the grounds of their experiential knowledge, along with the significance of the research questions to them. It is proposed by Denzin and Lincoln (1994), that “Many qualitative researchers employ purposeful and not random sampling methods. They seek out groups, settings and individuals ... where the processes being studied are most likely to occur” (p.202). Participants were subsequently selected according to the criteria relating to the three studies (as outlined in the method section of each respective study).

Purposeful sampling is consistent with IPA and its emphasis upon the “particular”, as opposed to the “general”. Researchers can therefore make “theoretical generalisations” relating to existing literature, contributing to the development of the “bigger picture”, whilst not making any claims that the data is representative of all individuals with similar characteristics (Smith & Osborn, 2003). As previously stated, there is no ‘correct’ sample size within IPA (Smith & Osborn, 2003). Nevertheless, IPA sample sizes are typically small in order to offer an in-depth, nuanced analysis (Smith & Osborn, 2003). In line with this, the present research utilised relatively small samples, with the aim of obtaining a detailed understanding of participant's experiences, whilst still being able to identify similarities and differences within the data (Smith, 1999; Smith and Osborn, 2003; Smith, 2004).

2.4.2 Data Collection

This research utilised semi-structured interviews, a widely held data collection method within IPA studies (Smith, 2004). Interviews are particularly appropriate when exploring potentially sensitive topics, where the participant is afforded the privacy in which to open up about their experiences. All interviews were guided by semi-structured interview schedules (see subsequent study method sections for a detailed outline of each interview schedule), giving participants the freedom to describe their experiences, while still preserving focus on the research question. This allowed participants to recount thoughts and experiences in their own words, as opposed to research themes being imposed by the researcher. Emphasis was placed on sustaining a "phenomenological attitude", i.e., concentrating on participant accounts in order to observe texture and quality within their experiences (Willig, 2008). Each interview had a duration of approximately 40-60 minutes. The initial focus of the interview was making sure participants felt at ease, meaning they were more likely to honestly express themselves, without fearing criticism. Interview styles were informal and conversational, with added prompts to further expand on the interview guide, or to explore interesting points raised. The researcher strove to maintain a neutral but empathetic position throughout the interview, to facilitate greater insight into participants "lived experiences".

2.4.3 Transcribing Process

Transcription took place as soon as possible following each interview, (typically within a few days). This allowed for exploration of the researcher's role, with the potential for amending the interview approach for subsequent participants. In addition to the spoken content of interviews, transcripts made note of any changes in tone of voice, significant pauses, as well as non-verbal communication throughout the interviews. These were important indicators of the participant's emotional status

(Silverman, 2000). Cited quotes from the transcripts replicated participant's verbal accounts as much as possible, although it should be noted that this process is selective and interpretative, and therefore not an objective interview representation. Data presentation took the form of representative quotations obtained from participant accounts. Emergent themes were supported by such quotes, which were chosen based on their relevance and representation of both the theme, and participant accounts.

2.4.4 Data Analysis

2.4.4.1 Maintaining an Inductive Approach. The objective of data analysis was to gain an insight into participants subjective perceptions of visual impairment experiences, as opposed to the researcher's imposition of a priori frameworks on the data. Laborious efforts were made towards grounding interpretations within the data, along with 'bracketing out' any preconceived beliefs with the potential to distort accounts of participant experiences (see above for further discussion). Nevertheless, it was noted that an interpretation completely free from bias was an almost impossible achievement (Larkin et al., 2006). However, it is possible to recognise preconceptions, and be reflexive and self-aware when evaluating judgements within research (Beck, 1993). Throughout interviews, emphasis was placed on the accounts of the participant, with no reference to any prior knowledge of the topic. This was aided by a limited prior examination of visual impairment literature, which deepened following identification of themes. Although analytical notation was undertaken throughout the research process, the majority of theorising occurred during concluding phases of analysis, in which interpretations were discussed in terms of their relation to previous literature, in order to obtain new understanding of the studied phenomena (Smith, 2004).

2.4.4.2 Levels of Analysis. A heuristic and empathetic analytical stance was adopted, encompassing emphasis on describing visual impairment experiences of participants, along with a more critical approach placing focus on data nuances, in particular, what participants did not say. In achieving this level of analysis, reading and re-reading the entire transcript was imperative in remaining close to the data. These analysis levels are not separate, instead, the participant's position reflects a way of connecting to what it means for participants to experience visual impairment (de Visser & Smith, 2006).

2.4.4.3 Analytical Notes. An initial analysis commenced both during and immediately after each interview. These analytical notes related to initial impressions, rather than specific systematic analyses. Nevertheless, they were helpful when discussing findings in relation to pre-existing literature later in the research process. Additionally, preliminary theorising formed part of the analytic procedure, which also informed the latter stages of analysis.

2.4.4.4 Analytical Steps. The procedure of analysis was informed by Smith and Osborn, (2003). An idiographic and reiterative position was taken, involving an in-depth examination and re-reading of each interview transcript, before moving onto the next account. All transcripts were examined independent of one another, to retain the inductive approach. Comparison of each participant's emergent themes were made across the data set, enabling identification of different meanings and concepts, which in turn informed the creation of new themes, or new expressions of existing themes. These were then incorporated into super-ordinate themes, which were representative of the entire sample (Willig, 2008). The homogeneity of the sample meant that participants shared a commonality within each study related to visual impairment. As such, the stance of this research was to gain a generalized conceptualisation of visual impairment through the development of superordinate themes that represented participant experiences. However, the uniqueness of visual impairment experience was also captured, as is characteristic of IPA's idiographic commitment (Smith & Eatough, 2006).

An in-depth description of the analytical steps is presented below:

[1] Firstly, a free-text analysis was undertaken, with each transcript re-read repeatedly in its entirety (Smith & Osborn, 2003). This allowed for a full understanding of the account, prior to analysing the transcript line by line. This is accordant with the phenomenological position, allowing for an enriched and complete understanding of participants concerns (Giorgi & Giorgi, 2003). This phase was complemented by preliminary observations, descriptions, and questions.

(2) The preliminary or “open” annotations (Willig, 2008) were then reviewed and written in the margin to the right of the relevant text. Some annotations summarised participant accounts, whereas others represented the beginnings of analyses.

(3) Further corresponding comments were added in the left margin, which offered a more concise representation of meaning attributed to participant accounts. Smith and Osborn, (2003) proposed that this stage of analysis could both be more abstract and make reference to psychological terms, whilst still remaining embedded in the data. In some cases, “in vivo” terms were adopted, i.e., use of participant-led terminology (Creswell, 2003). Using such terms ensured that observations remained truly representative of what participants said.

(4) Using the left margin comments, a provisional theme list was created for each participant. These themes were based on similarities within the data, and several re-adjustments were made. For example, themes that were not sufficiently represented by the data were removed, while other overlapping themes were amalgamated into one theme. Themes were repeatedly checked against the data, ensuring encapsulation of participant experiences. This proved a difficult phase of analysis involving use of intuition, as noted by Smith and Osborn, (2003) that “the “magnetic like” quality of some themes that draws others to them” (p. 71). This phase of analysis also involved awareness that the process of clustering themes may be overriding theme re-sequencing, in addition to potentially disregarding important themes that may have been prioritised by participants. It was noted by Smith and Osborn, (2003) that, whilst during prior analysis phases, themes appeared in sequential order, the current phase now contained “clustering” of related themes, distorting the sequence, but representing the beginning of superordinate theme development. This issue was addressed through noting the sequence of the participants concerns.

(5) Construction of a superordinate theme table was undertaken. In order to maintain representation and an iterative approach, superordinate themes and subthemes were checked against the data. The end result was a list of superordinate themes, each with related subthemes. Comparisons were made between themes throughout the data set, with themes that were representative of participant accounts

being presented and examined. Supporting data from each theme were presented using identifiers including the participants' pseudonym, page and line numbers (Smith & Osborn, 2003).

2.4.4.5 Validity Procedures. The present research adopted the suggestions of Osborn and Smith, (1998) and as such, attempts were made to present an articulate discussion of findings, supported by relevant evidence through quotations from participant accounts. Additionally, credibility was ensured through the following:

- An in-depth methods section to ensure reliability and transparency
- Reflexivity
- Triangulation procedures involving PhD supervisors checking theme validity

An outline of these processes is presented below.

2.4.4.6 Transparency and Reliability. Enhancement of qualitative research reliability is achieved when the research process is transparent (Yardley, 2000). This is accomplished when the methods section contains sufficient information in order to be replicable, often including use of research diaries etc (Giles, 2002; Silverman, 2000). While the present study did not include formal documentation of the research process, the research process was outlined in detail throughout the procedure section, which was informed by notes on methodology obtained throughout data collection and analysis (Richardson, 1994, cited in Silverman, 2000, p.95). Moreover, availability of documentation including interview transcripts enabled easy ‘tracking’ and establishment of reliability, as well as allowing for validity checks on the representativeness of participant quotes (Giles, 2002).

2.4.4.7 Reflexivity. Within qualitative research, reflexivity refers to the researcher's sensitivity to their role in shaping the outcome of the research. Woolgar, (1988) suggested that qualitative research including IPA, exists on a continuum between constitutive reflexivity (a post positivist stance with no difference between researcher and researched), and benign reflexivity influenced by a positivist position (which distinguishes between researcher and researched). Constitutive reflexivity acknowledges that the researcher forms an intrinsic aspect of constructed reality, and therefore reflexivity as fundamental for the analysis process. In contrast, benign reflexivity posits no connection of the researcher to the researched, whereby reflection merely clarifies analysis objectivity.

Within IPA, it is recognised by the researcher that they may share similarities with the individuals under study, i.e., they are individuals conducting research with other individuals, whilst simultaneously claiming adherence to scientific objectivity. Therefore, the role of the researcher within IPA research is to maintain a phenomenological position (see above), and manage potential conflict between recognising oneself as being part of any representation, while remaining distanced in order to present participant experiences in a way that represents the studied phenomenon, but is not merely a regurgitation. This involves much more than simply being reflective, i.e., thinking about what one is doing. Rather, the researcher must be careful in monitoring their responses, along with being critical in their acclamation of methods throughout the research (Woolgar, 1988, p. 22).

In achieving a representation that is closely aligned yet distinct, the researcher must be proactive in their self-management, through making specific reference to their theoretical position, in addition to any pre-existing assumptions or biases which could influence the research (Rennie, 2000; Murphy et al., 1998; Elliott et al., 1999). Potential influences may be addressed through peer debriefing, involving reflective discussion with a PhD supervisor or someone with no prior connection to the data collection (Murphy et al., 1998). Methodological strategies such as ‘bracketing out’ and disengagement from previous research literature on the study’s topic allows the researcher to remain open-minded regarding the participant’s perspective (Giorgi & Giorgi, 2003). However, it remains impossible to be completely objective within qualitative research, since potential bias is acknowledged as being part of the research process.

Within the present research, participants were not known to the researcher and vice versa. However, due to the fact that the researcher was herself living with a visual impairment, she did possess some prior conceptions and knowledge about visual impairment. Early in the research process, the researcher recognised that it was often difficult to remain completely inductive throughout progression of the research. This is supported by the recognition of this issue by Larkin et al., (2006), who likewise noted the inevitability of falling short of this target (Larkin et al., 2006).

Reflexivity was also assured in this research through discussions and debriefing with the PhD supervisor who offered feedback, particularly when the researcher's personal feelings included sympathy as an emotional response to some interviews. Interview transcripts were also reviewed by the supervisor to prevent any biases from entering the analysis process (Cresswell, 2003).

2.4.4.8 Triangulation. Triangulation describes the process of gaining various perspectives on the topic of research to validate results (Giles, 2004). Forms of triangulation comprise researcher triangulation, method triangulation, data triangulation and respondent validation. During researcher triangulation, the analysis is independently checked and verified, often by another researcher who has experience or expert knowledge of the research topic. This form of triangulation can also include collaboration or team analysis, though it should be noted that dynamics within the group e.g., group census, may cause bias (Rennie, 2000). Within method triangulation, a mixed-method approach is undertaken to explore a particular phenomenon. Although this approach is frequently employed within the social sciences, it does not always result in gaining a full picture, since uncomplimentary theoretical positions may be used, producing under-analysed data (Silverman, 2000). Data triangulation involves conducting interviews with different participants, or having interviews take place in differing settings, then making comparisons between findings. However, this may cause a build-up of varied versions, thus distorting any clarity within the findings (Rennie, 2000). Finally, respondent validation involves the researcher referring back to participants, checking if the analysis feels relevant to them, and echoes their own experiences. However, this type of triangulation may prove challenging when relating to validation, since the participant's agenda may differ from the researcher, or they may feel unwilling to voice issues for fear of conflict (Bloor, 1997). This approach was therefore dismissed for use within the present research, because showing participants their own interview transcripts was thought to potentially trigger sensitive issues and cause emotional distress. Instead, the present research adopted researcher triangulation, where independent reviewing of the transcripts and analysis was carried out by the PhD supervisor, who was an experienced researcher with expert knowledge on the psychological impact of living with chronic illness. Therefore, the supervisor "acted as a check on the emergent analytic accounts" (Osborn & Smith, 1998 p. 68).

Chapter 3 – Study 1: The Psychological Impact of Sight-loss

3.1 Introduction

Coming to terms with sight-loss is often a life-long process, likely to result in extensive consequences for the affected individual (Horowitz, 2004; Nyman, Gosney, and Victor, 2010; Pinquart & Pfeiffer, 2011). Due to the prolonged, and often irreparable damage caused by sight-loss, individuals are often met with numerous unique challenges within their everyday lives (Gieser, 2004). Such challenges include difficulties with reading (Williamson, Schauder, and Bow, 2000), mobility (Montarzino et al., 2007; Hersh & Johnson, 2008), medication management, meal preparation, and self-care (LaPlante, 1983; Keller et al., 1999; Lindo & Nordholm, 1999; West et al., 2002; Lamoureux, Hassell, & Keefe, 2004; Travis et al., 2004; Stevenson et al., 2004). When a significant life event such as diagnosis of visual impairment involves challenges and losses, this often results in occurrence of stress, necessitating adaptation, where the appraisal of impairment-related challenges exceeds the ability to adapt (Lazarus & Folkman, 1984). Stress may be experienced as a consequence of the increased level of both information-processing and mental effort needed to compensate for sight-loss (Turano, Geruschat, & Stahl, 1998). This process of adaptation may therefore result in experiences of several negative emotional difficulties such as depression, anxiety, and frustration that often follow from stress (Rovner & Casten, 2001; Horowitz, 2004; Rovner et al., 2006; Nyman et al., 2010; Pinquart & Pfeiffer, 2011). Negative emotional difficulties may in turn negatively influence socialisation (Bernbaum et al., 1993) and quality of life (Mangione et al., 1999). These psycho-emotional effects will be discussed in the following sections.

3.1.1 Experience of Loss

Models of responding to significant loss (e.g. Kubler-Ross 1970), suggest that individuals facing significant change and loss associated with visual impairment may go through stages of grief. Firstly, they might mourn their sight-loss, along with the loss of other related aspects of daily life, i.e. work, hobbies, and independence. The initial stage of this model represents a defence mechanism in the form of denial, where the individual rejects the reality of what is happening to them. The second stage involves feelings of anger, which can be both self-directed and aimed at others. Within the third stage, the individual engages in bargaining, through attempts to achieve a compromise with their deity. Depression makes up the fourth stage, wherein the individual experiences feelings of sadness, guilt, anxiety, and uncertainty. The fifth and final grief stage is acceptance, which occurs once the individual has come to terms with their situation (Schilling & Wahl, 2006; Bergeron & Wanet-Defalque, 2013). Kübler-Ross (1970) maintained that the grief process is extremely subjective in terms of chronology and experience of these stages. In the case of visual impairment, the grief model has been utilised on the basis that the ordeal of sight-loss is not essentially different from that of other forms of significant crises, changes, or losses (Giarratana-Oehler, 1976). Due to its functional losses, visual impairment therefore represents a significant crisis (Schilling & Wahl, 2006). Within the context of sight-loss, denial encompasses disbelief, with the individual refusing to acknowledge their impairment (Tuttle & Tuttle, 2004), whereas acceptance involves full acknowledgement of sight-loss, along with adoption of subsequent adaptive behaviours (Hicks, 1979), and is therefore seen as the final grief stage in terms of adapting to sight-loss (Conyers, 1992).

Use of the term “adaptation” could imply a wider conceptualisation, that involves processes such as acceptance, denial, depression, and wellbeing (Bergeron & Wanet-Defalque, 2013). Subsequently, in a more recent study, Bergeron and Wanet-Defalque (2013) explored the adaptation pattern among 700 visually impaired individuals who completed a structured interview to establish impairment duration, in addition to answering the “Brief Cope”, “Satisfaction with Life Scale” and the “Center for Epidemiologic Studies–Depression Scale” (CES-D). Results indicated that individuals having lived with their visual impairment for longer than 2 years attained significantly higher levels of acceptance and lower levels of denial comparative to individuals whose impairment occurred more recently. Additionally, a positive correlation was found between both acceptance and wellbeing, and denial and depression, with negative correlations between acceptance and depression, and denial and wellbeing (Bergeron & Wanet-Defalque, 2013). Therefore, in relation to grief models, these findings appear to indicate that visually impaired individuals are able to achieve acceptance and subsequent adaptation fairly early on in their sight-loss process, which has positive implications for their psychological wellbeing. Nevertheless, it should be noted that, due to the correlational findings of this research, any causal relationships between grief stages and wellbeing may not be inferable, where the “natural” progression of individual’s sight-loss experience may not be fully represented here. Additionally, consideration of the potential confound of comorbidity was absent within this research, where evidence shows that other health conditions including Diabetes and Atherosclerosis, may have significant influences on a visually impaired individual’s quality of life (Steinman & Allen, 2012). As such, consideration of the effects of comorbid health conditions on quality of life and the adaptation process independent of sight-loss is warranted.

When conceptualising disabilities such as visual impairment, there is a propensity for viewing impairment as a personal experience involving loss, requiring a journey through particular stages towards acceptance. However, criticism of the loss phenomenon has arisen, with models moving from the tendency to individualise what may in fact be socially derived issues (Oliver, 1983). Individualised disability models traditionally placed emphasis on impairments as abnormalities, which then trigger psychological distress. Considering impairment as a ‘loss’ needing psychological adjustment (Oliver, 1983). Alternatively, the social model views disability as a social disadvantage, stemming from society’s response to disabled individuals (Barnes, 1992; Thomas, 1999), that is, non-disabled people’s fears and imagination of what it would be like to be disabled (Finkelstein, 1980; Abberley, 1987). The idea of loss of a physical function such as sight becomes individualised when we view lack of acceptance of a potentially limited future as denial. These so-called dysfunctional responses are seen as arising from the impairment itself, without considering that limitations may originate externally, such as from negative social attitudes.

3.1.2 Emotional Responses to Sight-loss

Experiencing Depression. There is an abundance of research examining the negative emotional effects of sight loss including depression, anxiety and frustration (e.g. Brody et al., 2001; Horowitz et al., 2003; Evans, Fletcher, & Wormald, 2007; Bookwala & Lawson, 2011). These negative emotional responses arise when the individual begins to ruminate over their perceived losses (irrespective of whether these are true or not), which leads to feelings of doubt and distress (Tuttle & Tuttle, 2004). Increased risk for depression has been found, particularly amongst older individuals following sight loss (Carabellese et al., 1993; Rovner & Ganguli, 1998; Evans et al., 2007). Depression within this group of individuals may be prolonged (Rovner, Zisselman, & Shmuely-Dulitzki, 1996), and in extreme cases, may increase mortality rates and risk for suicide (De Leo et al., 1999; Lam et al., 2008; Karpa et al., 2009; Christ et al., 2014). One meta-analytic review by Pinquart & Pfeiffer (2011) included 198 studies comparing psychological wellbeing among individuals with and without visual impairment. Impairment-related wellbeing was found to significantly decline within the visually impaired sample, but less so when non-impairment factors were measured. This meta-analysis failed to control for potential confounds such as disparity in study methodology. For example, decline in wellbeing was stronger in studies employing convenience versus probability sampling, since convenience samples typically include extremely distressed individuals seeking help with their impairment-related difficulties. Further, a systematic review by Nyman, Gosney and Victor (2010) demonstrated a clear association of reports of depressive symptoms among older visually impaired individuals. However, no evidence was found regarding an increased occurrence of anxiety, which contrasts with findings from a later cross-sectional study by Van der Aa et al., (2015), which do indicate increased anxiety in older individuals with visual impairment.

Whilst the above evidence does appear to illustrate an increased risk for poor psychological wellbeing (particularly depression) within the context of visual impairment, much of the research describing this relationship has relied on data obtained from older individuals. It should be noted that older individuals without visual impairment may also experience depression, often due to numerous health problems (Barnett et al., 2012). Accordingly, we should be cautious when interpreting depression rates among older visually impaired individuals, since such rates may be similar for older individuals with medical illness (thus again raising the issue of comorbidity). Considering psychopathology amongst young and middle-aged visually impaired individuals, rates of depression and anxiety have been shown to be higher than that of older individuals (Brennan & Cardinali, 2000). A further point that warrants consideration, is the fact that many individuals may experience sub-threshold symptoms that do not fully meet diagnostic criteria (Murray et al., 2012), meaning that empirical evaluations of anxiety and depression among visually impaired individuals may be underestimated in studies that exclusively utilise diagnostic criteria to determine symptomatology. The adverse effect of visual impairment on wellbeing and sub-threshold depressive symptoms has been demonstrated (Branch, Horrowitz, & Carr, 1989; Williams et al., 1998), although studies investigating this association differed regarding methodology, and not all findings supported this relationship after age and physical illness was controlled for (Upton et al., 1998).

Experiencing Anxiety. Anxiety represents another psychological consequence following sight-loss, where the emotional reaction to such a stressful event may depend on numerous factors, e.g. age of onset (Ray et al., 2007), extent of disruption to functioning (Donoyama & Munakata, 2009), and availability of formal and informal support (Bailey & Hall, 1990). Anxiety among visually impaired individuals includes fear of navigating and orientating within unfamiliar environments (Czerwińska, 2015), fear of falling (White et al., 2015), along with placing oneself in challenging situations (such as being in a crowd or eating with others) (Van der Aa et al., 2015). Functional limitations resulting from sight-loss, in combination with the anticipation of an inaccessible environment, result in fear of engagement in activities (Czerwińska, 2015). Given the numerous alterations to life following acquired sight-loss, uncertainty is intrinsic to the individual’s resulting life experience (Brashers et al., 2000; Silverman-Nair & Wade, 2003). Perceived uncertainty occurs when individuals are unable to form cognitive schema relating to disability-oriented situations (Mishel, 1981). Several factors may influence uncertainty around disability, (particularly when the condition is progressive), including the ever-changing prognosis of the condition, availability of sufficient condition-related information, along with the discrepancy between what is expected of the condition, versus what is actually experienced (Babrow, Hines, & Kasch, 2000; Brashers et al., 2000; Elphee, 2008). Anxiety among visually impaired individuals may be triggered by uncertainty of potential further sight deterioration. Individuals with age-related macular degeneration were shown to exhibit greater anxiety following sight-loss in one eye (due to the ensuing fear of sight-loss in the second eye), compared to individuals who lost vision in both eyes (Williams et al., 1998). Likewise, heightened psychological distress (including anxiety) was experienced following milder sight-loss (Kilian et al., 1995; Donoyama & Munakata, 2009). This was attributed to the persistent fear of further sight-loss, whereas those with more severe impairments showed quicker acceptance of their impairment (Donoyama & Munakata, 2009). The response to anxiety of further sight-loss may vary from becoming cautious and avoidant of challenges, to engaging in risky behaviour as an attempt to deny sight limitations (Zaorska, 2015).

Experiencing Anger. Anger represents another frequent emotional response in individuals with disabilities such as sight-loss, (Jorgensen et al., 1996; Schum et al., 2003; Johnson & Carver, 2016). Anger may be related to psychological distress (Renshaw, Blais, & Smith, 2010) along with long-term risk for depression (Stringaris et al., 2009). It may stem from numerous negative condition-related aspects, including ongoing physical problems, inadequate responses from doctors regarding condition aetiology, and unsuccessful treatment attempts (Turk & Salovey, 1996). These responses can be separated either into internalized anger (self-directed), or externalized anger (outwardly directed retaliation) (Livneh & Antonak, 1997). Internalised anger occurs when the individual views themselves as responsible for their condition (Glinder & Compas, 1999; Livneh, 2001). Externalised anger is directed at others, such as medical staff or family members (Fernandez & Turk, 1995; Woodgate, 1998; Eggly & Tzelepis, 2001) or other environmental factors including attitudinal barriers (Joachim & Acorn, 2000; Corrigan, 2000; Millen & Walker, 2000).

The loss of independence in completing everyday tasks, along with increased limitations to mobility imposed by disabilities such as visual impairment may trigger anger, where the individual comes to realise that these limitations are likely to be present for the rest of their life (Lane, 1999). Cognitive-appraisal models of emotion ascribe persistent anger to perceptions of disrespect by others, where the individual wishes to restore this respect (Ortony, Clore, and Collins, 1988; Smedslund, 1993). Alternatively, cognitive-neoassociationistic models attribute persistent anger to enduring annoyance and frustration resulting from repeated physical or psychological cues, including pain or a sense of helplessness (Berkowitz, 1990; Fernandez & Turk, 1995). These two theoretical standpoints propose two essential characteristics of anger. Firstly, cognitive experiences of anger relate to displeasure towards undesirable situations (Ortony et al., 1988). Secondly, an action tendency is the likelihood of anger expression (Frijda, Kuipers, and Schure, 1989). Triggers of anger among individuals with disabilities involving physical limitation are thought to be socially driven, thus supporting cognitive-appraisal models (Ortony et al., 1988; Smedslund, 1993). For example, research with wheelchair users (Cahill & Eggleston, 1994) and individuals with severe physical limitations (Zola, 2022), found that frequent negative social interactions triggered anger in such individuals. These studies also showed that individuals with disabilities were anxious about outwardly expressing their anger, for fear of further social negativity such as being perceived as ungrateful for social support (Zola, 2022). Consistent with prior research, Brown & Turner (2012) demonstrated that physical limitation was associated with increased experience of anger. However, they also found higher levels of anger expression in accordance with increased physical limitation, indicating that physically limited individuals show less emotional restraint, at least where anger is concerned. This has raised the issue over what can be considered as ‘normal’ anger expression among disabled individuals (Brown & Turner, 2012).

3.1.3 Visual Impairment and Fatigue

Fatigue is a complicated concept, where the wide range of definitions makes research comparisons and generalisation difficult. There are two distinct conceptualisations of fatigue, subjective fatigue (i.e., fatigue-related feelings), and performance decrement (i.e., fatigue-related behaviour (Chaudhuri and Behan, 2000; Ackerman, 2011). This section will focus on subjective fatigue, since it is most pertinent to individual experience, which is the main emphasis of the current research. Descriptive terminology for subjective fatigue includes sensations of tiredness, lack of energy, or lack of motivation for task completion (Chaudhuri and Behan, 2000; O’Connor, 2004). Fatigue onset, severity, and duration also tend to be described subjectively (Dittner et al., 2004). There has been much debate whether subjective fatigue is a unidimensional or a multidimensional concept (Michielsen et al., 2004), since there are various dimensions influencing the experience of fatigue (Piper et al., 1998; Stein et al., 1998). One such dimension is the construct of energy, that is, when energy levels are high, we feel more able to complete physical and mental tasks (O’Connor, 2004). This is supported by strong negative correlations found between energy and fatigue (Lee et al., 1991; McNair and Heuchert, 2010). However, in spite of this association, energy and fatigue are shown to be separate constructs, rather than existing on a continuum (Lee et al., 1991;

McNair and Heuchert, 2010). While individuals with high fatigue levels typically report low energy levels, there are situations where this is not the case. For instance, a student who feels mentally fatigued after a challenging exam, may also be energised at the prospect of more enjoyable activities such as socialising with friends.

In the context of chronic illness, fatigue-related symptoms have been associated with negative psychological outcomes, such as decreased levels of wellbeing, quality of life, along with limited levels of employment (Wolf, Hawley, & Wilson, 1996; Weijman et al., 2004; Hewlett et al., 2005; Mustian et al., 2009; Nikolaus et al., 2013). Fatigue has been cited as a common experience for individuals living with visual impairment (Chia et al., 2004; Mojon-Azzi et al., 2008; Berger, 2012; Leissner et al., 2014; Schakel et al., 2018). Similar findings to those observed in chronic illness literature have been observed among visually impaired individuals, with impairment-related fatigue having negative effects on completing everyday tasks, concentration and memorising information, along with requiring extra effort for visual processing (Bruijning et al., 2014; Schakel et al., 2017). Visually impaired individuals experiencing fatigue describe it as a physically and emotionally overwhelming sensation of tiredness and heaviness, that is often uncontrollable and unpredictable in nature (Schakel et al., 2017). The experience of fatigue among visually impaired individuals has been attributed to loss of sight, where research has demonstrated higher levels of fatigue among those experiencing sight-loss compared with fully sighted individuals (Chia et al., 2004; Mojon-Azzi et al., 2008; Schakel et al., 2019). Thus, visual impairment-related fatigue appears to negatively impact on the performance of roles and activities, resulting in negative emotional responses. This is consistent with findings from studies on fatigue among individuals with conditions including cancer (Curt et al., 2000) and stroke survivors (Flinn and Stube, 2010), whereby participants often found it difficult to maintain meaningful activities, causing frustration and distress.

Within the context of visual impairment, fatigue may relate to the challenge of needing increased concentration for processing visual stimuli. Fatigue resulting from sensory processing difficulties in visual impairment may be comparable to that experienced by individuals with hearing impairments (Hornsby et al., 2016). Data obtained from interviews and surveys have revealed that hearing impaired adults experience greater levels of fatigue and stress at work compared to those with normal hearing, where fatigue resulted in reduced work productivity (Morata et al., 2005; Kramer et al., 2006; Bess & Hornsby, 2014). Additionally, research has shown that greater listening effort was demonstrated among hearing impaired individuals compared with controls (Zekveld, Kramer, and Festen 2011; Dwyer, Firszt, and Reeder, 2014). It is proposed that the declination in audibility caused by hearing loss increases the effort required for listening, which in turn creates cognitive drain, manifesting in fatigue (Hétu et al., 1988; McGarrigle et al., 2014; Hornsby, 2013). The use of assistive devices such as hearing aids in noisy environments often causes communication breakdowns, necessitating increased listening effort in order to process and understand communication (Hicks & Tharpe, 2002; McCoy et al., 2005; Gagne et al., 2010; Howard, Munro & Plack, 2010). This process of increased listening effort may continually occur throughout the day, culminating in accumulative stress and fatigue. Ultimately, the individual reaches a 'tipping point', where the effort is no longer manageable and is replaced by a low engagement strategy (Pichora-Fuller, 2003; Hockey, 2013). In visual impairment, fatigue experiences may likewise link to increased effort and intense concentration that is subsequently needed to process information in the absence of sufficient vision. This is consistent with findings by Schakel et al. (2017), who reported an association between high cognitive load and visual perception effort, and visual impairment-related fatigue. Visually impaired adults have emphasised the importance of rehabilitation strategies that aim to reduce fatigue (Bruijning et al., 2014), where the challenges associated with impairment-related fatigue warrants further exploration and prioritisation (Schakel et al., 2018).

3.1.4 The Social Impact of Visual Impairment

Many visual impairment-related challenges are arguably a reflection of attitudinal barriers, rather than actual disability (Akbarian, 2007). Individuals rely strongly on sight-oriented social cues (e.g., gestures and facial expressions) (Ripley & Politzer, 2010; Abateneh et al., 2013; Ajuwon & Ruth Bieber, 2014). The absence of these cues for visually impaired individuals therefore contributes to social awkwardness and embarrassment, leading to reduced social engagement and subsequent isolation (Safir, 1972; Cimarolli & Boerner, 2005; Bhagotra, Sharma, & Raina, 2008). Moreover, additional factors such as physical appearance (e.g., using a cane), may cause visually impaired individuals to “stand out” (Bhuvaneswari et al., 2016). Limited understanding of social consequences of visual impairment from sighted individuals may further lessen social contact (Wang & Boerner, 2008).

In order to fully appreciate the psychosocial impact of visual impairment, it is important to explore the types of relationships and support available to visually impaired individuals, and how they perceive this support. This is important, since the previous research appears to only consider relationship difficulty, without examining the nature of support individuals might be engaged with. Social support generates mutual responsibilities between individuals, whereby they feel appreciated and loved (Zaki, 2008). A distinction is made between social support and social relationships, in that relationships do not exclusively entail social support, unless individuals perceive them as such (Bastani, 2001). Living with a disability such as visual impairment often involves depending on family and friends to help with everyday tasks and provide emotional support (Kahn & Antonucci, 1980), where research has documented both the positive impact of this support, and potential negative impacts that may have adverse influences on wellbeing (Ingersoll-Dayton, Morgan, & Antonucci, 1997; Antonucci, Lansford, & Akiyama, 2001; Rook, 2001). Positive social support further differentiates between actually receiving support and the individual’s perception of support, that is, believing that support is obtainable (Okun & Keith, 1998). Contrastingly, negative social support may include interactions involving insensitivity, interference, and impatience (Ruehlman & Karoly, 1991; Finch et al., 1999), in addition to over-protectiveness by the support provider (Diehl & Willis, 2003). Empirical evidence indicates that positive social support (namely emotional support), is advantageous for wellbeing among individuals with disabilities such as visual impairment (Cohen, 1992; Hobfoll & Vaux, 1993; Gurung, Sarason, & Sarason, 1997). On the other hand, receiving practical support with everyday tasks (as opposed to emotional support) either has no effect, or is negatively associated with wellbeing (Lakey & Lutz, 1996; Kaul & Lakey, 2003). A possible explanation for this association is that receipt of support with everyday tasks (usually involving physical help e.g., guiding), may result in limited reciprocity, where the impaired individual feels unable to return this support, leading to frustration and negative interactions between provider and recipient (Wortman & Conway, 1985; Oxman et al., 1994).

Negative social support, particularly over-protectiveness by support-givers, has been linked with increased depression, and poorer adjustment among individuals with age-related sight loss (Cimarolli, 2002). Furthermore, evidence has also highlighted the issues faced by family and friends of visually impaired individuals, who often behave overprotectively toward the individual (particularly older adults), due to perceived safety concerns (Horowitz et al. 1998). The support-giver may also face uncertainty regarding when, how, and to what extent to help the visually impaired individual, in addition to how capable the individual might already be (Crews & Frey, 1993; Horowitz et al., 1998; Horowitz, Goodman, & Reinhardt, 2004). Implications of receiving support, both positive and negative, could also relate to the life-stage in which the individual is required to rely on support. As with research in other areas of visual impairment, the empirical effect of social support has largely been examined in older adults. Thus, there is limited representation of young or middle-aged visually impaired individuals experiences of positive and negative social support. This is important, since these age groups often encompass significant life achievements, including education, work, partner selection, and having children (Nurmi, 1992). The additional challenges of sight-loss, along with potential alterations in the amount and type of social support, is likely to impact on participation in such achievements, and therefore implicates a need for further research. Moreover, social support research tends to focus on the support-giver, with far less research addressing social support from the perspective of the recipient (e.g., Dunkel-Schetter, 1984; Lehman et al., 1986). Even when recipients are considered, their role in social support is presented as reactive rather than proactive (McColl et al., 1995).

3.1.5 Visual Impairment, Self, and Identity

Disability Identity Development. Irrespective of disability type, previous literature has highlighted the controversy and lack of understanding regarding identity development among disabled individuals, in comparison to other marginalized groups (Patton, Renn, Guido, & Quaye, 2016). Within psychology, identity encompasses the concepts of self, self-expression, and group membership, providing a basis for self-definition through individual characteristics, social roles, and social group affiliation (Oyserman, Elmore, and Smith, 2012). Environmental interactions enable the formation of identity, self-image, and self-esteem (Longres, 2000). Attitudes, beliefs, and emotions resulting from social interactions then determine an individual’s sense of self, identity, and conceptualisation of others who may be seen as ‘similar’ or ‘different’ (Clarke & James, 2003; Pierce, Kostova, & Dirks, 2003). According to Yuker (1988), disabled individuals express a variety of emotions relating to their disability, from resignation and anger, to seeing their disability as a positive opportunity. For many, their disability is ‘part’ of who they are, whilst simultaneously not entirely defining them as a person (Gibson, 2006). According to Linton (1998), the meaning attributed to a disability is shaped by interactions between the disabled individual and society, and the subsequent response to disability is dependent on this meaning. Hence, the disability meaning-making process is important for promoting disability identity formation, since it suggests acceptance of the disability (Dunn & Burcaw, 2013).

Gibson’s (2006) model of disability identity development, identifies three stages, recognising fluidity of disability identity, where there is potential for moving backwards through the stages. Stage one, termed Passive Awareness, is initiated during early life (or disability onset), whereby the individual is lacking in role models or information regarding their disability. As such, individuals in this stage typically avoid disability-related attention, along with social interaction with other disabled individuals (Gibson, 2006). Within stage two, the realisation stage, individuals begin to recognise they have a disability, resulting in negative self-perceptions, along with anxiety relating to others’ perception of them. Since this model was based on disability occurring early in life, Gibson (2006) assumed stage two to occur during adolescence. The third and final stage, acceptance, comprises positive acceptance and understanding of disability, where the individual feels able to socially integrate into an able-bodied society, whilst also socially engaging with others with disabilities, and viewing themselves as a disability ‘activist’. It is important to note that Gibson’s model presents disability identity development within the context of the lifespan developmental stages, which may not be representative of disability acquisition later in life such as that of sight-loss.

Identity and Visual Impairment. Within the ‘transition from sighted to blindness’, Thurston (2010) highlighted individual experiences of altered self-perceptions as being significant within the sight-loss adaptation process. Within this transition, individuals feel progressively able to cope with their sight loss, characterised by increasing acceptance of rehabilitation, rather than trying to conceal the impairment. Similarly, Hayeems et al., (2005) showed that individuals were more likely to disclose their impairment to others, be more readily accepting of assistive aids (e.g., white cane), and to feel more autonomous, when they were more identified as being ‘visually impaired’. While these studies were exclusively focused on adapting to Retinitis Pigmentosa, they nevertheless report on the often unrepresented intrapersonal variable of self-identifying with one’s impairment.

Individuals feel that they matter when they are noticed and cared about by others, in addition to feeling appreciated (Schlossberg, 1989). When individuals with visual impairments are noticed by others, they wish to be seen as ‘normal’ (Ball & Nicolle, 2015). Individuals with disabilities may feel oppressed by a dominant culture that emphasises their inabilities, where this oppression is internalised as a belief that they are “less capable than others” (Charlton, 2006, p. 220). Therefore, individuals often feel motivated to normalise themselves within society despite having a disability (Williams, 1993; Greco, 1993). This normalisation is particularly pertinent within societies that place emphasis on universalist success. As such, performing the ‘sick’ or ‘disabled’ role is disadvantageous to identity development, since individuals may feel restricted from adopting any other roles, and any subsequent approval from performing these roles (Segall, 1976; Shilling, 2002). Therefore, long-term disabilities result in a prolonged inability to foster identity, contributing to a loss of socially oriented personhood, in turn creating a loss of self (Charmaz, 1983).

Visual Impairment and Stigma. Stigmatised individuals (such as those with visual impairments) are frequently characterised as having a perceived negative attribute, and are subsequently viewed as flawed (Goffman, 2005). Thus, the stigmatising process is initiated by a visible sign (stigma), that is seen as deviating from the norm, resulting in devaluation. Nevertheless, simply having a visible difference is not sufficient for creating stigma. Rather, stigma occurs when this visible feature is deemed crucially devaluating in all situations (Goffman, 2005). While the stigmatised individual may become isolated and hindered in social participation, stigma is a dynamic phenomenon – it can be both acquired and lost (Pescolido & Martin, 2007). Relating to visual impairment, stigma is acquired on two levels. Firstly, the visible ‘otherness’ of some visually impaired individuals such as facial defects or uncharacteristic physical movements (termed blindisms), may cause negative emotional reactions from others, including fear and discomfort (Stangor & Crandall, 2008). These negative reactions increase the likelihood for avoidance of social interaction with the impaired individual. Secondly, visual impairment can be identified through other attributes, including use of a white cane or guide dog, which perform the role of identifying someone as visually impaired (Faucett et al., 2017). As such, these devices designed to help the individual are simultaneously full of negative connotations for sighted people, and consequently for the impaired person themselves (Radziewicz-Winnicki & Radziewicz-Winnicki, 2005). Faucett et al., (2017) noted that stigma related to assistive aids such as using a cane poses a threat to the individual's socialisation and lifestyle, since they may fear exposure of their disability, with ensuing social barriers. As a result, individuals may be reluctant, or outright avoidant of using their assistive aids, in turn avoiding unwanted focus on their disability (Hersh, 2015; Faucett et al., 2017). Nevertheless, the increasing popularity of more mainstream wearable technology such as smart glasses and watches, which also contain assistive features, may offer a new self-expression of the user's identity, that is free from self-consciousness and stigma (Shinohara & Wobbrock, 2016).

Adapting to Visual Impairment – Influence of Identity and Behaviour Change. Bringing together the above literature concerning the emotional and psychosocial consequences of sight-loss, it is apparent that adaptation is dynamic, consisting of numerous processes (e.g., Taylor, 1983). Utilising an in-depth qualitative approach, Hayeems et al., (2005) constructed a model of sight-loss adaptation. Initially, the process of receiving a sight-loss diagnosis, in combination with the individual's emotional response to their diagnosis, creates emotional distress. Following this, individuals attempt to understand their impairment and gain meaning from it, attributing causes including divine intervention or genetic factors (Hayeems et al., 2005). Overcoming impairment-related functional challenges is motivated by the individual's desire to alleviate their emotional distress, and is dependent on their ability to resolve their identity (i.e., 'sighted' versus 'visually impaired'). Identity resolution may involve changing behaviours that are deeply ingrained, a process characterised by five steps (e.g., Prochaska & DiClemente, 1983). During the first 'precontemplation' stage, individuals are described as not needing to change, not acknowledging the need to change, and not feeling ready to change. Within the second ‘contemplation’ stage, individuals begin to reflect on the discrepancy between being sighted versus visually impaired, where the negative aspects of change outweigh the potential positives (Hayeems et al., 2005). The third ‘preparation’ stage is characterised by a shift in the cost-benefit ratio, whereby individuals begin to prepare for behaviour change such as not driving or using a cane. The fourth ‘action’ stage is initiated when individuals begin to actually implement their new behaviours, using their assistive aids in public and ‘outing’ themselves as visually impaired. After coming ‘out’, individuals start to experience the benefits of being more independent, as opposed to fearing social negativity, which reinforces the maintenance of new behaviours (Hayeems et al., 2005). The final ‘adjustment’ stage is achieved when individuals self-identify as visually impaired, disclose their impairment to others, use adaptive aids, and engage in behaviours which promote their independence (Hayeems et al., 2005). Hayeems’ model is consistent with research by Zaborowski (1997), who proposed that adapting to visual impairment was contingent on recognising that being ‘blind’ was still compatible with being independent. Therefore, the work by Hayeems et al., (2005) illustrates how adaptation to sight-loss links to behaviour change via identity. It should be noted that the initial phase of this adaptation model refers to the formal diagnosis of visual impairment. However, the pre-diagnostic experiences as a ‘sighted’ individual undeniably impacts on the adaptation process, since the model describes transition from a sighted to visually impaired identity.

3.1.6 The Present Research

Within the concluding section of the book ‘Blindness and early childhood development’, Warren (1984) voiced his dissatisfaction relating to the failure of past visual impairment researchers to acknowledge the heterogeneity of the visually impaired population. In order to fully appreciate the psychology of sight-loss, it is vital to first appreciate the idiosyncratic nature of the individual as they experience and adapt to sight-loss. In recent years, researchers within psychology have made steps towards placing more emphasis on individual differences. However, there remains a precedence for mainstreaming this knowledge, i.e., for increasing public awareness and education. Whilst several studies have investigated individual emotional and psychosocial responses to sight-loss, there is a scarcity of research examining sight-loss as a holistic psychological process, and how individuals experience the entirety of their sight-loss. This seems surprising, since sight-loss often involves changes within the impairment itself, and subsequently alterations to the individual's psychosocial context. As a result, the psychological consequences of visual impairment have been represented either as stationary, or as stage-oriented phenomena, which do not capture the fluidity and diversity of sight-loss responses. Although quantitative research has provided information regarding important psychological constructs, there remains limited information regarding the intricacy of reasons for adopting a particular psychological response. For instance, none of the literature regarding the social impact of sight-loss explored the idea of disclosing visual impairment to sighted individuals, which would in turn impact on both the receipt and perception of social support. Additionally, much of the sight-loss literature focuses on the negative psychological impact, which is therefore not representative of the potential strength-promoting aspects that may exist in tandem with, or even grow from such negative responses. Moreover, sight-loss rehabilitation services such as those offering support with orientation and mobility tend to focus on development of physical skills, rather than psychological wellbeing (Baskett, 2005). Since impairment-related anxiety and vulnerability may become barriers to engagement with rehabilitation training (Seybold, 2005), a more in-depth comprehension of such barriers would enhance acknowledgement of psychological challenges of sight-loss, alongside the physical. Since there is no universal way to react to sight-loss, capturing unique experience is relevant for understanding the individual process of adaptation (Lee & Brennan, 2002; Stanford et al., 2009; Murray, McKay, & Nieuwoudt, 2010).

The present study aimed to generate an in-depth understanding of the complexity of living with sight-loss. There was particular focus on emotionally salient aspects of sight-loss, such as fear of future sight deterioration, fatigue, and any strength-promoting outcomes, as well as the social consequences of sight-loss, along with its impact on identity. A qualitative methodology was adopted to represent individual lived experience (Elliott, Fischer, and Rennie, 1999). Specifically, interpretative phenomenological analysis (IPA) was utilised, which provides a comprehensive conceptualisation of how individuals make sense of major life experiences (Smith, Flowers, and Larkin, 2009). A qualitative study may offer greater insights into how visually impaired individuals who have experienced sight-loss provide a sense of meaning to their impairment within its real-life context, from initial diagnosis to future implications. This study also aimed to provide practical implications and relevance within visual impairment research, particularly regarding the immediate and everyday requirements of visually impaired individuals.

3.2 Method

3.2.1 Participants

This study utilised a qualitative research design, involving experiential accounts from 10 individuals living registered as “sight impaired” (previously termed “partially sighted”) and those registered as “severely sight impaired” (previously termed “registered blind”). Certification of both sight impairment and severe sight impairment typically occurs following a full vision assessment conducted by a consultant ophthalmologist, who then determines eligibility for certification by completing the Certificate of Vision Impairment (CVI). Eligibility is determined by a combination of visual performance on both visual acuity and field of vision.

Certification of sight impairment generally depends on meeting any, several, or all of the categories below, whilst wearing any refractive aids (e.g. glasses or contact lenses):

- Visual acuity of 3/60 to 6/60 with a full field of vision.
- Visual acuity of up to 6/24 with a moderate reduction of field of vision or with a central part of vision that is cloudy or blurry.
- Visual acuity of 6/18 or even better if a large part of your field of vision, for example a whole half of your vision, is missing or a lot of your peripheral vision is missing.

Certification of severe sight impairment generally depends on meeting the following criteria:

- Visual acuity of less than 3/60 with a full visual field.
- Visual acuity between 3/60 and 6/60 with a severe reduction of field of vision, e.g. tunnel vision.

- Visual acuity of 6/60 or above but with a significantly reduced field of vision, particularly if a lot of sight is absent within the lower part of the field.

"Recent" diagnosis of visual impairment was quantified as including individuals registered as sight impaired or severely sight impaired within 1 year prior to their involvement in this study. Since the results of this study were analysed using IPA, a small, purposive sample of participants was used, until saturation of themes occurred (Sandelowski, 1995; Hammersley, 2015). A variety of visual impairments were included within the sample, since the aim of the study was not to investigate the effect of one particular impairment, but rather the personal and unique experience of living with visual impairment. Demographic/individual characteristics of participants are shown in Table 1 below (note that any names/other identifiers have been replaced with pseudonyms to ensure participant anonymity).

Table 1 Study 1 Participant Demographics

Participant number	Pseudonym	Gender	Age	Diagnosis	CVI registration
1	Kate	Female	57	Optic atrophy	Sight impaired
2	Debbie	Female	49	Bardot-Biedl syndrome	Severely sight impaired
3	Adam	Male	64	Diabetic maculopathy	Severely sight impaired
4	Mary	Female	89	Vitelliform macular degeneration	Sight impaired
5	Angela	Female	78	Age-related macular degeneration (AMD)	Sight impaired
6	John	Male	72	Retinal dystrophy	Sight impaired
7	James	Male	66	Usher's syndrome	Severely sight impaired
8	Betty	Female	95	AMD	Sight impaired
9	Sarah	Female	72	Glaucoma/ AMD	Severely sight impaired
10	Nadine	Female	59	Usher's Syndrome	Severely sight impaired

3.2.2 Materials

Given the unique nature of this research, special considerations were warranted regarding presenting the study information, along with participant consent giving. Due to the fact that all participants were visually impaired, presentation of written information (e.g. consent forms etc) may have proved problematic both in terms of participants being unable to read the information, and being unable to give written informed consent. Moreover, inclusion of “recent” diagnosis of visual impairments meant that participants may not yet have sufficiently learned alternative methods of written communication (e.g. Braille) with which to give written consent. In solution to this, participants were given the option of having all written information read aloud to them, as well as receiving the information in an accessible format of their preference (e.g. large print or braille). In addition to participant information sheet, informed consent and debriefing forms (see appendix 1, 2, and 3), semi-structured interviews (e.g. Kvale & Brinkmann, 2009) were employed to examine the psychological experience of visual impairment. Use of semi-structured interviews ensured neutrality of questions, thereby enabling flexibility of responses. Accordingly, through discussion of personal experience, interviews aimed to discover how each participant perceived the psychosocial impact of their visual impairment, and how this might relate to several psychological experiences and processes, including identity perceptions and socialisation. Interviews comprised nine open-ended questions, ranging from a general enquiry into the nature of participant’s visual impairment and its psychosocial effects (encompassing issues such as emotional impact and fatigue), to specific questions relating to the social impact of visual impairment, and exploration of identity perceptions following impairment diagnosis (see appendix 4 for full interview schedule).

3.2.3 Procedure

Participant recruitment involved collaboration with a Royal National Institute for the Blind (RNIB) Eye Clinic Liaison Officer (ECLO) based within the ophthalmology department at Singleton hospital in Swansea. ECLOs work directly with visually impaired individuals and their families following their diagnosis. They provide an early intervention service that offers information and advice (both practical and emotional), which includes signposting and referral to other local support services (Llewellyn et al., 2019). Thus, ECLOs facilitate a link for the individual, connecting them with healthcare, social care and the voluntary sector (Menon et al., 2020).

Potential participants who met the study inclusion criteria were identified via their referral to the ECLO following certification of visual impairment (CVI). Once identified, the ECLO made initial contact with potential participants, asking if they were interested in taking part. Upon affirmation of interest in the study, individuals were provided with a copy of the participant information sheet. If individuals were further interested in taking part in the study, they were given the opportunity to be contacted by the researcher through a method of their choice (e.g. by phone or email). Participant contact details, along with basic information such as age and diagnosed eye condition were then sent to the researcher in a password-protected document by the ECLO. Upon making initial contact with potential participants, they were given the opportunity to discuss the study further with the researcher, and, upon further affirmation of their wish to participate in the interviews, preparation for the interview was made. It was at this point that two individuals declined to take part in the interview process, due to not feeling ‘ready’ to talk about their experiences, along with concerns for their emotional wellbeing following the interview. In an attempt to address this concern, participants were given several options regarding interview setting:

- Conducting the interview in a quiet room within the Wellbeing Centre on the Swansea University campus, where participants could be met somewhere familiar by a sighted guide (e.g. at the Singleton hospital eye clinic) prior to the study to assist with mobility to the interview venue
- Conducting the interview at the participant’s home, where they have felt more comfortable and less anxious within familiar surroundings
- Conducting the interview over the telephone or via Skype

Prior to interview commencement, participants were issued with a copy of the information sheet and informed consent form, which were read out to them. Then verbal consent was given; this was audio-recorded at the start of each interview. Each interview started with an initial general dialogue about visual impairment-related experiences, covering several areas including practical and emotional impacts, coping, and experience of fatigue. The interview then proceeded to a discussion of more specific issues relating to sight-loss, such as social impact (e.g., social reaction to sight-loss and receipt of social support), identity perceptions, and any positive impacts of living with sight-loss. Following discussion of the scheduled interview topics, participants were given the opportunity to “add” any thoughts/feelings regarding their experiences. This allowed participants to freely voice thoughts that were unguided by the researcher, whilst presenting them with a chance to express anything missed during the interview. Afterwards, an informal "chat" with the researcher lasting around five minutes, gave the opportunity for a debrief, and enabled participants to address any questions or concerns. All interviews were audio-recorded, transcribed verbatim, and analysed using IPA.

3.3 Results

3.3.1 Analysis

IPA analysis is interpretative, since emphasis is placed on the "double hermeneutic". The researcher is attempting to interpret participant responses, whilst the participants themselves are simultaneously trying to make sense of their own experiences (Smith & Osborn, 2003; Smith et al., 2009). In keeping with the idiographic commitment in IPA, an initial detailed individual analysis was conducted on each interview (e.g., Smith et al., 2009). Transcripts were re-read repeatedly, allowing for an in-depth familiarisation with the data. Preliminary comments relating to description of initial thoughts on content, linguistics, and abstract/probing remarks were noted (Smith et al., 2009). Following the annotation, emergent themes encompassing the analysis were noted, reducing the volume of information whilst preserving analysis intricacy (Smith et al., 2009). Subsequent connections between themes were collectively explored for all transcripts, and theme repetition (in addition to similarities and differences between themes) were examined. This culminated in identification of superordinate themes, which were further subdivided into related themes and subthemes (Smith et al., 2009). In terms of sustaining quality assurance, independent supervisory examinations of transcripts were carried out, and analytical specifics were discussed with a supervisor, thus maintaining accord with "commitment/rigor" and "transparency/coherence" principles (Elliott et al., 1999; Yardley, 2000).

IPA analysis yielded five superordinate themes, subdivided into thirteen related themes and thirty-three subthemes. These are presented in table 2.

Table 2 – Study 1 Emergent themes

Superordinate Theme	Theme	Sub-theme
Response to crisis	Receiving the diagnosis	Lack of information – feeling “in the dark”
		Denial – “this isn’t happening to me”
Long-term losses and fears	Experience of Loss	Wish versus reality “as much as I like to think I could, I can’t”
		Loss of meaningful activity
		Fear of further sight-loss
	Effort and exhaustion	Physical and psychological experiences – “you just shut down”
		Extra mental effort; “I have to stop and think”
Social impact of sight-loss	The struggles of social interaction	Fear of social awkwardness/rejection; “I don’t want to offend people”
		Desire to connect with other visually impaired individuals versus feeling “segregated”
	Frustration of receipt of social support	Having to rely on others – “you kind of fit in around everybody else”
	Disclosing visual impairment	Being “well known” versus “private”
	Reaction of family and friends to sight-loss	Loss of friendships; “they hide away”
		Others reluctance to accept sight-loss – “they didn’t want to talk about it”
Sight-loss and identity	Unpacking “disability identity”	“Illness” identity versus “disability” identity
		‘Disability’ is a label; “it’s the term we use”
	The visibility visual impairment	The ‘invisible disability’; “nobody sees you”
		Cane as a ‘symbol’ of visual impairment
Rebuilding life after sight-loss	The road to acceptance	Attempting to gain meaning- “why have I had it?”
		What is acceptance? – Objective or subjective?
	Enlightenment through adversity	Increased empathy; “I have a more enlightened view”
		Advocating for visual impairment – “it made me more focussed on visual impairment rights and support”

3.3.2 Response to crisis

Receiving the Diagnosis.

Lack of Information – Feeling "In the Dark." Receiving a diagnosis of visual impairment was perceived as extremely challenging. The lack of information available from medical professionals represented a complex experience shared by many participants throughout their diagnosis process. Nadine, who had to wait a long time before receiving a definitive diagnosis, had frequently attempted to express her assertion that something was "wrong" through repeated visits to her optician and to hospital. There was a strong impression of feeling alone and abandoned, with a distinct lack of perceived support:

> Nadine: "going through my head was that I was going to go blind … There was no one to help! … So I just had to stay in the queue and wait … I have no answers, they haven't either!"

This sense of abandonment triggered anxiety and fear of further sight-loss, where "stay" and "wait" signified feelings of passivity, as opposed to feeling able to actively address the impairment. This forced passivity was further reinforced by having to rely on others (i.e., medical professionals) for answers, despite feeling they were incompetent, culminating in perceived loss of control. Despite having a definitive diagnosis, fear and negative perceptions regarding sight-loss were not allayed by medical professionals, and therefore did not alleviate anxiety related to further sight-loss. The fact that there was little existing research into Nadine's eye condition was equated to a lack of availability of support. This perpetuated her sense of abandonment and having to deal with her impairment alone (at least from a medical perspective).

Like Nadine, both Sarah and Peter felt abandoned and dismissed by their doctors during their diagnosis. Sarah used the phrase "I was in the dark", hinting at uncertainty resulting from not being given sufficient medical information regarding her condition. Peter stated that doctors "showed you the door", which implied a more metaphorical perceived abandonment. The "door" represented feelings of being shut out from receipt of medical information and support, thereby increasing the sense of having to "face the challenges" alone.

Denial – "This Isn't Happening to Me." Denial was additionally cited as a recurrent issue during the initial phase of experiencing visual impairment. For Mary, denial was emotionally driven, triggered by the shock of being told about her visual impairment. Repetition of "no" asserted her recurrent negation, highlighting her denial and unwillingness to accept her impairment:

> Mary: "I was shocked, I said "no…" and there it is, "No!" It came out like that … "No," But talking to my optician … she said "you can get a lot of help", … So … last when I was there with this consultant … I said "yes, that would be helpful to me."

However, the extent of Mary's denial altered following further discussion with her optician. Her eventual decision to accept her visual impairment registration was influenced by the implication of receiving practical help to manage her sight-loss. Hence, there was a cost-benefit ratio of sight-loss registration, whereby maintaining a view of herself as a sighted individual was weighed up against the potential receipt of support following registration. For Sarah, the initial phases of diagnosis involved suppression of potentially painful memories and emotions associated with losing her sight:

> Sarah: "I just think I sort of blocked it out … life went on but it was just like … this isn't happening to me"

This implied a self-protective mechanism, in that being unable to recall such negative memories and emotions decreased the likelihood of any residual negative psychological impact, e.g., future re-living those memories/emotions. The statement that "life went on" implied a need to maintain a sense of remaining normality even after the occurrence of a significant life event such as sight-loss, but also presented strong elements of denial as supported by "this isn't happening to me". As such, carrying on as normal represented the ensuing behaviour resulting from denial of the effects of the impairment. Sarah's denial directly related to attempts to block out the reality of her impairment, in order to try and alleviate subsequent negative emotions. Contrastingly, Mary's denial was triggered by shock, although arguably her denial also served the purpose of allowing her to distance from further negative emotions. Unlike Sarah, denial on Mary's part was concerned with the process of being registered as having a visual impairment, rather than denying the impairment itself. This might have represented an attempt to psychologically distance from the reality of her impairment, by focusing her efforts on denying something placed on her by someone else (i.e., being registered was equated with being labelled as visually impaired).

3.3.3 Long-term Losses and Fears

Experiencing Loss.

Wish Versus Reality – "As Much as I Like to Think I Could, I Can't." Within their experience of loss, participants referenced a discrepancy between 'wish versus reality' i.e., things they still wanted to achieve versus their actual physical capability following sight-loss. Kate made comparisons between her past versus present anxiety levels relating to task difficulty. She viewed herself as having had a greater sense of independence, freedom and choice in the past, which had been lost following her impairment.

> Kate: "when I didn't have all of these things to worry about, I would just take off and do what I want to do when I wanted to do it … Now I've got to double think, … I can't go there on my own. As much as I like to think I could, I can't."

Physical freedom (such as being able to travel independently) was a promoter of psychological freedom, in the form of allowing the pursuit of hobbies and valued activities. However, sight-loss obstructed independence, where physical restriction (due to practical constraints) led to feelings of psychological restriction. This psychological restriction manifested in anxiety, intensifying negative appraisal of physical challenges and perpetuating perceived inabilities. The wish to complete tasks no longer matched the reality of physical capability following sight-loss. Kate highlighted a discrepancy between her wish to remain independent (i.e., what she wanted to do), versus the reality of her present ability (i.e., what she felt physically able to do). Adam also compared the reality of his life with sight-loss to that prior to his impairment, where he presently perceived himself as less functional, less capable, and subsequently less independent:

> Adam: "You are trying to do things and you know you shouldn't be doing it and you can't do it but you still wanna do it … my wife gets annoyed with me … she'll say "let me do that now" and I'll be like "no go away!""

However, rather than this comparison being anxiety-inducing, it provoked frustration, which in turn prompted attempts to remain independent. This produced a cycle of self-directed frustration when tasks were challenging. Negative language such as "shouldn't" and "can't", highlighted current wishes for greater physical capability. Maintenance of the wish to complete visual tasks and remain independent, resulted in reluctance to receive help from others with tasks that were achievable prior to sight-loss. This incited frustration directed at others, which negatively affected relationships, since frustration was then reciprocated.

Loss of Meaningful Activities. In terms of experiencing 'loss of meaningful activities’, all participants reported a significant reduction in their ability to engage in previously meaningful or enjoyable activities following their sight-loss. For example, the loss of driving ability became a major barrier to personal independence, as described by Angela:

> Angela: “they took my driving licence off me and that’s been the biggest handicap I have had … the time I waste having to travel on public transport”

“They” suggested that others had made the decision for Angela to stop driving, thus creating a sense of loss regarding her own choices and decisions. There was an underlying sense of blaming others for taking away her driving licence. This possibly allowed the justification of outwardly projecting her frustration at not being able to drive toward others, rather than directing this frustration inwardly (i.e., towards her impairment). Hence blaming others was self-protective in displacing her frustration. Loss of driving ability was equated with increased recognition of her own perceived disability, alluding to her sense of restriction and lack of freedom and independence. This was further highlighted through her comparison between use of public transport and driving, where the “waste” of time spent on public transport triggered frustration resulting from an additional perceived loss (i.e., loss of time that would otherwise have been preserved had she still been able to drive).

Fear of Further Sight-loss. "Fear of further sight-loss’ was a significant issue for participants. There was a combination of depression related to the uncertainty of potential deterioration of sight, along with anxiety and attempts to imagine a future with less sight:

> Nadine: “I have spent many a night sitting up in bed crying … I often think … will I be able to see in the morning? … this time next year … I might be blind … And they can only guarantee me two percent that I won’t be … how will I cope? And who would look after me?”

Nadine’s future predictions induced further worry relating to how future sight-loss might negatively impact on her. Her repeated questions demonstrated an ongoing sense of uncertainty, perpetuating depression and fear of future negative outcomes. These negative emotions were intensified by her perceived certainty of future sight-loss in the absence of medical reassurance to the contrary. Her fear of future sight-loss additionally related to the potential suddenness of its onset i.e., "will I be able to see in the morning?". Her interpretation of this rapid deterioration was that attempts to adapt to this significant loss would be unsuccessful, hence the anxiety surrounding "how will I cope?". Like Nadine, Sarah also experienced uncertainty prompted by her future-related thoughts about the instability of her sight.

> Sarah: "you just don't know what's around the corner … so I am very, very cautious … and then the minute you see any changes you just take off to the hospital"

Sarah's fear of further sight-loss was deepened by warnings from medical professionals, where her trust in their opinion was reflected in her cautious behaviour. Her caution manifested itself in engagement in health-related and risk-reducing behaviours, in addition to heightened symptom awareness "the minute you see any changes". As such, Sarah's fear of further sight-loss prompted her into taking active steps into reducing the likelihood of this (which in turn reduced her anxiety). This appeared in contrast to the sense of helplessness and passive acceptance of the perceived certainty of sight-loss by Nadine.

Effort and Exhaustion.

Physical and Psychological Experiences – "You Just Shut Down."

Fatigue resulting from sight-loss was cited as a major barrier to optimal physical and psychological functioning, and was experienced by many participants as a combination of both physical and psychological sensations. Fatigue was viewed as being linked to frustration of trying to complete tasks. Thus, fatigue was both triggered, and triggered by negative emotions:

> Kate: "I can get more frustrated with something … So I don't feel like myself … and that can feel scary … I get totally knocked out, just wanna stop, … you can't even relax, you just shut down."

Not only did Kate express her experience of fatigue via verbal description, but her use of short, clipped phrases, separated by punctuation or pauses also captured the physical and psychological sense of exhaustion she was trying to convey. The struggle to complete tasks (initial fatigue) resulted in the employment of extra mental effort. This caused further fatigue, generating stress and frustration, prompting emotional fatigue. Kate expressed her negative perception of these negative feelings, indicating her possible desire to consciously ‘fight back’ against the negative psychological aspects of fatigue. However, this may in itself have perpetuated her fatigue, since she felt unable to accept these feelings, and was therefore struggling against psychological (as well as physical) challenges. She also alluded to the concept of fatigue negatively affecting her identity “I don’t feel like myself”. The term “myself” indicated someone who could previously do things without becoming frustrated, stressed and fatigued. Thus, the fatigue sensations were rejected as not being part of “myself”. Therefore, this rejection was arguably self-protective. However, not feeling “myself” resulted in anxiety, where fatigue produced a loss of identity with no new satisfactory replacement. The physical element of fatigue prevented relaxation, triggering physical exhaustion, thereby increasing stress levels and inducing a more psychological sensation of fatigue.

Extra effort – “I Have to Stop and Think.” Throughout Nadine’s extract, her experience of fatigue related to the extra mental effort required for task completion, in light of the increased task difficulty resulting from visual impairment:

> Nadine: “everything is harder … when everything is moved … I am lost. … and then you have to stop and think “Am I going to be able to do this?” And then I could end up thinking and talking myself out of it … it makes me knackered! Thinking about it … even more than doing it!”

Task difficulty and extra mental effort was also linked to familiarity of surroundings, i.e., the need to maintain a stable physical and mental map. This created a greater sense of personal control over surroundings, as well as decreasing perceived task difficulty. However, disruption to this mental visualisation of surroundings caused confusion and loss of control, intensifying mental effort and subsequent fatigue. Greater concentration was required to locate objects and regain mastery over completion of tasks, without sufficient visual input in place of a mental map. Feeling “lost” hinted at a double meaning, as it implied being physically lost, but also psychologically lost in the absence of visual information to rectify confusion. Anticipatory anxiety of completing tasks was seen as a greater influence on fatigue compared to actually carrying out the task. This implicated the extra mental effort required for building up intentions to achieve goals “will I be able to do this?”. Questioning of ability produced a tendency to avoid tasks, and in turn the avoidance of potential disappointment if tasks proved challenging. Conversely, this strategy in itself perpetuated anxiety surrounding task completion, since negative perceptions were not being challenged.

3.3.4 Social Impact of Sight-loss

The Struggles of Social Interaction.

Fear of Social Awkwardness/Rejection – "I Don't Want To Offend People." Several participants reported feelings of anxiety relating to the potential for social awkwardness or rejection resulting from their impairments. Mary's inability to recognise others resulted in social embarrassment relating to not knowing who she was speaking to. This created social uncertainty, and the fear of others' social perceptions that she was "ignoring" them:

> Mary: "I don't want to ups- offend people … by ignoring them … I don't want people to think that I am ignoring them if I don't greet them … that's my problem, feeling embarrassed that I haven't acknowledged them before they come up to me."

The fear of accidently ignoring others increased social anxiety. The quote also illustrated self-criticism i.e., blaming herself for "ignoring" others. Self criticism further implicated fear of social rejection, since being seen as 'ignorant' might deter others from wanting to socialise with her. Fear of negative social consequences also linked to a sense of social responsibility, i.e., feeling obligated to acknowledge and greet others "before they come up to me". Failure to do this as a result of visual impairment led to feelings of social inadequacy. Sarah also described being unable to recognise familiar faces in social situations, resulting in anxiety regarding being perceived as ignorant:

> Sarah: "people will say, "I saw you in Tesco's and you didn't speak to me!" … a neighbour shouted at me …Because she told me I ignored her, well I didn't see her … but she didn't understand"

Like Mary, Sarah engaged in self-blame, feeling guilty for her inability to recognise others, fearing subsequent criticism and anger. However, unlike Mary, for whom social rejection was an anticipatory outcome, Sarah described having experienced social conflict resulting from her visual impairment. There was an interesting paradox relating to the idea of social recognition, whereby sighted individuals may also experience difficulty in understanding social challenges faced by visually impaired individuals. Therefore, perceived social “ignorance” may exist on both sides, since sighted individuals make negative assumptions based on the visually impaired individual’s inability to socially engage, and the visually impaired individual socially misinterprets others due to their visual impairment.

Desire to Connect with Other Visually Impaired Individuals Versus Feeling “Segregated.” Many participants expressed a desire to connect with others with visual impairment, although this desire was contrasted against feelings of social segregation. For example, joining visual impairment support groups was perceived as beneficial in terms of acceptance of one’s own impairment. Sarah described creating close and meaningful relationships through social connectedness to others with visual impairment, with a strong sense of gratitude to them for helping her adapt to her own sight-loss:

> Sarah “she had macular degeneration! … I owe her a lot … she got me going really … Then I joined the RNIB as a volunteer. And I just never ever looked back … It just became a different life for me … This is my life … I just learned so much … which I now share with others! … Now, if I see a white cane, I talk to the person!”

Seeing others living independently with sight-loss prompted Sarah to regain her own sense of independence. Becoming an RNIB volunteer gave a sense of purpose in gaining a positive outlook from sight-loss. The phrase “this is my life” implied acceptance and ownership of visual impairment, which was achieved through gaining knowledge about available support for sight-loss, and being able to share this knowledge as a volunteer. As such, connecting with other visually impaired individuals was a rewarding experience, due to the ability to reciprocate past valuable support, thereby balancing out the sense of gratitude. Sarah also described an increased awareness of others’ visual impairment as heightened by her own impairment. Visual impairment became a commonality that promoted social interaction with others, with a strengthened connection through shared perceived similarities.

Conversely, despite the positive experiences of socially connecting with other visually impaired individuals, such connections were sometimes tinged with a sense of social segregation. Kate voiced her negative perceptions of interacting with disability exclusive social groups, alluding to a paradoxical lack of “inclusiveness”:

> Kate: “you get invited to groups …they are all visually impaired … where is the inclusiveness in that? … you then get segregated and you get “sectioned” off … “you are visually impaired, you stand over there, and do that, and do it this way,”

Kate described feeling “segregated” and “sectioned off”, possibly constituting a form of social isolation in feeling that she was only able to be part of social groups relating to her disability. The underlying emotional response was frustration, directed at a society that appears to socially pigeonhole people based on their abilities/disabilities. The phrase “stand over there” suggested further feelings of being cut off from others, where “over there” illustrated social distance from others with whom she wished to connect with. Being told what to do indicated loss of freedom and personal choice. This in turn suggested underlying anxiety relating to the negative social and attitudinal implication of being associated with a disability, along with fear of social rejection by sighted individuals.

Frustrations at Receiving Social Support.

Having to Rely on Others – “You Kind of Fit in Around Everybody Else.” Within the theme of ‘receipt of social support’, several participants took a negative view of having to rely on others for support following their visual impairment, which resulted in feelings of having lost their sense of control and independence. This was illustrated by both Nadine and Kate:

> Nadine: “it is not down to me, it will depend if my husband can take a day off, if my son is about …not being able to live my life the way I want! … I am restricted … you kind of fit in around everybody else rather than them fitting in around you”

> Kate: “I haven’t got … I feel like I haven’t got the freedom and the independence that I had … people say if you have PAs (Personal Assistants) and you have carers … that it’s to help and assist you, but it doesn’t offer that freedom of choice … it has to be a co-operation”

The phrase “it is not down to me” demonstrated how social support was perceived as being dependent on the availability of others to give support, with feelings of obligation to work around others, putting personal needs on hold. This alluded to an underlying feeling of inferiority in comparison to support-givers, in having to wait until they were able to help, i.e., they possessed greater control. Comparison to support-givers created a sense of loss regarding personal control and independence “it is not down to me”. The emotive side of this phrase indicated helplessness and frustration, which was both self-directed (i.e., the impairment was blamed for taking away independence), and directed at support-givers for not granting a certain level of control by ‘fitting’ around personal needs. This implied envy directed at support-givers, i.e., they had the perceived freedom to independently do what they want when they want. This contrasted against feelings of being “restricted” (both by physical limitations and by having to “fit” around support-givers). Social support was also equated with being unable to “live the way you want to live”, thereby further illustrating a diminished sense of control over life which was now dictated by others. Kate altered her statement of “I haven’t got” to “I feel like I haven’t got”. This created a transition from concrete loss, to a more self-perceptive and personal loss. Kate was attempting to rationalise her feelings of loss as being more abstract “I feel”, thereby denying the reality-implying phrase of “I haven’t got”. She recognised that others might view social support as helpful, however this did not match her own negative perception of support. Control was seen as being limited to compromising with the person giving the support. The unspoken implication was further lack of choice, since failure to compromise might result in greater restrictions to “freedom of choice”. Unlike Nadine, who described receiving support from family members (who were emotionally close), Kate’s support-givers were described as “PA’s” and “carers”. Using these terms may have increase negative feelings towards receiving support, where potential negative connotations of “carer” may increasingly remind her of her own physical limitations, thus increasing her emotional distress at receiving support.

Disclosing Visual Impairment.

Being “Well-known” Versus “Private.” Interestingly, much of the discussion surrounding the social impact of visual impairment centred around participants being able to disclose their visual impairment to others. Specifically, a distinction was made between the concepts of being “well-known” versus “private” in terms of others knowing about their impairment. Adam’s assertions of being well-known provided both self-validation and a sense of his own importance and value within his social group:

> Adam: “They all know me … and I’ll put a call out and somebody will come back to me, … So once people get to know you, the support is always there … they

> all make allowances for you, they know you … I don't like asking for help. It doesn't come natural to me at all".

The phrase "they all know me" indicated receipt of social recognition by others, thereby increasing the perceived likelihood of receiving support if needed. "Somebody will come back to me"; here use of the word "will" denoted certainty of receiving help. Possibly this reinforced help-seeking behaviour, i.e., certainty of a positive response increased social confidence in asking for help. Being well-known also enhanced the experience of socialisation, in addition to receiving support for visual impairment. Interestingly, no explicit mention of visual impairment was made within statements about being well-known. Instead of saying "they know about my impairment", Adam stated "they all know me", referring to himself as a whole, rather than specific aspects such as disability. This suggested that support was provided on the basis of friendship, as opposed to helping someone who is visually impaired (which may have negative connotations such as perceiving pity from others). The statement "I don't like asking for help" tied in with the idea of wanting to be well-known, i.e., there was no need to disclose visual impairment or ask for help if others were already aware of the visual impairment.

Whilst some participants had a clear preference for being well-known, others expressed the need for privacy. For Nadine, the idea of remaining private represented a form of self-protection, affording a greater sense of control through actively choosing not to disclose anything personal to strangers:

> Nadine: "Nobody knows nothing about me … I suppose being equal … I had a communicator guide for a few months and for some weird reason I found it an invasion of my privacy…I am the main speaker for "Deaf Blind UK" … They all know about me but they are all people like you and me! As for … say two people across the road … it's none of their business"

Visual impairment intensified the desire for privacy, and was viewed as personal and not disclosable to others. Being private was equated with a sense of social equality, where disclosing visual impairment to others might imbalance both perceived control and social equality. If others knew about the impairment, this could trigger anxiety related to being seen as being socially unequal. This relates back to social support, as support specific to visual impairment was viewed as "an invasion of my privacy". Disclosure was thus perceived as a social and emotional threat. Nadine made a comparison to disclosure of her impairment to others with similar impairments. The statement that “they are all like you and me” suggested perceived relatability (e.g., sharing the same impairment). This fostered improved social equality, therefore promoting openness to others about her impairment.

Reactions of Family and Friends to Sight-loss.

Loss of Friendships – “They Hide Away.” Many participants described how others (e.g., family and friends) reacted to their visual impairment. Loss of friendships was cited as a significant negative reaction by others, as demonstrated by Peter and Sarah:

> Peter: “Some people lose friendship because … “I don’t want them” … They don’t know how to approach, how to communicate, how to react to certain situations”
>
> Sarah: “I’ve probably lost one or two friends … because they just didn’t cope… one has gradually come back now …because her husband has developed it and now she has an understanding … but our friendship will never be the same, I will never let her in now … They hide away …Instead of coming forward and saying “can you help me cope with you?””

Both extracts conveyed social rejection by others when faced with visual impairment. For Peter, fear of social awkwardness resulted in others socially distancing from having to interact with him, but this was interpreted as a personal rejection i.e., “I don’t want them”. Sarah highlighted the idea that others around her were also having to cope with her visual impairment. Breakdown of friendships occurred when others distanced themselves from her impairment due to lack of understanding and their own perceived inability to cope. Despite attempts at re-establishing friendships over time, Sarah felt a loss of trust, along with fear of repeated desertion, social rejection and subsequent further feelings of loss “I will never let her in now”. Sarah described those who were unable to cope with her impairment as “hiding”, where ‘hiding’ implied shame at not being able to cope. Within the phrase “can you help me cope with you?”. Coping with “you” suggested that an inability to cope with visual impairment was equated with inability to “cope” with the individual as a whole. As such, distancing from the visually impaired individual was experienced more personally and subsequently more negatively.

Other’s Reluctance to Accept Sight-loss – “They Didn’t Want to Talk About It.” Several participants also cited the reluctance of others (namely family) to accept their visual impairment. Peter described a reluctance to disclose and discuss the full extent of his impairment with his family, due to their own reluctance to recognise and accept his impairment:

> Peter: “my family … have shut it away …they didn’t want to talk about it … it is only the case when I was going around with a white cane … that people would pick up and say “oh, I see he has a sight problem?””

The phrase “shut it away” implied possible shame of visual impairment by family members, but also could embody their psychological pain and distress at knowing that a family member was losing his sight. Therefore, the response to both possibilities was to psychologically “shut” away negative thoughts and feelings. This represented a form of denial of his impairment’s existence, whilst attempting to maintain perceived normality. Peter’s worsening impairment, along with the increased need to use a cane resulted in others becoming more aware of his impairment. Subsequently, his family were forced to accept the reality of his sight-loss. In contrast to Peter, Nadine’s husband’s difficulty in accepting her impairment was more related to his forgetting the extent of her impairment, as opposed to a more conscious and intentional avoiding of acceptance:

> Nadine: “My husband has struggled … he completely forgets … he’ll say “look at this” and I’ll say “but I can’t see that” … and I can see on his face “oh, for god’s sake” … there was a long time when I thought he just didn’t believe me”

Nadine interpreted her husband’s forgetfulness as “struggling” or denial to accept her impairment, even if this denial was unconscious and therefore not recognisable to her husband. She also referred to fear of disbelief and rejection from her husband regarding the extent of her sight-loss. Misinterpretations of her level of sight were viewed by Nadine as reflecting disbelief, prompting mistrust of her husband. She anticipated negative reactions from her husband to her sight-loss, which further reinforced her view that he was “struggling” to accept her visual impairment.

3.3.5 Sight-loss and Identity

Unpacking “Disability Identity.”

“Illness” Identity Versus “Disability” Identity. When exploring the concept of disability identity among participants, interesting discussions arose, particularly in relation to illness identity versus disability identity. None of the participants perceived themselves or their impairment as an “illness”, stating a distinct preference for ‘disability’ identity over ‘illness’ identity. For example, Debbie showed a clear rejection of the term ‘ill’, rather she defined her impairment as a ‘disability’:

> Debbie: “I wouldn’t think that I am ill …I just got this disability, … people have got all disabilities … obviously I am limited … but it doesn’t stop me from thinking oh right well I will try that … somebody ill is … ill in bed, … but a disability is … you can still do things.”

Whilst being aware of the limitations imposed by sight-loss, Debbie was nevertheless determined to overcome challenges. For Debbie, “illness” was equated with being limiting, whereas “disability” was seen as something which could be overcome. Illness perceptions related to pre-conceived ideas regarding how someone with an ‘illness’ might behave, as characterised by her description of illness-related behaviours i.e., staying “in bed”. Contrastingly, she took a more optimistic and preferential view towards the term “disability”, with the view that disabled individuals must attempt to rise above their physical limitations, not letting such limitations “stop” them. This linked to social comparison, since Debbie mentioned others who “have got all disabilities”, and clearly strongly identified herself within the positive outlook attributed to those disabled others, which then merged into a description of her own attitude. Peter also showed a preference for identification with the term “disability” over “illness”:

> Peter: “No! no! I don’t think it is an illness … well, it is in a way … it is making me bad … because it is making me change my moods …I’d like to think it’ll be like a disability more than an illness… I am looking for a word that I can’t quite grasp … I find that those two, disease and disability, are very close.”

In his initial response, a strong negation was shown for the term “illness”, but this was followed by an inner debate, thereby demonstrating appreciation for this complex issue. Illness perceptions related to negative psychological effects on mood. This led to reconsideration of illness identity, since he was able to personally relate to the link between “illness” and mood. However, he then stated a preference for “disability”, with the phrase “I’d like to think”. This indicated a possible struggle to psychologically fit with what he would “like to think”, despite also identifying with his own illness perceptions. The ambiguity and difficulty of separating the two terms was highlighted, thus further supporting his confusion regarding illness versus disability.

Disability is a Label – “It’s the Term We Use.” In addition to the complex distinction between illness and disability identity, the term ‘disability’ itself presented its own issues, since many participants felt that it represented a label given to them by others in society. An in-depth discussion of this issue is shown in Nadine's extract:

> Nadine: "They categorise visual impairment under disability … but I don't see myself as disabled …Maybe I should … restricted is what I'd say … not disabled but it is disabled isn't it? It's the term we use"

Nadine demonstrated a conflict between an objective disability identity i.e., how she was seen by others, versus her own self-perception that she was not disabled. The phrase "maybe I should" suggested the experience of societal pressure to incorporate disability into identity, despite not associating with this term on a personal level. Confusion was created by the dissonance between attempting to maintain a 'non-disabled' identity, despite contrary perceived demand from society (e.g., how visual impairment was 'categorised' and 'termed'). "Disability" was viewed as a label placed by others, where "we" referred to a society in which Nadine was trying to feel included (at least from an outwardly projected perspective). Disability was recognised as representative of visual impairment on an intellectual level, but this did not reflect Nadine's true feelings towards herself.

The Visibility of Visual Impairment.

The "Invisible" Disability – "Nobody Sees You." The issue of disability identity was further coloured by the fact that visual impairment was viewed as being an "invisible disability", thus affecting its reception by others, which in turn influenced participants identification with the term 'disability'. The concept of visual impairment as "invisible" at first seemed preferable, due to dislike of being labelled as visually impaired. This label rejection was stated by Sarah:

> Sarah: "I would never wear a badge saying I am visually impaired … But I will always say … "I am visually impaired … it's about me … I never say to people "I am disabled" because they probably think I am not … it is a disability but I don't promote that."

Possibly a visual "badge" might exacerbate negative judgement by others, leading to social stigma or rejection. On the other hand, verbally disclosing visual impairment to others would allow engagement in actual social interaction i.e., talking to others about sight-loss. This in turn would heighten Sarah's sense of personal control and empowerment. Encouraging others to acknowledge her on a social and personal level, as opposed to just seeing her impairment "it's about me". However, despite Sarah's assertions that she was willing to disclose her impairment and identify with the term 'disability', there was a contradictory reluctance to "promote" this to others. This further implicated the issue of visual impairment as an 'invisible disability', with the anticipation and fear of disbelief. Nadine also raised the issue of visual impairment as 'invisible', interestingly making a comparison of her own attitude towards visual impairment, and how this had evolved through her own experience of sight-loss:

> Nadine: "before I was diagnosed …I never took any notice of people … it's only when it happens to you … you realise … you are invisible really, aren't you? People don't realise there is something wrong with you … nobody sees you …"

Nadine was able to relate to the invisibility of visual impairment, since this is how she viewed it prior to her own impairment. Her statement that "nobody sees you" represented a paradox, i.e., she was physically unable to "see" others due to her impairment, while they in turn were unable to "see" the physical/psychological challenges resulting from her visual impairment.

Cane as a "Symbol" of Visual Impairment. Incorporating visual impairment (and by extension disability) into identity was linked to the notion of being 'visibly' identifiable as having an impairment. For many participants, the use of assistive aids such as a white cane acted as a visible 'symbol' to others. This visible symbol stood in place of the afore-mentioned invisible nature of visual impairment:

> Debbie: "The stick is for you, but it is for other people as well, I wouldn't look as if I'd got any impairments, … the stick just warns people… it's just to say, I have something wrong with my eyes"

The statement that a cane was beneficial to others in addition to being a mobility aid possibly represented an attempt to make cane use psychologically easier. This was achieved through shifting and sharing the cane's purpose to include others - justifying its use by stating it might be beneficial to others allowed deflection of potential negative emotional consequences of using the cane. Debbie felt altruistic for helping others recognise her impairment, rather than the more demeaning experience of using a cane for her own mobility. Cane use additionally helped her to avoid having to verbally disclose her disability to others, whereby "say" implied that her cane was speaking for her. Adam's response reflected an evolution of disabled identity, where still having some remaining sight meant he felt able to reject the idea of being disabled. He viewed "disability" as a negative identity, wanting to remain private about his sight-loss for fear of negative judgement/social rejection. However, after experiencing social negativity from others, he started using a cane:

> Adam: “I didn’t classify myself as “disabled” … there is no way I would tell people I was disabled … but it got to the stage where I had to have a white cane …because I was bumping into people … because I had no visual way of showing them that I had problems with my eyesight … I am the disabled person now”

As with Debbie, Adam’s cane was viewed by him as a visual symbol of his impairment, in the absence of alternative indicators. His cane represented the turning point in accepting his impairment, and subsequently incorporating it into his identity “I am the disabled person now”.

3.3.6 Rebuilding Life After Sight-loss

The Road to Acceptance.

Attempting to Gain Meaning – “Why Have I Had It?” Along the ‘road to acceptance’ of visual impairment, attempting to gain meaning from visual impairment was described as a significant issue. For example, Debbie attempted to gain a sense of meaning following her diagnosis, after having long-standing concerns regarding her sight:

> Debbie: “I was always bumping into things and everybody’d say, “Go and have your eyes checked” … then further investigation showed that I had a syndrome … it is genetic, there are four siblings in the family so I am the one that’s had it …Unfort- … Well, not unfortunately”

Impairment related behaviours such as “bumping into things” were viewed as a source of social embarrassment, since they drew others attention to visual difficulties. Subsequently, these behaviours coupled with admonitions to “get your eyes checked”, suggested that attempts to gain meaning regarding the impairment were primarily socially driven. Upon discovery that her condition was genetic, Debbie’s efforts to attribute meaning to this reflected a possible conflict regarding how to view and describe her condition (i.e. positive versus negative). “Unfortunate” was the initial automatic descriptor, but this was then overridden in a far more conscious contradiction “not unfortunately”, representing a struggle to remain (or be seen to remain) positive. The shift between the fortunate and unfortunate view of her condition additionally indicated relief that Debbie’s siblings were spared from the challenges that come with sight-loss. In contrast to Debbie who perceived an on-going difficulty with her sight, Angela perceived herself as healthy:

> Angela: “I had a bleed on my brain …very unexpected, I don’t suffer from blood pressure … it suddenly came out of the blue, … I don’t know, I just I don’t know … why have I had it?”

Angela’s self-perception of being a healthy individual intensified her shock of being diagnosed with a bleed on the brain, further implying a greater challenge in gaining a sense of meaning from the situation. Phrases such as “out of the blue” reflected shock, emphasising her assertions that her diagnosis (and by extent her impairment) were not causally attributed to herself, or to being unhealthy. However, in rejecting a more self-directed cause of her impairment, she was unable to place a solid sense of meaning on her diagnosis. This is illustrated by repetition of “I don’t know”, signifying her doubt, confusion, and an ongoing search for meaning.

What is acceptance? – Objective or Subjective? The issue of sight-loss acceptance proved a complex one for participants, who appeared torn between expressing socially oriented views about acceptance, versus their own personal experiences. This dilemma was illustrated by Peter:

> Peter: “you have got to accept that you are losing your sight, it is going to be a challenge, you are going to change your outlook in life and you are gonna change the way that you take on the challenges”

A more objective standpoint regarding sight-loss acceptance was demonstrated through use of second person speech, possibly reflecting a desire to psychologically distance from the challenging nature of accepting sight-loss. This also reflected an avoidance of discussing (or being seen to discuss) personal impairment acceptance, implying heightened awareness of how these personal feelings might be perceived by others. The depth of Peter’s insight into the experience of thoughts and feelings relating to acceptance, suggested that he may have been projecting his own experiences on what appeared to be a more generalised discussion of psychologically adapting to visual impairment.

Sarah used the motto “accept, adapt and achieve” to incapsulate the experience of sight-loss acceptance.

> Sarah: “the one I tend to use is the “accept, adapt and achieve”! Because I think acceptance is the right- is hardest thing of all”

This motto was viewed as the “right” response to sight-loss, and served as a social reminder of how to react to sight-loss. The motto was also implied as being shared with others, in order to give support relating to the psychological adaptation to their impairment. Consequently, “accept, adapt, and achieve” took on an objective, altruistic meaning for the empowerment of others, as opposed to being exclusively personal. There was alternation between referring to sight-loss acceptance as “the right” versus “the hardest thing”. The “right” thing suggested that acceptance was socially viewed as the correct response to sight-loss, whereas “the hardest” emphasised a more personal experience of the challenges relating to acceptance.

Enlightenment Through Adversity.

Increased Empathy – “I Have a More Enlightened View.” Finally, results yielded the theme of ‘regaining hope’, i.e., taking positive meaning and experience from visual impairment. For some, this included gaining a sense of increased empathy for others. Kate described her increased empathy as a positive impact resulting from her visual impairment. There was an element of social comparison to those who were perceived as being worse off (i.e., children with visual impairment), which fostered appreciation of her own positive memories prior to sight-loss:

> Kate: “the biggest positive impact would be the empathy that I would have for others, certainly for children. I have had a really good life … I can have … a great concern for how we move forward with the visual impairment community … so I have a more enlightened view … it makes me more aware of my surroundings.”

Kate felt a shared connection with others with visual impairment through her own sight loss, prompting feelings of concern and a desire to change and improve services for the “visual impairment community”. She evidently felt part of this “community” (as supported by the collective term “we”), perceiving a clear sense of responsibility to “move forward”. ‘Moving forward’, whilst relating to the improvement of services for visually impaired individuals, also alluded to ‘moving forward’ in terms of acceptance of life with sight-loss. Kate’s statement that she was “more aware of my surroundings” represented another dual meaning. She possessed increased awareness of the surrounding environment itself, in terms of how she perceived and navigated as a visually impaired person. However, she also had a greater awareness of surrounding people and their experiences, illustrated through her heightened empathy. Contrastingly, whereas Kate’s heightened empathy related to others who were visually impaired, Adam displayed more patience and empathy for sighted individuals, particularly those offering support:

> Adam: “You learn to be a bit more … patient with people … you’ve gotta learn that they don’t know how you feel or what you can see or what you can’t see … you gotta take the help that they are offering not what you want.”

Here there was a paradox, where Adam demonstrated his own understanding of the fact that others might not understand his perspective. He additionally showed understanding and empathy for the support-giver’s standpoint and possible motivation for offering support. There was a sense of not wanting to offend the support-giver, coupled with feelings of gratitude. However, there was also an element of inferiority, i.e., the support-giver was in control since they could withdraw support if they felt it was unappreciated.

Advocating for Visual Impairment – “It Made me More Focused on Visual Impairment Rights and Support.” Lastly, within the theme of ‘regaining hope’, several participants expressed a desire for advocation and education regarding visual impairment.

Both Sarah and Peter highlighted the need for increased representation of visually impaired individuals, both in terms of visual impairment-related rights (as demonstrated in Peter’s extract), and also in terms of visual impairment depiction within the media (as suggested by Sarah). However, the two extracts appear to differ in their perception of responsibility regarding visual impairment promotion:

> Sarah: “I just wish there was more things on the television to emphasize and promote sensory loss … you get the advert with the guide dogs … but people are interested in the dog … not the person … I just wish there was more out there to educate people about sight loss.

> Peter: “it made me more determined for visual impairments rights … I do a lot of support for other visually impaired people … I object to things that are going against visually impaired people if I see they are not right.”

Sarah’s desire for greater sight-loss media coverage implied that it was up to others (i.e., media producers) to emphasise and encourage awareness. This was further accentuated by Sarah’s use of the phrase “I wish”, suggesting a personally passive take on advocating for visual impairment. “Wish” suggested something she hoped would happen in the future, rather than representing an issue she felt able to actively tackle at present. Contrastingly, Peter’s extract illustrated a far more personally involved role in sight-loss advocation. Repeated use of the “I” pronoun emphasised the perception of his own responsibility in bringing about positive change. Therefore, sight-loss advocation provided a greater sense of control, promoting empowerment through the empowerment of others. This offered an alternative view on the afore-mentioned idea of social support, since Peter was now the one providing support and opportunities for others. Thus, he felt needed and relied upon, in contrast to the psychologically negative experience of having to rely on others for support. The concept of advocating for visual impairment also appeared to inter-relate with the previously discussed theme of identity, particularly the ‘invisible’ nature of visual impairment. Sarah felt that visual impairment was often overshadowed by focus on symbolic representations of sight-loss i.e., a guide dog, which created a generic view of visual impairment and drew attention away from “the person”.

3.4 Discussion

3.4.1 Implications for Sight-loss Diagnosis

Being diagnosed with sight-loss is a highly charged emotional experience, characterised by feelings of shock and devastation (Rees et al., 2010; Garcia et al., 2017). This places responsibility on clinicians to convey a positive message to patients, despite delivering bad news (Stivers & Timmermans, 2017). The delivery of this diagnosis, in particular the words and demeanour of clinicians, has a lasting impact on the diagnosed individual (Dean et al., 2017; Ferrey, Moore, & Jolly, 2022). The negative psychological reaction to sight-loss diagnosis can be diminished by clinicians responding in a sensitive and empathetic manner, with adequate provision of information regarding the individual’s condition (Fallowfield, 1993; Rosenzweig, 2012). However, there is a scarcity of research reporting the specific experience of individuals navigating a diagnosis of sight-loss.

The present study offers a unique standpoint in voicing participants perceptions of support at the point of diagnosis. Psychologically journeying through the diagnosis of visual impairment was characterised by an ongoing search for definitive medical answers, with a sense of uncertainty and aloneness when this information was lacking. Though participants received diagnoses of their eye conditions, the uncertainty colouring interview extracts indicated a desire for more answers relating to their future with sight-loss, both medically and psychosocially. While the degenerative nature of certain conditions like Retinitis Pigmentosa make it difficult to medically predict future outcomes, introducing individuals to social support at the point of diagnosis could combat their sense of being “alone”. Such support does exist in the form of ECLOs and sight-loss support groups (Llewellyn et al., 2019; Menon et al., 2020), yet participants still asserted their uncertainty and aloneness. One possible explanation for this is that initial psychological reactions to sight-loss, including denial, may prohibit individuals seeking support in the early stages of sight loss. In denying the impact of sight-loss, potential support is also denied, thereby limiting the potential for meaning-making and connectedness to others in a similar predicament.

People reported experience of dealing with a diagnosis alone highlights the value of proactivity on the part of clinicians, in particular the importance of enabling and encouraging individuals to seek help and answers about their conditions (Nyman et al., 2012). Adopting a person-centred approach to sight-loss diagnosis may enhance the diagnosis experience. Sight-loss needs to be considered from an individual perspective, acknowledging each person’s own unique symptoms and illness account, thus capturing “the person’s suffering in the context of their everyday lifeworld, in contrast to medical narratives that reflect the process of diagnosing and treating the disease” (Britten, 2017). In building up a dynamic partnership between clinician and diagnosed individual, individuals would become better informed about their condition through the opportunity for them to ask questions and set goals. An increased practical understanding regarding their condition would in turn increase confidence and foster a greater sense of independence (Wolf et al., 2017).

Denial has been proposed as a way of maintaining positive self-perception following disability onset within the context of chronic illness or disability (including sight-loss) (Naugle, 1988; Wheeler & Lord, 1999). Denial is typically present during the initial phases of disability, and has been considered as an attempt to hide the existence of a condition, for fear that it would devalue the individual within society (Wright, 1983; Vandereycke, 2005). Denial is achieved through negation of the severity or duration of the disability, along with rejecting any changes required to accommodate loss of physical function (Katz et al., 2002). Therefore, the role of denial relates to minimising acknowledgement of the reality of one’s disability/impairment (Collins et al., 1995; Wheeler & Lord, 1999), reducing feelings of anxiety and helplessness (Goldberger, 1983; Russell, 1993), along with preservation of positive self-image (Morley, 1997; Vandereycken, 2005). Cognitive indicators of denial include adopting unrealistic positive attitudes, along with portraying a ‘business-as-usual” (Billings & Moos, 1981; Livneh, 1986; Weisman, 1989; Livneh, 2009), whereas behavioural aspects of denial may include reluctance to engage with treatment or rehabilitation, with angry responses to medical advice (Croog et al., 1971; Deaton, 1986; Kortte & Wegener, 2004).

In line with previous research, denial in the present study acted as a shock absorber following diagnosis of sight-loss, where participants were unwilling to face the reality of their visual impairments. Hence, denial served as a self-protective mechanism in alleviating the shock and anxiety accompanying diagnosis. Participants also made references to cognitive and behavioural elements of their denial, in adopting a “life went on” attitude and refusing official registration of their sight-loss. Interestingly, refusal of sight-loss registration reflected denial of the label of visual impairment, indicating awareness of possible societal devaluation, as suggested by Wright (1983). In maintaining the self-image as a ‘sighted’ individual, denial protected against the anxiety of devaluation. However, for some participants, the extent of denial fluctuated following realisation that denial might hinder acceptance of sight-loss support, which in turn would benefit long-term psychological adaptation. These findings place emphasis on denial as a dynamic and context-dependent experience (e.g., Russell, 1993; Stewart, 1994; Lazarus, 2000; Vandereycken, 2005; Telford et al., 2006; Lindsay, 2011). As such, clinicians and sight-loss rehabilitation service providers should be mindful of changes in a visually impaired individual’s thought processes, emotions, and behaviour that could reflect denial following diagnosis, and have implications for rehabilitation and adaptation.

3.4.2 Implications for Loss and Uncertainty

As previously discussed, there is a tendency to consider disabilities such as visual impairment within the context of individualised loss, a concept that has been rejected in favour of a more socially derived imposition of loss and response to disability (Oliver, 1983; Barnes, 1992; Thomas, 1999). For example, when we interpret an individual’s refusal to accept their disability as ‘denial’, we are in fact individualising and imposing this sense of loss on the individual. This study lends support to this latter argument, whereby initial denial of a visual impairment diagnosis reflected resistance to the idea of being registered as visually impaired, for fear of being seen by others as disabled and therefore potentially inferior. Moreover, perceptions of sight-loss as “the biggest handicap” was externally imposed by others, who were seen as creating limitations to a fuller life. When considering psychological reactions to sight-loss, we need to acknowledge the fact that individuals were previously unimpaired, and their attitudes were thereby formed as a non-disabled person. Such attitudes may persist after impairment onset. These attitudes are internal to the individual, but they may stem from a non-disabled external world. This point was particularly relevant within the theme of “wish versus reality”, whereby, participants “wish” to remain fully functional reflected their previously formed attitudes as ‘non-disabled’. However, these thoughts clashed with the reality of functional limitation following sight-loss. Therefore, the negative experience of loss was amplified, when stacked up against previous self-images of being a ‘free’ and ‘independent’ person.

Diagnosis of visual impairment is often the start of further sight deterioration (Schilling & Wahl, 2006; Strada, 2009). The potential for this deterioration is coupled with anxiety, particularly if sight-loss occurs in only one eye (Williams et al., 1998), or is of less severity (Kilian et al., 1995). The potential for deterioration of sight is perceived as being a greater loss when the current impairment is milder, in comparison to those with greater impairment severity (Donoyama & Munakata, 2009). Since the purpose of this study was not to investigate the impact of sight-loss severity, but the personal/unique experience of living with sight-loss, no supporting evidence has arisen regarding anxiety levels among those with milder versus more severe impairments. Anxiety relating to fear of further sight-loss was instead related to perceived certainty of losing more sight, in combination with uncertainty regarding a timeframe for deterioration. This combination of certainty and uncertainty persisted when there was no medical information to provide reassurance. Anxiety over further sight-loss was also heightened by participants being warned by medical professionals that their sight might get worse. Stemming from this, participants engaged in caution and risk-reduction, supporting prior evidence of such behaviours (Zaorska, 2015). However, participants did not engage in risky behaviour, possibly because they were no longer experiencing denial of their impairment. The implication of the role of medical professionals in the extent of anxiety surrounding sight deterioration represents an important message from visually impaired individuals. While they wish to receive accurate medical information, balancing a realistic prognosis with optimism might help combat their anxieties, giving them more hope for the future.

In the absence of hope for the future, hopelessness is described as increased pessimism towards the future, with absence or decreased optimism (Lavender & Watkins, 2004; O'Connor et al., 2002). Hopelessness has been linked to disabilities that restrict the individual's daily life (Everson et al., 2000; Dunn, 2005). These functional limitations create negative expectations regarding one's own abilities (Dunn, 2005; Gannon & Nolan, 2007), which then lead to heightened levels of hopelessness. When hopelessness is prolonged, this results in loss of energy, which perpetuates functional limitation, further contributing to lower functional status (VanServellen et al., 1996; Kristenson et al., 2004). Supporting the concept of hopelessness, participants experiencing sight-loss was met with a pessimistic view of the future, particularly when discussing the potential for further sight-loss. For some, loss of personal control over their future created a sense of passivity and resignation, whereas others felt compelled to be proactive in reducing their anxiety and subsequent hopelessness. Therefore, while hopelessness accompanied anxiety of further sight-loss, it was not a permanent feature for all participants, and could be combatted by increasing personal control through taking an active role in one's health. Moreover, hopelessness was linked to the experience of fatigue in this study, where negative expectations regarding task difficulty led to feelings of psychological exhaustion, culminating in avoidance of difficult tasks (discussed below).

3.4.3 Implications for Fatigue

Supporting prior evidence (e.g., Shen et al., 2006; Schakel et al., 2017), this study demonstrated the intricacy of physical and psychological fatigue sensations. The negative psychological element of fatigue was intensified by the anxiety of the emotional fatigue itself, creating a cycle of trying to battle against losing emotional control due to fatigue, which in itself became an emotionally draining process.

Moreover, fatigue was triggered by the extra mental effort for task completion, where the thought process of task completion was seen as a greater influence on fatigue compared to actually carrying out the task. The findings around fatigue offer a unique and detailed insight into the experience of fatigue resulting from extra effort, an association which has been previously reported (Schakel et al., 2017). However, contrary to the previously noted idea that vision-related fatigue results in difficulties including completion of daily activities (Bruijning et al., 2010; Schakel et al., 2017), the present study suggests that the prior anxiety and questioning of physical capability was a greater influence on fatigue than task completion itself. The pattern of fatigue-related challenges reported in the present study also offer a narrative of visual impairment-related fatigue that is comparable to that shown among individuals with hearing loss (Hornsby, 2013; McGarrigle et al., 2014). Present findings propose that the decline in visual functioning following sight-loss increases the effort required for maintaining a similar level of physical capability to before the onset of sight-loss. This in turn creates cognitive drain, manifesting in experience of fatigue (Bruijning et al., 2014). External challenges to daily activity (such as when objects are “moved” or when surroundings become unfamiliar”, results in extra effort required to retain a sense of independence and personal control. Increased effort may accumulate throughout the day, further amplifying stress and fatigue. When a ‘tipping point’ is reached, the individual no longer wishes to engage in tasks that may prove difficult. These findings emphasise the necessity for the development of rehabilitation strategies that can alleviate fatigue (e.g., Bruijning et al., 2014).

3.4.4 Implications for Socialisation

Social interaction and support are vital for psychological adaptation to sight loss (Wang& Boerner, 2008; Barrow et al., 2018). The experience of sight-loss is unique with regards to its impact on development and maintenance of social contact. Specifically, individuals are heavily dependent on visual cues during socialisation (Ripley & Politzer, 2010; Ajuwon & Ruth Bieber, 2014). When these cues are absent due to visual impairment, this creates socialisation difficulty, and subsequently diminishes social engagement (Cimarolli & Boerner, 2005; Wang & Boerner, 2008; Bassey et al., 2019). Several participants in this study reported fearing social awkwardness/rejection resulting from their visual impairment. This created social uncertainty for both the visually impaired individual and their sighted counterpart; where the former felt responsible for causing socialisation difficulties. These findings are supportive of previous research by Hill, Bennett and Hunter (2021), where participants were also found to engage in self-blame following social challenges due to the absence of visual social cues. The sense of social responsibility and subsequent social inadequacy appears in contrast to other previous research, which typically places emphasis on the role of sighted individuals socialising with visually impaired individuals (Bhagotra et al., 2008; Bhuvanesvari et al., 2016). Social findings again link back to the idea of loss i.e., participants felt they had lost their previous capability of social etiquette following their sight-loss. Perceived loss and subsequent self-blame may reflect societal attitudes towards individual responsibility in social interaction (Akbarian, 2007).

The present study uncovered the debate surrounding socialisation with other visually impaired individuals, versus feelings of social segregation due to this socialisation. Several participants felt a shared connection with others who had been through the same experiences, with a desire to use their own experiences as a means of supporting and empowering others. However, other participants felt resentful towards visual impairment-specific social groups, which were perceived as being a barrier to “inclusivity” within wider society. This conflict may reflect a wider debate concerning the idea of a “blind culture”. Deaf individuals are often described as belonging to a ‘deaf culture’, where they feel proud to be associated with this community, viewing their deafness as a characteristic rather than a disability (Maxwell-McCaw & Zea, 2011; Moore & Mertens, 2015). In contrast, there is controversy surrounding whether visually impaired individuals associate themselves with a ‘blind culture’. The ‘blind culture’ phenomenon has arisen from sighted individuals assumption that ‘blind’ people share a cultural identity comparable to that of other minority groups with similar shared experiences (Himes, 2018). These perceptions are supported by the fact that visually impaired individuals often use alternative written communication (arguably a linguistic difference), visual symbols of their impairment e.g., a cane or guide dog, and engage with visual impairment specific groups/organisations to discuss and promote vision-specific issues. However, there is much criticism of this idea, where visually impaired commentators have pointed out that visually impaired individuals integrate themselves within the broader culture and community, and do not define their impairment as part of their cultural identity (Hopfe, 1999; Pierce, 2008; Weisleder, 2012). In the absence of a discernible ‘blind culture’, individuals may feel displaced and misunderstood, with a desire to fit in with the ‘sighted world’ (Popel et al., 2020), as was demonstrated by the present findings. This desire to ‘fit in’ may also have reflected oppression by a society that accentuated ‘inabilities’ (Charlton, 2006), leading to a motivation for normalisation within society (Williams, 1993; Greco, 1993).

Within the context of social support, living with sight-loss often involves being dependent on others (e.g., family and friends) for both practical and emotional support (Kahn & Antonucci, 1980). Prior research has documented the impact of both positive and negative forms of social support (Ingersoll-Dayton et al., 1997; Antonucci et al., 2001; Rook, 2001). Within the present study, participants viewed support from sighted individuals in a negative light, where they equated having to rely on others for help with daily tasks with their own loss of freedom and independence. More specifically, participants felt that they were inferior to their support-givers (i.e., feeling obligated to “wait” until support became available), creating feelings of envy and frustration. This is consistent with prior evidence that practical support is negatively associated with wellbeing (Lakey & Lutz, 1996; Kaul & Lakey, 2003), whereby inferiority stemmed from the visually impaired individual’s inability to reciprocate practical support (e.g., Wortman & Conway, 1985; Oxman et al., 1994). Moreover, the expression of frustration towards practical support from others is consistent with the idea that disability-related anger reflects realisation of physical limitation and loss of independence (Lane, 1999). Although participants frustration was directed at the inconsistency of support availability, it likely represented a much deeper understanding of the truly life-changing nature of sight-loss. This study did not support the concept of enhancing wellbeing through positive social support, as a result of participants primary focus on the negative aspects of support. However, this focus in itself demonstrates that negative support is often a salient issue for visually impaired individuals.

Another issue within the context of social support, was when and how participants let others know about their visual impairment. For example, when participants were ‘well-known’ within their social group, they perceived support as being more readily available, without them having to openly disclose their need for support. This reluctance for disclosure stemmed from a dislike of “asking for help”, which links back to the afore-mentioned idea of social inferiority, i.e., acknowledging need for support meant facing up to loss of independence. Papakonstantinou and Papadopoulos (2010) proposed that social support is related to social contact, i.e., the receipt of, or expectation of assistance from others. Participants in the present study had established valued social networks prior to their sight-loss. These networks proved beneficial for receiving social support following sight-loss i.e., it was easier to accept help from a pre-acquainted friend rather than someone whose only social contact was established after sight-loss. Positive social support distinguishes between whether support is actually received, or whether the individual believes that support is available (Okun & Keith, 1998). Supporting this, it was participants anticipation of receiving support, rather than the support itself, that fostered positive feelings towards their social status. Other participants expressed a need for remaining private about their impairment, affording themselves with a sense of control which contrasted against the loss of control experienced through social support. Additionally, maintaining privacy upheld a sense of social equality. One possible explanation for this is that disclosing visual impairment to others might create the perception that the individual would require practical support, leading the individual to feel inferior to others (previously discussed). These findings thus offer an original stance on how disclosing visual impairment to others may mediate the visually impaired individual’s perception of their social support. They also show how recipients of social support (i.e., visually impaired individuals) can take a proactive rather than reactive role in communicatively managing wanted/unwanted assistance from others.

This study also highlighted negative reactions of family and friends to sight-loss. Participants reported that friends became withdrawn and distant due to lack of understanding and fear of awkward social interactions with the visually impaired individual. At the same time, family members were seen as “struggling” to come to terms with participants impairments, often seeming to refuse to acknowledge the impairment’s existence. Wang and Boerner (2008) suggested that lack of sight-loss-related understanding from sighted individuals may result in the visually impaired individual becoming socially isolated. This diminution in social contact would further perpetuate lack of understanding, since pre-conceptions about sight-loss would not be challenged through actual contact with visually impaired individuals. These negative reactions reflect attitudinal barriers, which in turn underpin the social model of disability i.e., disability results from social interactions between individuals with impairments and societal barriers that might limit equal social participation (Goering, 2015).

3.4.5 Implications for Identity

The present study provides a unique discussion relating to the concept of 'illness' identity versus 'disability' identity. All participants showed a clear rejection of their visual impairment as an 'illness', instead preferring to term their impairment as a 'disability'. Society's high value of universalistic success means that taking on the role of being 'ill' prevents individuals from performing other societal roles, which then prevents them from attaining social approval (Shilling, 2002). Additionally, strong illness identities (i.e., self-perceptions as an "ill person") have been associated with negative condition outcomes, e.g., increased anxiety and depression (Jopson & Moss-Morris, 2003; Paschalides et al., 2004; Scharloo et al., 2007; Wittkowski et al., 2007). Participants in the present study were aware of the negative connotations of 'illness', but they did not associate their own experiences of sight-loss with these representations. The term 'disability' was viewed in a more optimistic light compared with 'illness', i.e., 'disability' offered the potential to rise above physical limitations, whereas 'illness' was experienced as a far more restricting term, both physically and psychologically.

'Disability' identity related to social comparison in this study, whereby other disabled individuals who were seen as thriving despite their challenges were used as a means of aspiring to think positively about one's own disability. Traditionally, 'worse-off' or 'downward' social comparison has been linked with positive self-image (Wills, 1981). However, if the comparison target is seen as similar, upward social comparison can be utilised as a motive for self-enhancement (Buunk et al., 1990; Smith, 2000). When an individual is taking on a new identity following sight-loss, the identity standard is not fully complete, nor is awareness of the full set of meanings of the new identity. Subsequently, social comparison may be helpful in allowing individuals to gain information about the identity standard through mirroring of others. Individuals may observe others' reactions to events (in this case, to disability), infer meaning from these reactions, and construct their own identity meanings. Gradually, individuals may adopt such meanings as their own. For example, when individuals first experience sight-loss, they likely possess some knowledge about the meaning of having an impairment/disability. However, as they make contact and interact with other disabled individuals, they learn additional meanings through social comparison that shape their identity formation as being ‘disabled’. Seeing others show resilience despite their health conditions involves social comparison of the self against others, where observed meanings are integrated into the ‘disability’ identity, and are used to shape the individual’s subsequent behaviour. It should be noted that this process only relates to seeing others as ‘similar’, and the present study only highlighted upward social comparison. There is a scarcity of research examining the relationship between social comparison and disability identity, still less on how individuals with acquired disabilities (such as sight-loss) utilise social comparison in their psychological adaptation process. Moreover, this study raises questions about the process of assimilation prior to using social comparison to facilitate disability identity, if the impairment is acquired later in life after the individual has developed their identity as ‘able-bodied’. Specifically, at what point do individuals with acquired visual impairment start to view themselves as similar to other disabled individuals, and thus use positive attributes of others to foster their own ‘disabled’ identity.

Following the distinction between illness and disability identity, the term ‘disability’ itself was viewed by some as a label placed upon them by society. There was a conflict between wanting to remain ‘non-disabled’ as before sight-loss, and societal pressure to identify with the term ‘disability, since this reflected how visual impairment was “categorised”. Disability self-image is created through both physical stimuli, along with social reactions, labelling, and other’s perceptions of ‘disability’ (Skura, 2019). Labelling occurs when descriptors are created relating to individuals who differ from the norm (Darrow & White, 1998). Social identity theory posits that individuals in minority groups manage stigma (or labelling) by either ‘passing’ as normal in the case of disability, or by identifying with the minority group (i.e., ‘disability’ identity) (e.g., Tajfel & Turner, 1979).

Disability identity may be a positive experience (Schrader, Jones, & Shattell, 2013) for some. However, others may reject a disability identity despite having an impairment that impacts on their daily life (Asaba & Jackson, 2011; Chalk, 2016). In the present study, stigma/labelling was related to disability identification, where the perspective of individuals with impairments supported the validity of the social model of disability i.e., the concept of disability is perceived as being socially constructed (e.g., Olkin & Pledger, 2003). The rejection-identification hypothesis proposes that individuals who experience stigma will consequently identify with their stigmatized group (Branscombe et al., 1999; Bogart et al., 2017). Lejzerowicz (2017) has suggested that, in addition to stigmatisation by others, the impaired individual engages in self-stigmatisation, viewing themselves through the eyes of others. Indeed, some participants in the present study felt socially pressured to identify as 'disabled', but this outwardly projected identity clashed with their desire to 'pass' as normal despite their impairment. These findings demonstrate the complexity surrounding disability identification, and argue for continuation of the conversation relating to how impaired individuals think and feel about the term 'disability'.

Much of the disability literature, and more specifically the literature concerning visual impairment, has focused on the 'visible characteristics' of the impaired individual (such as using mobility aids or assistive equipment) (Soderstrom & Ytterhus, 2010; Shinohara & Wobbrock, 2011; Faucett et al., 2017). However, the present study has highlighted the concept of visual impairment, for some, as an "invisible disability"; a concept that has received little attention within visual impairment literature. When visual impairment was perceived as being invisible, a dilemma arose relating to a desire to maintain concealment of the impairment (since concealment allowed avoidance of impairment labelling), versus impairment disclosure (which offered an opportunity for educating others about visual impairment). For some, 'invisibility' afforded a greater sense of control over choosing when and to whom to disclose, however, there still remained an underlying anxiety of rejection or disbelief from others.

These findings support previous propositions that individuals with visible impairments frequently encounter pre-conceived attitudes towards their impairment from others, whereas these attitudes are not always present towards those with invisible impairments (Lingsom, 2008). Therefore, individuals with invisible impairments are sometimes able to 'pass' as normal, although they constantly face the challenge of whether, when or how to disclose or conceal their impairment (Matthews & Harrington, 2000; Samuels, 2003; Dale Stone, 2005). Ultimately, the disclosure process is a complex one (Matthews, 1996; Clair et al., 2005; Chaudoir & Quinn, 2010), where individuals who “come out” as ‘disabled’ are aware of the fact that their disability-related experiences have been shaped by pre-conceived ideas about ‘normalcy’ (Titchkosky, 2001). Interestingly, some of the participants who described their sight-loss as an ‘invisible disability’, were the same individuals who wanted to remain ‘private’ about their impairment (discussed previously). Therefore, the advantages of remaining ‘private’ were subsequently counterbalanced by the drawbacks of regularly having to disclose visual impairment to others.

Despite participant reports of the ‘invisibility’ of visual impairment, this study also highlighted the very noticeable aspects of visual impairment, particularly use of a cane. In addition to the mobility-enhancing features of using a cane, many participants also viewed their canes as symbols to others that they were visually impaired. The cane therefore countered the otherwise invisible nature of visual impairment, since without the cane, participants felt that they appeared sighted to others. Cane use also linked to the concept of disability disclosure, since a visible symbol of visual impairment presented a unique opportunity to “let others know” about one’s impairment without the anxiety and exhaustion associated with verbal disclosure (e.g., Goffman, 1963; Pachankis, 2007; Lingsom, 2008; Santuzzi et al., 2014). The cane as a ‘symbol of blindness’ has been previously identified as a significant issue for visually impaired individuals (Barland, 2007; Hersh, 2015). However, the symbolic aspects of cane use have been associated with social embarrassment and subsequent reluctance to use the cane (Fourie, 2007; Southwell, 2012). These findings are inconsistent with those of the present study, which demonstrated a far more positive attitude to cane use. Research has suggested that individuals experiencing sight-loss differ with regards to their self-identification as either ‘visually impaired’, ‘sighted’, or in transition between the two (Hayeems et al., 2005). Within this research, those individuals retaining a ‘sighted’ identity tended to conceal their impairment, whilst resisting the use of assistive aids such as a cane. On the other hand, those identifying as ‘visually impaired’ viewed their assistive aids as an adaptive step towards independence (Hayeems et al., 2005). While increased independence was not specifically mentioned in relation to cane use in the present study, cane use was linked with increased recognition and identification with visual impairment, as demonstrated by the quote “I am the disabled person now”. It therefore remains vital to consider the psychosocial aspects (both positive and negative) of assistive aids such as canes, in addition to their more functional purposes. The fact that these assistive aids are so visible to others presents a unique situation for the visually impaired individual, and a unique opportunity for research to examine the link between use of such aids and identity.

3.4.6 Implications for Sight-loss Acceptance and Resilience

The present study has highlighted the complexity of sight-loss acceptance, recognising the potential effect of social expectations of disabled individuals to conform to stages of loss (Reeve, 2002). In contrast to the grief stages model, the dual process approach emphasises individuals shifting between loss and restoration orientation. Thus, as opposed to accepting impairment at the end stage of grief, individuals may fluctuate in their experience of loss, which may be triggered by memories or anniversaries of events (Thompson, 2002). In the present study, conflict was observed between the social expectation for individuals to accept their impairment, versus ongoing internal struggle to do so. This resulted in an outward projection of impairment acceptance, which did not always reflect true feelings. These findings are interesting as they indicate the controversy surrounding acceptance, raising the question as to whether acceptance should be viewed as a socially driven concept, versus a more private experience still coloured by uncertainty.

Despite the challenging nature of sight-loss, this study did highlight some strength-promoting features arising from the sight-loss experience, such as increased empathy and empowerment through advocation. Empathy is defined as a cognitive and emotional response to the state of another individual (Hoffman, 1975, 2014; Strayer, 1989). Better ‘empathisers’ show an enhanced ability to interpret the perspective of others, and understand causes of their emotions (Strayer, 1993; Hoffman, 2014). Empathic development occurs through experience (Fabes, Eisenberg, and Miller, 1990; Eisenberg et al., 1992). For example, when spending time in hospitals surrounded by others who are also experiencing fear or discomfort, individuals with health conditions are exposed to various models of empathy within this environment (Masters, Cerreto, and Mendlowitz, 1983; Hamlett, Pellegrini, & Katz, 1992). Contact with others who have a physical disability (Handlers & Austin, 1980; Simpson, 1980; Westwood, Vargo, and Vargo, 1981), and visual impairments (Scheffers, 1977) has been shown to promote acceptance of others, thereby improving attitudes toward such individuals. In this study, the theme of ‘regaining hope’ was related to increased empathy, both in terms of awareness of other’s conditions, and enhanced opportunities to help others. Participants described how their sight-loss had promoted acceptance of other’s differences, thereby improving their attitude towards, and appreciation of their own situation. Interestingly, participants also showed increased empathy for their sighted support-givers, suggesting that empathy increased regardless of whether others were seen as ‘similar’ or not.

This study additionally highlighted the importance of feeling empowered to advocate for better services and greater awareness of sight-loss. The sense of responsibility did differ, with some feeling personally moved to increase awareness using their own experiences, whereas others advocated for a more wide-spread exposure to sight-loss. The concept of advocation simultaneously linked to gaining greater empathy through belonging and shared experience and to taking a new, more positive meaning of the sight-loss experience. This offers a novel stance on how some visually impaired individuals perceive their own experience as an opportunity to support and advocate for others. Beyond sight-loss acceptance, there is still room for frustration over social barriers to sight-loss, where instead of merely adjusting to the world, visually impaired individuals wish to change it. Belonging to the visually impaired “community” created greater connectedness and shared experience, appearing in contrast to the initial isolation following diagnosis (i.e., an evolution from “alone” to “together”). Therefore, while some visually impaired individuals feel responsible for promoting change and awareness, clarity of communication from medical professionals, along with clinician patient communication, is central to beginning the sight-loss process on a more enlightened note.

3.4.7 Implications for Theory and Practice

The findings of the present study have several implications for psychological theory and practise. Given that participants experience of sight-loss were largely socially/societally oriented, there is an argument for consideration of the changing role of psychology within disability theory and practice (Gill, Kewman & Brannon, 2003; Lutz & Bowers, 2003; Smart & Smart, 2006; Tang & Lee, 2010). Firstly, at the academic level, an inclusion of growing academic knowledge on disability, particularly those involving mobility/sensory challenges, would enable psychologists to further develop relevant interventions (Pledger, 2003). Secondly, consideration is warranted regarding the values and beliefs of psychologists working with individuals with disabilities such as visual impairment. Several authors have noted the potential risk of 'disablism' from professionals (Reeve, 2000; Smart & Smart, 2006). In discussing reasons for this, Reeve (2000) suggested that the facts that there are few psychologists with disabilities themselves, means that there is a lack of views positioned from 'within'. The present study has acknowledged and addressed this criticism, since the researcher was herself living with a visual impairment, and therefore could position psychological views in alinement with participant experiences.

Moreover, when considering change within psychological intervention, the social model of disability (frequently supported throughout the present study) is critical towards the position within psychology of achieving change. Specifically, theories of loss and acceptance of one's impairment imply that the impairment is a tragic life event, with psychological devastation as the inevitable outcome (Oliver, 1996). This pathologisation is characteristic of the medical model of disability, which often fails to recognise the individual's psychological reaction to a 'disabling' social environment. Therefore, differentiating between impairment and disability (i.e., functional or societal barriers) might negate the need for theories of loss (Reeve, 2000).

3.4.8 Evaluation and Summary

When considering potential limitations of the present research, the sample was made up of ten individuals living with sight-loss. This is a small sample when compared to quantitative research, however a small sample size is supportive of the ideographic commitment within IPA (Smith and Eatough, 2008). A small, purposeful sample allowed for a detailed data analysis, with the ability to attend to commonalities and variation within the data, which is typically unacknowledged in large scale surveys. While findings have provided some support for pre-existing empirical evidence, the fact that sight-loss experiences comprised individual self-reports, means that any given support may be limited in terms of its generalisability (King, Keohane, and Verba, 1994), particularly in consideration of novel concepts raised in this study e.g., the socialisation preferences of visually impaired individuals, along with the social versus personal nature of sight-loss acceptance. Additionally, the use of convenience sampling means that this study is comprised of individuals who felt ‘ready’ to discuss their experiences of sight-loss. During recruitment, several individuals who at first showed interest in the study, later declined to be interviewed, due to feeling that they were not yet able to talk about their experiences, without suffering significant emotional distress. Subsequently, the lack of these individual experiences within the data set may have imbalanced the emergent themes, particularly those relating to the more positive/strength-promoting aspects of living with sight-loss.

This IPA study has developed insight into the subjective experiences of living with sight-loss within its real-life context. The present study does not make the claim that findings are representative of all individuals living with sight-loss, but rather they promote a useful awareness of several issues relating to the sight-loss experience, which would be helpful for both health and social professionals working within the field of visual impairment and sight-loss. In support of previous literature, living with sight-loss had numerous psychological impacts, from the initial uncertainty of receiving diagnoses, together with long-term experiences of anxiety and fatigue. Moreover, sight-loss was heavily involved within primarily socially derived challenges, such as socialisation, social support, and the dilemmas of disability identity and disability disclosure. Finally, sight-loss was met with acceptance, and counter-balanced by regaining hope and a sense of “community”. However, several experience-related differences were cited, including the conflict between personal and social displays of acceptance, as well as the responsibility for sight-loss advocation. These findings have implications for sight-loss as a complex, multifaceted psychological experience. Initially, there are negative psychological reactions to’ sight-loss, however this reaction evolves to a synergistic ‘living with’ sight-loss, as individuals learn to rebuild their lives and recognise personal strengths. This study represents the first of its kind in offering an enriched understanding of what it means to experience sight-loss in its entirety, as individuals attempt to re-evaluate and rebuild their lives within a sighted world.

Chapter 4 – Study 2 – The Psychological Impact of Childhood Visual Impairment on the Family

4.1 Introduction

4.1.1 Background

Disability affects not only the disabled individual, but the whole family system and the system in turn shapes the experience of the individual in a reflective cycle. When considering disabilities such as visual impairment across the lifespan, the role and experience of the family is relevant as “the primary and the most powerful system in which a person ever belongs” (Marshak, Seligman, & Prezant, 1999: P.2). Families may have distinct psychological responses to a child who has a disability. These responses relate both to the nature of the child’s impairment, along with the family’s available resources and pre-existing attitudes towards disability. As stated by Ryan and Runswick-Cole (2008), we should be cautious when viewing families of children with disabilities as “a discrete phenomenon”, since such families “are so variable that they probably have as much in common with mainstream families as with each other” (P.202). Moreover, depending on the underlying cause of the child’s disability, many visually impaired children often have additional impairments (Blohmé, Bengtsson-Stigmar, & Tornqvist, 2000; Hatton, Ivy, & Boyer, 2013), which further complicate the family’s psychological reaction to the child’s visual impairment.

Raising a disabled child is often a challenging process for the family; not only must they function efficiently, but they must also face the difficulties associated with this experience (Meirsschaut, Roeyers & Warreyn, 2010). As such, the presence of a child’s disability impacts on daily family life, in addition to relationships both within the family unit, and those beyond the family due to stigma and isolation (Woodgate, Ateah, & Secco, 2008). Moreover, the additional needs of children with disabilities may call for increased family organisation, along with adaptation to a new way of functioning as a family, prompting a search for new forms of social support (Banach et al., 2010). Available literature on families with disabled children is scarce, and research in the area of families with a visually impaired child are even fewer and farther between (Lowenfeld, 1971; Gardner. 1982; Tuttle, 1986; Troster, 2001). The family impact of raising a child with visual impairment is comparable to that of children with other disability types (e.g., Cohen et al. 1992; Herring, 1996). However, the nature and functional aspects of visual impairment may present unique differences for families raising a visually impaired child. Where possible, the following sections will draw on prior literature examining the psychological family impact of childhood visual impairment. However, since research in this area is sparse, more general disability literature will be examined where relevant.

4.1.2 Diagnosis

The time of diagnosis poses significant psychological challenges for parents of children with a disability or impairment (Da Paz et al., 2018; Kolemen et al., 2021). Receiving an initial diagnosis for a child with disabilities such as visual impairment is a major milestone for parents (Nixon, 1991; Youngson-Reilly et al., 1994; Cole-Hamilton & McBride, 1996; Read, 2000). Parents need to become accustomed to new rules, requirements, decisions, barriers, and in some cases, even a new language (Bingham, Correa, & Huber, 2012). Upon a child receiving a diagnosis of visual impairment, the entire family unit is affected. The family becomes heavily involved in the child’s treatment/rehabilitation programme (Al-Bakri et al., 2019), in addition to the psychological implications of the impairment for both the child and the family (Turriff et al., 2020).

The process of doctors communicating a diagnosis to parents of a disabled child, along with parent satisfaction with this communication has been extensively researched. Findings consistently indicate that parents are often dissatisfied with their child’s diagnostic process (Quine & Pahl, 1987; Sloper & Turner, 1993; Quine & Rutter, 1994; Pearson et al., 1999). One factor identified as crucial for parental satisfaction is the temporal distance between initial suspicion of disability and actual diagnosis (Nursey et al. 1991; Baird et al. 2000). For some families, diagnosis of their child’s disability occurs prior to birth, through the use of medical technology including ultrasound or amniocentesis (Erikson, 2003). However, whilst diagnosis of some conditions is possible by identifying genetic markers or obvious symptoms, other conditions (including many types of visual impairment), may not be identified by either parents or medical professionals until much later (Hatton et al., 2013). In many situations of childhood disability, parents are often unaware of their child's impairment until after the child is born (Hedderly, Baird, & McConachie, 2003; Landsman, 2009), although parents may sense that something is wrong during this time (Marshak et al., 1999; Adelson, 2005). In a comparison of stress levels of mothers of children diagnosed with disabilities at varying time intervals, Most et al., (2006) found that mother's stress levels were higher if the child was older at the time of diagnosis. In line with this, Glidden, Billings, and Jobe (2006) reported that, when a child's condition was diagnosed prior to birth, parents utilised coping strategies more effectively, since they had more time to extensively seek information and resources for their child's needs. Therefore, parents attached significance and meaning to receipt of a diagnosis, which transpired into coping strategies and subsequent stress reduction (Graungaard & Skov, 2007).

Uncertainty represents another parental stressor at the time of diagnosis, particularly if the child's condition is nonspecific and no clear answers/information are given (Quine & Rutter, 1994; Lauchlan & Boyle, 2007). Uncertainty relates to the diagnosis timeframe, since the longer parents must wait for answers, the more they are likely to experience stress (Most et al., 2006). O'Brien (2007) found that an unclear diagnosis, along with unpredictable prognosis were associated with heightened parental stress among families living with autism spectrum disorder. Likewise, Higgins et al. (2002) indicated that parents search for a correct diagnosis for their child was a source of psychological struggle, whereas a clear diagnosis provided reassurance that they were meeting the child's needs through provision of the correct support and interventions. However, uncertainty may persist even after receiving a diagnosis, since a definitive prognosis is often impossible to predict (Bingham et al., 2012). These findings suggest that families would experience more favourable psychological outcomes when healthcare professionals were aware of the complexity and variety of stressors involved during the diagnosis process, and if parents were encouraged to access support services to enable them to cope with their emotional responses more effectively (Most et al., 2006).

When parents are faced with having to live without a definitive answer as to what caused their child's disability, self-blame is often the engaged response (Nixon, 1993). According to Kaufman (1996), “the essence of the self-blame identity script is the repeated accusation of the self for real or imagined mishaps” (p. 103). Self-blame is also a response to a stressful event, such as receiving a disability diagnosis for a child (Huang, Kellett, & St John, 2010). Parents will often feel guilty for having caused their child’s condition (Ferriter et al., 2003; Moses, 2010; Eaton et al., 2016; Uba & Nwoga, 2016) or may feel that they are ‘bad’ parents (Ferriter et al., 2003; Moses, 2010). In a study of the parental impact of cerebral palsy, Huang et al. (2010) found that all mothers reported experiencing self-blame, believing that their child’s disability was a result of malnutrition throughout pregnancy. Given such findings, it is unsurprising that parental self-blame has been associated with increased depression and burnout levels, along with poorer self-concept among parents (Huang et al., 2010; Moses, 2010). However, self-blame is not a definite response from parents. Landsman (2009) reported that, while some mothers felt that having a ‘healthy’ baby was a “just consequence of having made the right choices” during pregnancy (P. 37), others held medical professionals responsible for having mismanaged “their child’s birth or subsequent health care,” portraying them “as having undermined all the hard work they had personally done to ensure the healthy development of the fetus” (P. 39–40). Additionally, Colic and Miladic-Vidojevic (2019) found low levels of self-blame among parents of children with ASD and physical disabilities. A possible explanation for this is the variability in methodology, where studies using questionnaires tended to report lower self-blame in comparison to qualitative studies, as parents may feel more comfortable sharing intimate feelings (Colic & Miladic-Vidojevic, 2019).

4.1.3 Conceptualising Disability Through Experience of Motherhood

Motherhood has been described as a process of transition (Barkin & Wisner, 2013), as mothers are faced with the implications of caring for and forming attachments to their babies (Fouquier, 2011; Basnyat & Dutta, 2012). This transition is thought to be complete when mothers show self-confidence in caring for their infants (Mercer, 2004). However, this transition period is often much longer for mothers of children with disabilities, due to increased complexities requiring psychological adjustment (Azad, Blacher, & Marcoulides, 2013). Traditional disability models have taken a medical perspective that emphasises pathology and deviation from the ‘norm’ (Ryan, 2005; Watermeyer, 2012). This perspective therefore focuses on a disabled child’s non-normativity, rather than viewing the child holistically. Mothers may adopt this negative position on disability, even before the child is conceived. This message of an “incomplete” child may still be present if the child is born with a disability, which may result in mother’s feeling helpless or inadequate (McKenzie and Muller, 2006). In contrast, supporters of the social disability model situate disability within an oppressive social context (Sheldon, 2004; Ryan, 2005). Within this perspective, the question is raised as to how mothers might project their own constructions of disablism onto their babies, based on their own prior exposure to these constructions.

When non-disabled individuals encounter disability, their emotional reactions are often complex, involving conflicting feelings of fascination and repulsion (Sinason, 1992). Several authors have suggested that implications of ‘disability’, such as the idea of dependency and vulnerability, may result in anxiety for non-disabled individuals, since they may find these aspects uncomfortable to contemplate (Marks, 1999; Harvey, 2015). This would have implications for a non-disabled mother of a disabled child, since mothers may have prior uncomfortable feelings about disability, along with apprehension about how others in society might react to both them and their child (Harvey, 2015). Therefore, a mother might experience guilt or shame for her disabled child, since she has lost the non-disabled baby of her idealised imagination (Sinason, 2001; Harvey, 2015). Moreover, Sinason (2010) proposed that disabled individuals may experience a threat to their identity, since they belong to a social ‘out group’. Building on this, mothers of disabled children may also experience this sense of vulnerability, since they must raise a child belonging to an ‘out group’ (Harvey, 2015). Although this literature is useful in understanding how motherhood is experienced through disability frameworks, the scope of this understanding may be limited by the fact that many of these conceptualisations are based on research with disabled individuals themselves, rather than those in close emotional proximity i.e., mothers.

4.1.4 Familial Relationships and Interactions

Parent-child attachment is a long-lasting, loving connection between a parent and their child, (Bowlby, 1982a). The concept of sensitive responsiveness is important when considering attachment theory, since infants are born with a desire to seek proximity and contact with caregivers (e.g., Bowlby, 1969; Ainsworth, 1973). The caregivers response is therefore crucial for providing a safe and secure basis from which the child can explore the world. Evidence has suggested that children with disabilities may be more disorganised in their attachment as opposed to forming secure attachments, which has negative implications for their development (van Ijzendoorn, Schuengel, & Bakermanskranenburg, 1999). In the context of childhood visual impairment, sensitive responsiveness from parents may become more challenging since the child may use alternative forms of seeking proximity (Fraiberg 1975).

Approximately 80% of learning requires vision, whereby children gain information about their environment through observation of objects, places, and people (Brasher & Holbrook, 1996). Whilst visually impaired children progress through the same developmental stages as their sighted counterparts, their approach in meeting these milestones may differ due to their lack of vision (Berryman, 2002). Therefore, each developmental stage may pose challenges for families (Finello, Hanson, & Kekelis, 1992; Ferrell, 1996). Visual impairment may constrain the child’s learning by restricting opportunities for them to visually explore their surroundings, where alternative methods of sensory exploration may not be present (e.g., many objects may be out of reach or not produce sound). Instead of relying on sight, language becomes the primary method of self-stimulation for visually impaired children (Finello et al., 1992; Ferrell, 1996). However, language can only be contextualised for visually impaired children through touch i.e., objects become a point of reference (Froyd, 1973). Consequently, visually impaired children require increased assistance for object identification, with both verbal and tactile input (Finello et al., 1992; Ferrell, 1996). Sighted children do not require this level of assistance, since the child is able to independently explore and interact with their environment (Brasher & Holbrook, 1996).

Providing such intensive input to visually impaired children is a time-consuming process for parents, as they must adopt a proactive role in facilitating the child’s inquisitiveness for the environment (Behl et al., 1996; Conti-Ramsden &

Perez-Pereira, 1999). As such, parents need to structure the child's surroundings with the child's safety in mind, whilst also ensuring that the environment is stimulating (Correa, 1987; Erchul & Turner, 1987). Consequently, the dyadic interaction between parent and child is not symmetric. This is not a result of the visually impaired child interacting less, but rather the parent needs to contribute more in order to understand and bond with the child (Kekelis & Prinz, 1996; Conti-Ramsden & Perez-Pereira, 1999; Perez-Pereira & Conti-Ramsden, 2001). Compared to parents of sighted children, parents of visually impaired children are more directive, and show a preference for controlled activities (Behl et al., 1996; Campbell 2003). It has been suggested that this directive interaction is detrimental to a child's development (Kekelis & Andersen, 1984; Rogers & Puchalski, 1984; Rowland, 1984), while others argue that directive interaction is an appropriate response to the needs imposed by absence of sight (Behl et al., 1996; Conti-Ramsden & Perez-Pereira, 1999; Hughes et al., 1999; Perez-Pereira & Conti-Ramsden, 2001). These increased demands may result in parental anxiety, where parents fear that they will struggle to effectively meet the child's needs, in addition to balancing needs of other family members (Bolinger & Bolinger, 1996; Ferrell. 1996; Herring, 1996). While this empirical evidence explains the impact of childhood visual impairment on early development of parent-child relationship, along with parental responses to these variables, there is little evidence to explain what such variables (i.e., directive interaction) might mean for parent-child relationship throughout the child's later development.

Having examined child-related variables within the context of visual impairment that can impact the parent-child relationship, parental overprotection is a salient parent-related variable that is relevant for children with a chronic illness or disability (Patterson et al., 1993; Holmbeck et al., 2002; Friedman et al., 2004; Mullins et al., 2004). Parental overprotection is defined as a level of maternal/paternal protective behaviour toward a child that is excessive in relation to the child's stage of development (Thomasgard et al.1995). Studies have reported an association between higher levels of parental overprotection and negative psychosocial impacts on the child, including increased depression, oppositional behaviour, and decreased future behavioural autonomy i.e., the ability to make one's own decisions (Cappelli, McGrath, & MacDonald, 1989; Miller et al., 1992; Holmbeck et al., 2002). The majority of chronic illnesses/disabilities in children require extensive medical intervention (along with rehabilitative intervention in the case of visual impairment). This places significant physical, emotional and social strain on parents (Kazak, Segal-Andrews, & Johnson, 1995; Holmbeck et al., 1997). As such, overprotection may act as an adaptive response in attempting to maintain the child's health, whilst simultaneously self-regulating parental stress. However, excessive and prolonged protection may be maladaptive in these families over time (Anderson & Coyne, 1993).

When a child has a chronic illness/disability, there is a conflict between two parental directives: ensuring the child's optimum health, versus enabling the child to be more independent (Anderson & Coyne, 1993). Prolonged overprotection may create tension between parent and child, where the child's developing autonomy is constrained by the parent's investment in optimum health. This interpersonal tension may be intensified during the child's transition to adolescence, since there are normative changes within the decision-making responsibilities, that may be unfavourable to parents due to the child's disability (Anderson & Coyne, 1991; Collins, Harris, & Susman, 1995; Collins et al., 1996). If the responsibility for decision-making does not shift from parent to child at the appropriate developmental stage due to over-involvement of the parent, the child may either respond with externalised behaviour i.e., resistance/defiance, or internalised behaviour i.e., becoming socially withdrawn (Anderson & Coyne, 1991; Thomasgard & Metz, 1993; Lollar, 1994; Silverberg & Gondoli, 1996). It could be argued that overprotection in parents of disabled children may result from the child's need for more 'protection', and therefore overprotection reflects how any parent would naturally respond to a child perceived as vulnerable (Lollar, 1994). Nevertheless, the evidence linking overprotection with decreased behavioural autonomy and internalising/externalising issues supports the notion of excessive overprotection as a negative influence, rather than an adaptive response to a child's disability.

Within the family context of childhood disability, it is not only parents who experience psychological consequences (Herring, 1996). Siblings of the disabled child are also affected, leading to alterations in relationships and family dynamics (Yura, 1987). Since the parental subsystem is a focal point within the family system as a hole, parent-sibling communication regarding the disabled child is likely to impact on sibling psychological reactions (Berryman, 2002). A lack of openness between parents and siblings has been shown to increase negative emotional responses in the sibling, such as anxiety, guilt and embarrassment (Featherstone, 1980; Breslau & Prabucki, 1987; Bolinger & Bolinger, 1996). In a survey of 40 families in which a child was receiving treatment for Leukaemia, Kaplan, Grobstein, and Smith (1976) found that families communicating openly about the current illness-related crisis, along with other life events, were less likely to experience long-term negative psychological consequences. Moreover, other authors (e.g., Scott et al., 1985; Porter & McKenzie, 2000) have suggested that siblings may avoid discussing their feelings of guilt/embarrassment, due to their fear that such feelings would be received negatively by parents. This highlights the importance of open communication between parents and siblings, so that both positive and negative feelings can be validated (Scott et al., 1985; Herring, 1996). Additionally, lack of disability awareness may further impact a sibling’s feelings towards their disabled brother/sister. In a study of the psychological impact of visual impairment on siblings, Steinzor (1967) reported that sighted siblings had rarely encountered individuals with visual impairment, and consequently held stereotypic, often negative views of visual impairment. However, siblings expressed a wish to learn more, both about visual impairment, and about their own experiences as a sighted sibling. Whilst this study implicates a need for greater support for siblings, to promote disability understanding/combat feelings of isolation, the datedness of this study calls for a more current perspective on siblings living with disabilities such as visual impairment.

Another factor affecting sibling wellbeing is parental neglect (Bolinger & Bolinger, 1996; Foster et al., 2001). Within the visual impairment literature, Correa et al. (1986) reported that the visually impaired child typically receives more parental attention than their siblings, leading to feelings of neglect and resentment among sighted siblings. In ‘Can't Your Child See: A Guide for Parents of Visually Impaired Children’ (Scott et al., 1985), recommendations were made for parents to involve sighted siblings in helping the visually impaired child become more independent. This enlistment was thought to be a therapeutic process for siblings, allowing them to feel self-important and needed. On the other hand, research has implicated sibling caring responsibilities as a potential stressor, since it may lead to role strain (Pearlin, 1989; Pearlin et al., 1990). Role strain defined as stress associated with trying to perform excessive role obligations; (Goode, 1960), may be present among siblings of a disabled child, as siblings are expected to balance caring roles with other identities, such as being a ‘good son/daughter’, a ‘good pupil’ etc. if their sibling caring responsibilities become too demanding, the resultant role strain may negatively impact on emotional wellbeing, such as increased depression, anxiety, or even abandonment of the caring role (Pearlin, 1989; Pearlin et al., 1990; Stoneman, 2005).

4.1.5 Interactions Outside the Family

As parents develop their own understanding and awareness of their child’s disability, they take on the role of extending this awareness beyond the family. The role of advocate begins at the point of the child’s disability diagnosis (Cain & Fanshawe, 2021). This is true of visual impairment, since the nature of the child’s sight-loss will require assistance and adaptations beyond family life, including academic and social inclusion (Tadic et al., 2015). Ryan and Runswick-Cole (2008) have described how mother roles were perceived by their disabled children. Mothers were viewed as being allies, and a source of advocacy. As such, mothers needed to develop a new skill set, including the ability to negotiate and mediate on the child’s behalf. These findings echoed those of Lutenbacher et al (2005), where parents became experts regarding their child’s condition. Given that the child’s needs are likely to change as they grow and develop, parents must adapt their advocacy skills accordingly in order to maximise the child’s access to support. In a systematic review of parents of visually impaired children, Lupón, Armayones, and Cardona (2018) showed that parent concerns were primarily focused on communicating with medical professionals, the child’s education, and uncertainty regarding transition to adulthood. Other studies have supported these findings (Lee, Tsang, & Chui, 2014), highlighting frustration experienced by parents when support was perceived as inadequate, particularly from education providers. In response to this dissatisfaction, parents feel they must advocate for their children, even if this advocation may put strain on relationships with education providers (Bacon & Causton-Theoharis, 2013). Parents are often left feeling disempowered in their relationships with professionals

(Lalvani 2015), and that extensive knowledge regarding their child's disability is under-appreciated (Hodge & Runswick-Cole 2008).

Despite the empirical observations of parents constantly advocating for their disabled children, disability literature has repeatedly documented a lack of physical, emotional, and social support for families (Hewitt-Taylor, 2005; Mackey & Goddard, 2006; MacDonald & Callery, 2008). Lutenbacher et al. (2005) investigated the difficulties faced by families of disabled children, where frustration was directed at healthcare, school and social services. Parents feeling alone has been reported as another indicator of lack of support (Mackey & Goddard, 2006). Whilst most parents received some support from family members etc, a sense of aloneness persisted, where mothers felt they had no choice but to continue trying to cope and survive. Likewise, Murphy et al. (2006) found that parents felt unable to share the burden of caring for their child.

4.1.6 The Present Research

Both medical advancement and public policy revisions have had positive implications for children with disabilities. As such, professionals from medical, social, and psychological services are becoming more involved with interventions for disabled children and their families. Past childhood disability research has been focused on stress, adaptation and coping, however research pertaining to the family as an interactive system within the context of disability appears fragmented (Leyser et al., 1996). Furthermore, as the previous sections of this chapter indicate, childhood/family disability research tends to portray childhood disability as a broad phenomenon, which may not account for the idiosyncratic challenges and experiences that accompany specific disability types. Research within the areas of physical/sensory deficits (including visual impairment) is scarce. Existing visual impairment studies are outdated, or have a primary focus on the physical challenges associated with childhood vision loss, rather than psychological factors. Childhood visual impairment inevitably becomes a family issue (Bolinger & Bolinger, 1996), reflecting the approach taken by the profession of family therapy (Bragg, Brown, & Berninger, 1992; Judge, 1998; Foster et al., 2001). Although there is some research identifying psychological implications for families living with a visually impaired child, findings tend to be nonspecific and lack consistency due to scarcity of supportive findings. Moreover, much of the literature fails to examine the family living with a visually impaired child as a holistic experience across all stages of the child's early lifespan i.e., from birth to young adulthood. This hampers awareness of the inter-relation of various psychological experiences (such as initial diagnosis/guilt), with latter family interactional patterns (such as parental overprotection/advocacy) (e.g., Bubolz & Whiren, 1984). In addition to scarcity of empirical research, professionals may lack awareness of the unique needs and challenges of living with visual impairment as a family, despite wanting to become involved in this area. Consequently, they may lack confidence in tailoring family interventions to the specificity of visual impairment (Berryman, 2002).

The present study addresses these issues by exploring the psychological experience of living with visual impairment as a family, with reference to specific psychological factors, such as emotional responses to a child's diagnosis, impacts on family relationships, and experiencing support from sources external to the family. It is the aim of the present study to address current research gaps, by providing a holistic exploration of parents' psychological experiences relating to their child's visual impairment, focusing on the journey through diagnosis, impacts on parental roles and relationships, and perceptions of external responses and support for the family. Understanding such experiences has significant implications for identifying and addressing psychological wellbeing among family members of visually impaired children.

4.2 Method

4.2.1 Participants

Given the fact that childhood visual impairment is a low-incidence disability, selection of families for participation proved challenging. Participant recruitment was directed towards all parents/caregivers of visually impaired children, but only mothers responded for participation. This is in keeping with previous research, where mothers were seen as the primary caregivers for children with disabilities, and were therefore invested in psychological research (Ayrault, 1977; Johnson-Martin et al., 1989; Burden, 1991; Floyd & Gallagher, 1997). In line with the qualitative research design, data was obtained from semi-structures interviews with fifteen mothers of children (from age 0-18), living with a visual impairment. 'Visual impairment' included children registered as either “sight impaired” or “severely sight impaired” (see as chapter 3 methods). The use of IPA requires a small, purposive sample of participants (i.e., 15 female individuals), until saturation of themes was reached (Sandelowski, 1995; Hammersley, 2015). Eligibility criteria was based on participants being over 18 years of age, and being a parent of at least one child with a visual impairment. A diverse range of impairments were included within the sample, since the aim of the study was not to examine the effect of a specific impairment, but rather the personal and unique experience of living with visual impairment as a family. Demographic/individual characteristics of participants are shown in Table 3 below (note that any names/other identifiers have been replaced with pseudonyms to ensure participant anonymity).

Table 3 – Study 2 Participants Demographics

Participant number	Pseudonym	Participant age	Age of child	Gender of child	Child’s VI registration	Child’s eye condition
1	Kate	41	13	Female	Severely sight impaired	Marfan Syndrome
2	Tess	42	11	Male	Severely sight impaired	Norrie Disease
3	Susan	41	10	Male	Severely sight impaired	Not specified
4	Helen	35	6	Female	Severely sight impaired	Undiagnosed
5	Pam	39	14	Female	Severely sight impaired	Retinopathy of Prematurity (ROP)
6	Pennie	40	9	Male	Severely sight impaired	Nystagmus
7	Emily	39	15	Female	Sight impaired	Complications resulting from a brain tumour
8	Mel	32	5	Female	Sight impaired	ROP
9	Laura	29	3	Male	Severely sight impaired	Autosomal-Dominant Congenital Cataracts with Microphthalmia
10	Samantha	46	9	Male	Severely sight impaired	Midline brain defect
11	Rosie	36	11	Female	Severely sight impaired	Micropthalmia and coloboma

12	Sinead	42	19 months	Female	Severely sight impaired	Micropthalmia and coloboma
13	Daisy	40	13	Male	Sight impaired	Cerebral visual impairment (CVI)
14	Emma	27	5 months	Male	Severely sight impaired	Microphthalmia
15	Jess	25	3	Male	Sight impaired	Albinism

4.2.2 Materials

In addition to participant information sheet, informed consent and debriefing forms (see appendix 5, 6, and 7), semi-structured interviews (e.g., Kvale & Brinkmann, 2009) were used to investigate the psychological impact of childhood visual impairment on the family (see appendix). These interviews aimed to explore how each parent psychologically responded to their child's visual impairment, with specific reference to emotional responses, family relationships, and social interactions outside the family unit. Interviews were made up of eleven open-ended questions, ranging from a general enquiry into the nature of the child's visual impairment and its related psychosocial effect on family life (encompassing issues such as practical and emotional impact), to specific questions relating to the wider social impact of the child's visual impairment (i.e., psychosocial effects on family members, as well as perceived effects on others outside of the family). A full schedule of interview questions is presented in appendix 8.

4.2.3 Procedure

The present study was conducted during the Covid-19 pandemic. As such, in line with government guidelines in place at the time, face-to-face participant recruitment and subsequent interviews were not possible. Therefore, to maximise reach, participants were recruited via online advertisements placed within two Facebook groups specific to families of visually impaired children; "The VICTA Parent Network" and "MACS Support for Families" (see appendix 9 for advertisement). The VICTA Parent Network is aimed at empowering parents of visually impaired children to offer advice and support to each other, and also organises groups and events in order to create parent networks across the UK. The VICTA Facebook group offers a safe space for parents to ask questions or seek advice. In a similar vein, MACS Support for Families is a closed online group providing support for families (parents, grandparents, children, adults and siblings) living with visual impairment in the UK. MACS was founded in 1993 by a group of parents of visually impaired children affected by Microphthalmia (small eyes), Anophthalmia (no eyes) and Coloboma (where part of the eye structure is missing).

Both organisations expressed genuine interest in being involved with this research, since they felt that supporting research of this kind would have future benefits for their service users. The researcher took part in an online “family event” - organised by MACS in November 2020. The aim of this event was to promote skills and support services that are available to families of visually impaired children, allowing them to connect with these services and gain valuable information. It also allowed and encouraged both parents and children to connect with each other socially, thus enhancing their level of social support. This event therefore presented a unique opportunity for participant recruitment, since family members were already at the event. As such, the researcher remained present throughout the event, in order to verbally introduce the study to family members and answer any queries. If interested, family members were given the researchers contact details. Following the family event, MACS posted an advertisement for the study on their Facebook group (see appendix), containing information about the study, as well as the researcher’s contact details. This same advertisement was also posted within the VICTA Parents Network group. If family members were further interested in participating in interviews, they were able to contact the researcher to arrange a suitable time to be interviewed. All interviews were conducted remotely via telephone. Prior to each interview, participants were emailed a copy of the participant information sheet and consent form, where informed consent was given in writing.

Each interview began with an initial general dialog about parental experience of visual impairment, covering several areas including when/how the child’s impairment was diagnosed, and the practical/emotional impact of living with visual impairment as a family. The interview then proceeded to discuss more specific issues relating to the family-oriented impact of visual impairment, such as effects on relationships both inside and outside the family, in addition to any positive impact of the child’s visual impairment on family life. Following discussion of scheduled interview topics, participants were given the opportunity to ‘add’ any additional thoughts/feelings regarding the psychological impact of their child’s visual impairment. This enabled parents to freely voice thoughts that were unguided by the researcher, whilst presenting them with a chance to express anything missed during the interview. Following completion of the interview, an informal ‘chat’ lasting around 5 minutes gave the opportunity for a verbal debrief, and allowed participants to address any questions or concerns. Participants were also emailed a written copy of the debrief form. All interviews were audio-recorded, transcribed verbatim, and analysed using IPA.

4.3 Results

4.3.1 Analysis

Acknowledging the “double hermeneutic” and idiographic commitment within IPA (Smith & Osborn, 2003; Smith et al., 2009), a preliminary analysis was carried out on each interview individually. To optimise data familiarity, transcripts were re-read. Initial comments relating to content, linguistics, and abstract/probing remarks were noted (Smith et al., 2009). After the annotation process, emergent themes were recorded, reducing the volume of information whilst preserving analysis intricacy (Smith et al., 2009). Inter-relation of themes was examined, along with theme repetition, similarity, and difference. This yielded superordinate themes, subdivided into related themes and subthemes (Smith et al., 2009). In terms of sustaining quality assurance, independent supervisory examinations of transcripts were carried out, and analytical specifics were discussed with a supervisor, thus maintaining accord with “commitment/rigor” and “transparency/coherence” principles (Elliott et al., 1999; Yardley, 2000).

IPA analysis produced three superordinate themes, subdivided into eight related themes and twenty-one subthemes. These are presented below in table 4.

Table 4 Study 2 Emergent themes

Superordinate Theme	Theme	Sub-theme
Living with VI as a family	The impact of diagnosis	Guilt – “I made my baby wrong”
		Distress at diagnosis
		“There’s no fix for this”
	Facing the unknown	The child’s experience – “what can they see?”

		Comparison to other children- “is that normal?”
		The need for planning – “you are constantly having to think ahead”
Roles and relationships	Roles: beyond being a parent	The advocate – “the constant fight”
		“Carer” versus “mum.”
	Parent-child relationship	Managing expectations – “you don’t want to be the bearer of bad news”
		Protectiveness – “there is more vigilance” versus unwrapping the cotton wool – “we are on this independence path now”
		Nurturing identity – “I want her to be …confident and happy with herself”
	Relationships with siblings	Parental guilt; “I don’t want my other son to resent that”
		Fear of sibling comparison; “why can’t I do that? Why am I not doing that?”
Thinking about the future	Future concerns	Anticipated outcomes – “what if?” and “what’s next?”
		“When I am not around”
	Cautious optimism versus futility	Proving society wrong – “he is perfectly capable”
Beyond the family	Dealing with difference	Breaking the news to others – “I couldn’t face anybody”
		Pity from others – “she’s not a pet, she’s human!”
		Feeling judged – “you have to explain to everybody …what the situation is”
	Outside support	Feeling alone – “who’s there on the other end of the phone? Who?”
		Increased connectedness

4.3.2 Living with Visual Impairment as a Family

The Impact of Diagnosis. ***Guilt: "I made my Baby Wrong."*** Participants experiences of motherhood were frequently overshadowed by feelings of guilt and personal responsibility for their children's visual impairment. Receiving a visual impairment diagnosis for their child caused the mothers to think back over their pregnancy, with a sense that they themselves should have behaved differently to prevent the visual impairment.

> Helen: "I spend a lot of time thinking that I made my baby wrong … I actually work in a special school, for children with severe learning difficulties…it's sort of tricky because I don't blame the parents of my kids in my class for their children's disability … yet … I almost blame myself … for her disability" (mother of a 6 year old girl with an undiagnosed eye condition).

Helen, mother of a six-year-old girl with an undiagnosed eye condition highlighted having felt responsible for her daughter's visual impairment, saying "I made my baby wrong", implying her guilt and feelings of inadequacy as a mother. The underlying implication was that the mother role was equated with 'making' a baby without any disabilities, subsequently guilt occurred when the child was "made wrong". "Wrong" in this sense did not seem to refer to disability itself, but rather pregnancy and its outcomes were perceived as "wrong". Guilt was a "tricky" experience for Helen, since her personal guilt contradicted her empathy and lack of blame towards other parents of disabled children. On some level, Helen was aware that her own guilt was unfounded. However, she felt unable to stop blaming herself.

Guilt was not time limited and was instead an ongoing phenomenon. As described by Pam, mother of a fourteen-year-old girl with ROP, "the guilt is always there".

> Pam: "when I see other children her age … going out and having fun … I really feel for her … as a parent, her mum, who carried her child, you know for only 24 weeks when I should have actually carried her for 40 weeks … I just can't overcome it if I am honest with you … as a mum … the guilt is always there what did I do wrong? she used to come home and cry and say "mummy why can't I be a normal child".

Pam's guilt was coloured by a sense of failure for not having carried her baby to full term. This sense of failure was intensified through comparisons between the visually impaired child and "other children her age", along with the child's own expressed emotional distress and answer-seeking regarding their impairment “why can’t I be a normal child?”.

Distress at Diagnosis. This theme highlights participants recollections of their reactions to their child’s diagnosis, specifically, reacting to the flood of medical information and potential prognoses. Both Pennie (mother of a nine-year-old boy with Nystagmus) and Rosie (mother of an eleven-year-old girl with bilateral microphthalmia), described finding out about their child’s visual impairment along with the potential for additional disabilities:

> Pennie: “we were told quite horrific things about his potential future … we were told he wouldn’t survive … we were told he wouldn’t live more than two weeks … we were told he’ll never walk, … he’ll never be able to eat on his own …but for some reason … not having sight … felt more of an impact to me … on his life then being in a wheelchair! it just felt like “oh my god” … he is never gonna see the beautiful flowers, he’s never gonna see … the trees, it was like I felt this real sense of loss on his behalf ”
>
> Rosie: “We were pretty much oblivious at this stage, …that there was something wrong? … we were called back in …. and she started talking about registration, and I said, “what does that mean? She’s like, ‘blind’, and then it hit us … so we just shifted from one point thinking a baby might need glasses, to a baby that was blind, and then to a baby that could have a whole load of other problems, it was awful, so the goalposts just shifted that whole day!”

Pennie described being given “horrific” medical information regarding the potential impact of her son’s disability. Medical professionals used words such as “wouldn’t” and “he’ll never”, implying certainty of these negative outcomes. However, amidst the negative prognoses regarding her son’s additional disabilities, visual impairment stood out to Pennie as being the greatest “loss”, both for her son’s potential future, and for herself as a parent. The underlying implication was that she would be unable as a parent, to share the joys of ‘seeing’ the world with her son. Visual impairment also carried a sense of futility and helplessness i.e., Pennie could help her son to walk or eat, but she would be unable to help him see. In contrast to Pennie, Rosie described being “oblivious” to the potential severity of her daughter’s disability, with the ensuing “shock” when potential disability was discovered. Interestingly, the diagnosis of visual impairment had differing levels of emotional focus for the two mothers, when stacked against the potential of other disabilities. For Pennie, her son’s visual impairment was seen by her as a far greater and more negative impact compared to his other disabilities, conveyed in repeated use of the phrase “he’s never gonna”, thus mirroring the earlier mentioned element of pessimistic certainty used by doctors. Rosie described the shift from “‘oh my goodness, she’s blind’ into ‘I hope she’s just blind’”, where dread and anxiety were focused on the potential for additional disabilities. For Rosie, the experience of loss was suggested through the emotional shift of firstly thinking a baby “might need glasses” to a baby that was “blind”. Each time there was an emotional shift in the situation, this created a sensation of losing another version of the child. The parent was then emotionally forced to part with the pre-existing certainty that their child was healthy, and gradually come to terms with the idea that their family’s future might now be altered.

One participant, Laura, mother of a three-year-old boy, also discussed the “shock” of receiving a visual impairment diagnosis for a child, whilst both she and her husband were living with visual impairment:

> Laura: “For me personally … it has come as such a big shock … and even now … we are still trying to get our head round the fact that … he has got what his dad has, … he has got a visual impairment …and as much as people say … we are visually impaired as well … it’s “oh you’ll be all fine … cause you know what it’s like and you know what’s coming” but the fact that we know what’s coming … the fact that we know what he’s expecting … it is a bit emotional for me ….”

Repetition of “he has got” represented the on-going struggle to accept the child’s impairment, as though Laura was trying to constantly remind herself of the reality of her son’s impairment. There were also elements of contrast between the unexpected and the expected. The unforeseen diagnosis of the child’s visual impairment with its resulting “shock”, was then followed by a sense of dread for the child’s potential future. These expectations were based on Laura’s own negative experiences of growing up with a visual impairment, with the subsequent anxiety of personally relating to her child’s impairment and anticipating the child’s own experiences with visual impairment. Frustration was expressed towards a lack of understanding by others of what it is like to be in the unique position as a visually impaired mother. Others were seen as being naive in their assumptions that being visually impaired meant being better prepared for dealing with the child’s impairment “oh you’ll be all fine”. Contrary to these assumptions, knowing what it’s like in fact meant knowing and anticipating challenges.

"There's no Fix for This." Mothers described a progression from feeling a need to try and "fix" their child's impairment, towards accepting the impairment, along with the fact that it could not be "fixed":

> Helen: "I can't take this away from her, I can't make this better…and that is really difficult because … as a parent … your almost natural instinct is to make it better… If she fell over and hurt herself, you'd give it a kiss and put a plaster on it and give her a cuddle and make it better …But I can't make this better … but what I can do … is give her the skills as best I can … to cope with it… trying to give her the emotional resilience … to … be okay with it herself"

There was a sense of helplessness and perceived inability to provide comfort. Repeated use of "I can't" illustrated powerlessness and frustration at being unable to help, where perceived inabilities clashed against the "natural instinct" as a parent. This was particularly prominent during feelings of hindrance and subsequent guilt at being unable to act on parental instincts. Parents felt compelled to help, where the parental task of 'making it better' represented self-expectation and the sole responsibility as a mother; "I make it better". In accepting the inability to "fix" the impairment, there was a shift from a passive stance "I can't" to recognition of being able to emotionally support the child "give her the skills as best I can". Therefore, there was a move away from focusing on the physical side of visual impairment (i.e., being unable to 'put a plaster on' the visual impairment and making it 'go away'), towards encouragement of the child's emotional acceptance of visual impairment, through the parent's own gradual acceptance. Alternatively, other extracts described frantic attempts to find a "fix" for the child's impairment:

> Rosie: "But it was the stage I was at, like shall we take her to America? We're going to take her to America, I was ready with guns blazing, … shall we do x, y, z, it was such a feeling that we had to fix her … It took me, like I say, until she was about two and a half before we realised, right, just calm down, there's no fix for this, But I think that we had to journey that as parents ourselves, to feel that we did everything for her"

The search for a "fix" was described as a "stage I was at", implying that the "feeling that we had to fix her" was not permanent. There was a sense of desperation and the need for action, demonstrated by the use of verbs (i.e., "shall we take her … shall we do x"). In the continuous search for answers, parents were maintaining their sense of being proactive and instrumental in their child's care "we did everything for her", thereby preserving self-perceptions as a successful parent. Again, the notion of a successful parent was being able to "fix" their child. However, the proactivity afforded by searching for answers allowed avoidance of accepting that the child's impairment could not be rectified, where the phrase "right, just calm down" illustrated attempts to suppress the need to fix things. Here too there was a shift from feeling "possessed" of the necessity to make things better, to a realisation that accepting the impairment would have far greater long-term benefits for the family. Nevertheless, this process of acceptance was viewed as a necessary "journey as parents", where all possible avenues had to be exhausted prior to accepting that "there is no fix for this".

Facing the Unknown.

The child's experience - "What can they see?" In 'facing the unknown', mothers expressed anxiety over not being able to know how much their child was able/unable to see:

> Kate: "it's hard when they are little because they can't articulate you know what they are seeing … when she last had her retinal detachment … she didn't really talk about what she was seeing … she just told me that my face … looked like it was deformed …and I was thinking to myself … well when she was younger and that was happening then that must have been very frightening for her … like if she has just opened her eyes … and see what's like a monster …just made me think you know, how … scary it must have been for her."

In discussing visual ability with her thirteen-year-old daughter, Kate reported feeling emotionally distressed when her daughter described seeing her as "deformed". This led to parental feelings of guilt at not being able to previously know, and therefore support the child through "how scary it must have been". This would have been particularly distressing from a parental perspective, since rather than being seen as a protector of negative emotions such as fear, the parent was instead described being seen by their child as "a monster", and therefore the instigator of fear.

> Mel: "we didn't realise perhaps till we had my younger son, how much she can't see … I think it was a lot harder … when she couldn't tell us … sometimes when I say to her, can she see, she says "yes", I don't know if she's just saying "yes" …And I don't know how bad … if her eyesight will get worse and worse as she gets older?"

Other parents such as Mel, mother of a five-year-old girl with ROP, described a gradual shift from the uncertainty of how much the child was able to see, to a more informed understanding using points of comparison. Firstly, sighted siblings helped establish the extent of the child’s impairment, which was contrasted against a prior sense of doubt “we didn’t realise”. However, far from bringing reassurance, the increasing knowledge regarding impairment extent served to highlight the child’s inabilities, which were actually worse than previously thought “how much she can’t see”. “I don’t know what she sees” conveyed parental frustration and desire to feel close to the child through sharing visual experiences. The fact that the child was now able to articulate their level of sight did not alleviate parental uncertainty, because they felt that the child was trying to please them by saying they could see “ I don’t know if she’s just saying “yes””. Becoming more aware of the child’s impairment only created further anxiety and ambiguity, with the fear that the situation would continuously shift and change. This was demonstrated by worries regarding potential future deterioration of sight “if her eyesight will get worse and worse”.

Comparison to Other Children: “Is That Normal?” Several participants described feelings of anxiety and concern over their visually impaired child’s behaviour, where they felt compelled to make comparisons to other (non-visually impaired) children, to determine if the behaviour resulted from visual impairment or not:

> Helen: “Because she is our first child … and she is our only child … it’s hard to figure out if … certain things, is that normal? Or is it because of her vision? Because we don’t have anything else to compare it to … we are constantly questioning … That I don’t think other people sort of have to think about”

Uncertainty and confusion over trying to understand the child’s behaviour was framed as a series of questions “Is this because of her vision?”. Uncertainty implied a lack of confidence on the part of the parent in their own capability to parent a visually impaired child, in addition to fear of having missed important impairment-related features that might hinder the child “we are constantly questioning”. The phrase “we just don’t know!” epitomised helplessness in the face of uncertainty, which was exacerbated by the lack of other children to make comparisons with “because she is our only child”. Instead, comparisons were made with other parents of non-disabled children “I don’t think other people sort of have to think about”, when the uncertainty of visual impairment was perceived as an added extra to the difficulty of parenting.

> Mel: “not knowing the right ways to support them. Not knowing the best way to help them ....And because I find it hard that other children obviously can just do stuff … you’re trying to find ways so that she can be the same as everyone else ..and you have to rely on other people…. And also it’s not black and white … it’s not like my child is partially sighted, someone else’s child is partially sighted, they’re gonna need the same software on their computer … even though it’s got one label I think it’s quite varied”

Moreover, frustration was expressed towards the uncertainty of how to best support the visually impaired child, where “not knowing” was equated with parental inadequacy. This inadequacy was highlighted through having to “rely on others” who were seen as being more knowledgeable. Comparisons were also made between the visually impaired child and sighted children who “can just do stuff”, where “just” illustrated the ease of other children’s ability versus the challenge of giving the visually impaired child a sense of equality “so that she can be the same as everyone else”. However, while comparisons were engaged between the visually impaired child and sighted children, comparison to other visually impaired children proved more difficult, as reflected in emphasis of the diverse nature of visual impairment “it’s not black and white”. Recognition of this fact further heightened the sense of “not knowing”, since there was an inability to use other children as a base to establish the child’s needs.

> Emma: “You’re looking at how everyone else’s babies are doing …and it’s like constantly looking, has he hit that milestone? … when we were comparing him to other children … they’d all smile …and he sort of wasn’t reacting to us … I found that really hard. So “come on, just give us a smile, we just want one smile” but seeing the other family, with their little girl, when we met them and the little girl, she sat in the pub and she took her eye out, she did it all herself … that to us was very reassuring, to think well actually … that’ll be him in a couple of years’ time ….Things will get easier … and more clearer.”

For Emma, mother of a five-month-old boy, comparison to other babies and the developmental milestones they were reaching proved detrimental to the uncertainty regarding the visually impaired child. “Constantly looking” and worrying about “has he hit that milestone?” was reminiscent of the need for caution and repeated questioning. If and when the visually impaired child wasn’t completing developmental stages at the same pace as others, this created a sense of loss and having missed out on precious moments with the baby “we just want one smile”. Nevertheless, there was a sense of hope for through comparison with older visually impaired children who were seen as thriving and independent “she did it all herself”.

This provided reassurance through visualisation of the child's potential future "that'll be him in a couple of years", with the certainty that "things will get easier".

The Need for Planning: "You are Constantly Having to Think Ahead." A significant source of anxiety for mothers was the need to remain constantly vigilant of the visually impaired child's needs. In an attempt to manage this anxiety, parents engaged in excessive planning, although this in itself often proved to be stressful and emotionally draining:

> Pennie: "you are constantly having to think ahead … you are constantly having to assess the situation around you … you are basically … always on high alert for something that's going to be different. Because that potentially can trigger anxiety for him … I think the emotional impact it has on me … and probably all of us as a family is just the fact that you feel quite anxious as well … you are always on a high level of anxiety because … you know that you have to be forewarning him."

Repetition of "constantly" and "always" emphasised a perpetual state of vigilance and awareness of surroundings on the part of the parent, in order to describe them to the visually impaired child. There was an undercurrent of the challenge of both being physically "alert" for changes in surroundings, whilst simultaneously monitoring the child's emotional state "that potentially can trigger anxiety". This resulted in excessive planning which allowed the child, and by extent the parent, to avoid stress and anxiety resulting from unexpected obstacles and situations. The phrase "if I can see ahead of me" could be taken in a literal sense of looking out for obstacles, but also could imply the need to predict the future emotional cost of encountering change. The visually impaired child was perceived as viewing the world as a potentially dangerous place due to its unpredictability in the absence of sight. Therefore, parents experienced pressure to use their own vision on the child's behalf. Possibly this self-pressure stemmed from parental guilt over the child's impairment, which manifested itself in anxiety at the child's emotional distress "you feel quite anxious as well". Using their own sight to help the child was a way for the parent to give something back to the child that was perceived to have been lost. However, the heightened awareness was likely perpetuating the child's anxiety relating to change, since anxiety was not challenged by allowing personal experience of change (i.e., experience of change was psychologically distanced since it was experienced through the parent).

> Daisy: “if we wanted to go somewhere as a family … I’d have to recruit somebody else to help … if we go anywhere that’s busy … we take a wheelchair for safety reasons …one of us has to push the wheelchair and then I’ve got a four year old and another son, you know, so it’s like … There’s a lot of stuff that … either we can’t do or we have to do in a sort of … very certain way… then I have learned over the years that it just isn’t worth it.”

For Daisy, mother of a thirteen-year-old boy, having to “recruit somebody else” indicated reluctance to request support, possibly due to guilty feelings over bringing somebody else into a stressful situation. This extract was also tinged with the notion of juggling multiple considerations, along with attempts to predict the likelihood of encountering environmental challenges “if they don’t have disabled toilets … if it’s not level enough ground”. The underlying connotation of repeating the word “if” was ‘what if’ i.e., the potential anxieties and uncertainties accompanying unfamiliar surroundings. Predictability of surroundings was equated with a greater sense of mastery over mobility-related situations, whereas uncertainty provoked a sense of physical and mental exhaustion “too much hard work”. Here there was a cost-benefit ratio of going “out as a family”, implying desire to involve and include the visually impaired children, stacked against the potential physical and emotional consequences “it just isn’t worth it”.

4.3.3 Roles and Relationships

Beyond Being a Parent.

The advocate: “the constant fight.” Many mothers took on the role of being an “advocate”, in order to promote their child’s rights and needs. This role was seen by parents as being additional to their role as the child’s parent, with an additional emotional toll:

> Susan: “it can be hard having to constantly promote your child’s needs and fight for things… I think you can’t be an introvert when you have a disabled child, you have to become an extrovert and really be quite firm in what you have to say… and I think that can be quite difficult to get to grips with”

For Susan, mother of a ten-year-old boy, taking on the role of an advocate was synonymous with the idea of altering her own personality characteristics for the sake of her child “you can’t be an introvert”. “You can’t” indicated the unavoidable requirement to exchange her previous life as an “introvert” to become an “extravert”. Becoming extraverted was equated with acquiring the necessary traits (i.e., being “firm” and assertive), in order to advocate for her child’s needs. However, ‘getting to grips' with a new role proved "difficult" for Susan, since she was forcing herself to behave in a way that she was not previously accustomed to.

> Tess: "all the kind of hoops you have to jump through to get what they need. The form filling, you have to be negative about your child … on a form in order to get them the things that work, that they should just be entitled to … and that's very difficult, … I have to put down in writing … what his limitations might be …I shouldn't have to be saying this"

The challenge in becoming an advocate was echoed by Tess, mother of an eleven-year-old boy, who portrayed the emotional exhaustion of having to 'jump through hoops' in order to get her child "what he needs", implying obligation. Being "negative" about her child and having to highlight his "limitations" to other people, forced Tess to then focus on these negativities herself. The subsequent negative emotions arising from this hyper-analysis led Tess to feel frustrated by her situation of forced advocacy, with frustration also being directed outwardly towards those who she perceived as forcing her to be negative "I shouldn't have to be saying this".

> Pam: "it's a constant battle, … constantly trying to fight for my child … what happens if me and my husband drop down tomorrow? Who is going to be ready to look after her? No one! and that's what I find really frustrating, there is a lot out there for children with autism, lots of help, lots of parent groups, but nothing for children with visual impairment … There is not enough awareness for these children, it's never brought to light, it's kind of like hidden …as if it doesn't exist! … we are suffering in silence because who'd we go to?"

Other mothers alternated between highlighting the "constant fight", implying a sense of affinity with other parents going through the same struggle, to "fight for my child", suggesting loneliness as a sole advocate. This idea of being solely responsible for promoting the child's needs was further emphasised by expression of fear relating to the child's potential future without advocating parents "Who is going to be ready to look after her? No one!" the theme of 'the advocate' was strongly represented through fierce firing of short, clipped questions "how about their needs? What impact it has on them?" Supplemented by the combative implications of "fight" and "battle". Unlike other parents, whose frustration appeared under the surface of their responses, Pam's response was openly angry at the perceived injustice of lacking support for visually impaired children "it's never brought to light, it's kind of like hidden". While visually impaired children were described to be lacking in support, the underlying implication was that parents were also feeling the emotional strain of having to struggle alone. Therefore, frustration was not only on the child’s behalf, but also for the struggle as a parent, and their responsibility of being ‘the advocate”.

“Carer” Versus “Mum.” For some, raising a visually impaired child carried the extra responsibility of being a “carer”, which appeared as a separate role from being a “Mum”:

> Pennie: “I am his mum …but it’s much more … I am his carer as well …it’s a much more emotive relationship in terms of … me kind of supporting him in the world … it’s much more of a depended relationship … You’ve not just got the mum level …there is much more emotion involved … it’s just very different. … it’s much more powerful I think.”

The added “carer” element was perceived as involving both emotional and more practical support. The phrase “much more” was frequently used to emphasise the extra and additional dimension to parenting a visually impaired child. Rather than being separate to the “Mum” role, the “carer” role provided an added “emotive” layer of “worry” and being “alert”, linking back to the previously discussed “emotional journey” through visual impairment as a family.

> Tess: “I should be getting him to do more but … again it’s that time thing, it’s just easier to either do it myself … if I am trying to kind of teach my son how to do that … he will probably get frustrated … and …it’s not like he can just watch what I do and then copy … so I am guessing there is a slight element of that carer role …rather than just that mum and son role which is different from I guess my other son.”

Following this emotionally charged journey, the visually impaired child was seen as being more dependent, necessitating greater parental emotional investment that was difficult to disengage with over time. In terms of giving practical support, the extra parental involvement in helping the child with everyday tasks was tinged with guilt at not feeling proactive enough in promoting the child’s independence “I should be getting him to do more”, stacked up against the frustration at not having enough time. Moreover, there was an element of fear towards performing a carer/teacher role, where mothers felt anxious about showing their child how to perform tasks, in case this created parent-child emotional tension “having an impact on his feelings towards me”, which in turn might negatively impact on the “mum and son role”. Therefore, in providing extra practical support to the child, the “Mum” role could be protected.

Parent-child Relationship.

Managing expectations – "you don't want to be the bearer of bad news."

For several mothers, there was the unique challenge of managing their child's expectations of the reality of living with their visual impairment:

> Daisy: "They're talking at school about "what are you gonna do when you are a grown up?" And he is like … "I'm gonna be in the police!" I'm like, "You are blind" and school have not helped at this at all. I have had words with them all the time about it … it always feels like I am the person, that has to kind of … break the bad news."

Daisy described the complex issue of reminding her son of his impairment in order to encourage him to consider potential careers that were appropriate for his situation "I'm like, "You are blind"". There was a sense of being alone in dealing with this challenge "it always feels like I am the person", with frustration directed at others who were seen as actively encouraging unrealistic expectations despite knowing better "you and I both know that that is not happening". The role as a "Mum" was also implicated here, whereby conflict arose when the child rejected attempts to encourage him to consider his visual impairment "'cos I am his mum he isn't listening". Attempting to be realistic about the implications of visual impairment also appeared in conflict with the role as a mother, and in turn, with the mother-child relationship. Having to be "the bearer of bad news" contrasted against the parental instinct to be encouraging and supportive of the child's wishes, as supported by "you don't want to be the person".

> Rosie: "one night we were talking about babies …And I say, 'When you're a mummy when you grow up', 'mummy, how can I have a baby?' and I says 'what do you mean?' and she says 'I wouldn't be able to make the food'… It just breaks my heart, she's quite clever at sort of thinking through, what she can do, and I find that really hard, I find it really upsetting."

While some children were avoidant of the future implications of their visual impairment, others showed greater awareness, which led to negative perceptions about their future. This created a need for parental reassurance, a form of managing expectations that contrasted against needing to be "the bearer of bad news". However, despite wanting to give parental reassurance, this proved difficult "I find that really hard" when faced with the child's own realism "she's bright enough to know". As the child came to terms with what their potential future might look like, the parent was also forced to acknowledge the potential negative implications of their child's impairment, creating a sense of loss on the child's behalf "It just breaks my heart".

Protectiveness - "There is More Vigilance" Versus Unwrapping the Cotton Wool - "We Are on this Independence Path Now." Many mothers engaged in a discussion of the issue of being protective of their visually impaired children, versus a desire to take a step back and be more promotive of the child's independence:

> Susan: "I think as a mum, as a VI parent, you protect your child a bit too much … it's sometimes easier to put his shoes on … than for him to go and find them and put them on himself … we are on this independence path now where I have to sort of take a step back …it's really hard for you to see your child struggle."

Mothers frequently showed awareness of their own protectiveness "I know I am more vigilant", and this awareness was accompanied by self-criticism for being overprotective "you protect them too much". Interestingly, being protective was for one parent, firstly cited as part of the role of being "a Mum" (implying that all mothers struggle with this issue), but later changed to relating to the role "as a VI parent", suggesting a further need for protectiveness that was attached to this unique identity. Along with self-criticism, parents felt guilty for providing their child with extra help, in what was perceived by them as taking the easy option "it's sometimes easier to put his shoes on". There was an unspoken implication that things being "quicker and easier" in the short-term might be detrimental to the child's independence later on, with a cost-benefit ratio of the emotional turmoil of "seeing your child struggle", versus "every struggle" being "a success" for the child, and by extent the parent. The sense of security and stability afforded by protectiveness "he wants everything in one place not to move" was contrasted against a need to simulate a more realistic representation of the ever-changing nature of life "but that doesn't happen in life, does it?". Therefore, the natural parental instinct of wanting to protect one's child was exacerbated due to the child's impairment i.e., the added pain of watching the child "struggle" with things that other children could accomplish more easily.

> Pam: "I started seeing some children with special needs and the way the parents where molly coddling them … and the kids weren't able to do anything you know and it was such an eye opener … thinking I don't want my daughter to be one of those children! … I decided that she is gonna be treated as a normal child"

Comparison was also a significant influence on wanting to avoid being overprotective “the way the parents were molly coddling them”. Parents were seen as the cause of visually impaired children’s lack of independence, prompting an active attempt to avoid self-blame and a sense of failure as a parent. There was frequent reference to maintaining a sense of normality within the context of parenting style “she is gonna be treated as a normal child”. The phrase “I decided” implied taking back a sense of control within the uncertain situation of visual impairment, leading to a greater sense of parental success.

Relationships with Siblings.

Parental guilt - “I don’t want my other son to resent that.” When the visually impaired child had non-disabled siblings, parents cited the dilemma of needing to spend more time supporting the visually impaired child’s needs, versus feeling guilty that the child’s siblings might perceive this extra time as neglectful towards them:

> Tess: “we got another son, he is younger … he doesn’t have any impairments so, I am always very conscious of the time and energy we are having to spend getting stuff sorted for our son who is vision impaired … and I don’t want my other son to kind of resent that or think ‘why do you have to spend all that time’.”

Guilt coincided with consideration of the impact of childhood visual impairment on sighted siblings within the family. Parents expressed concern over the extra time and effort involved with caring for the visually impaired child, and were anxious about how this might be perceived by the child’s siblings “I am conscious of … all that time spend”. Guilt arose when the comparison between the “time and energy” spent on the two children was seen as being unequal, leading the parent to feel that they were neglecting their sighted child. This feeling of guilt led to anxiety that the sibling might “resent” this differential treatment, which could then negatively impact both the sibling’s relationship with the parent, and the visually impaired child. This resentment appeared to be anticipatory on the part of the parent, rather than being an actual expression on the part of the sibling.

> Pennie: “his brother is a very caring person …you can see he has taken on … partly a carers role as well … he is very aware of his brother’s disabilities and what he is capable of and what he isn’t … and generally will kind of try to adapt things.”

There was also a slight element of guilt when discussing the fact that sighted siblings had adopted a “carers role” subsequent to interacting with the visually impaired child. Guilt arose when considering the extra responsibility that the sibling was perceived to have, mirroring the parent’s own increased awareness and vigilance. However, this possible guilt was overshadowed by a sense of parental pride that the sibling was learning positive traits from their experience (i.e., being more “caring”).

Sibling Comparison - “Why Can’t I Do That? Why am I Not Doing That?” Mothers described having observed comparisons between their visually impaired and sighted children, as well as the visually impaired child making comparison with their siblings. Pennie, a mother of twin boys (one with a visual impairment and one without), observed that her visually impaired son often felt unequal to his brother in terms of physical ability, which created feelings of envy and frustration:

> Pennie: “the jealousy from Tom’s point of view, he can get very, very jealous …and the things that his brother can do and he can’t …with him just getting angry at his brother …because he wants to be able to do what his brother is doing … why can’t I do that? Why am I not doing that? And then that’s hard on us, I have to explain that … you can’t do that.”

The visually impaired child’s frequent questioning and comparison to their sibling “why can’t I do that? Why am I not doing that?”, were perceived by the parent as almost accusatory, leading to feelings of helplessness and guilt. As was the case with managing the child’s expectations (previously discussed), parents were placed in the awkward position of having to explain to their visually impaired child that they were sometimes physically unable to do the same things as their siblings. The parental distress at observing sibling jealousy reflected feelings of loss, i.e., the parents (and the siblings) were missing out on the natural mirroring of behaviour, promoting growth within the sibling relationship.

> Emily: “she has got two younger sisters … obviously they still want to look up to their older sister but then she is not necessarily doing things, that they want to aspire to … I think they find it quite bel- bewildering …what they can do with her and what sort of games they can play with her … it’s sort of tainted every part of their relationship really.”

Emily, mother of a fifteen-year-old girl, described how her daughter’s siblings seemed to have overtaken their sister developmentally. Again, there was an underlying sense of loss, in that the siblings no longer felt able to “look up to their older sister". Therefore, Emily felt that her sighted children had lost an "older sister" in terms of having a role model and someone to "aspire to", while the visual impairment had robbed the affected child of the opportunity to be this role model. Her extract ended with the emotive phrase "it's sort of tainted every part of their relationship", which epitomised Emily's sense of loss on behalf of herself, the visually impaired child, and the child's siblings, with resentment towards the child's impairment for causing this loss.

4.3.4 Beyond the Family

Dealing with Difference. ***Breaking the news to others***. The dilemma of telling others about their child's visual impairment was heightened by the emotional difficulty of receiving sympathy and pity from others. Others were perceived as directing unwanted sympathy towards the parent "feel like really sorry for you", which was perceived by some as being more emotionally challenging than receiving the child's diagnosis, possibly since parents felt forced to respond to others negative emotions in addition to their own.

> Tess: "the most difficult was, kind of having to tell other people… I think other people's immediate reaction to that kind of news is to feel like really sorry for you …I didn't really want that … I think the reaction of some of our family to it, my husband's mother, she rang people up and cried … I found that more difficult … then actually just getting the news in the first place."

There was an underlying sense of frustration with other family members who became emotionally distressed by the news "she rang people up and cried". Since pity from others was rejected, there was a perceived pressure to be emotionally strong, where showing negative emotions would result in others "feeling sorry". Therefore, there was a slight element of envy towards other family members for being able to fully express their emotions, emotions that the parents were still grappling with themselves.

Other mothers expressed their frustration of receiving pity from others more explicitly "I just want to stick it up somebody's nostrils!".

> Rosie: "then I had to ring everybody and tell them what was wrong, I couldn't face anybody, …' people used to drive me mad 'cos it was all just Irish blessings, 'God bless yours' and I just want to stick it up somebody's nostrils… There was 6 of my old school friends, and we all had babies within 4 months of each other, I can remember the first time coming in with her, and everybody just sat there and just pretended, it was like the elephant in the room! … Right she's

> blind, … that was really hard… steeling yourself to go in… see the other babies …thinking right okay, you know what, this is it, … or you missed an opportunity bringing it up or, there's always a point when you're thinking oh when shall I say?"

The perceived need to break the news to others "I had to ring everybody up", contrasted against the trepidation of how others might react, particularly other mothers "it was like the elephant in the room!". Seeing "the other babies" implied feelings of social alienation by prompting focus on the child's perceived difference, along with anxiety over the uncertainty of responses from others. The parent would then "steal" themselves to almost forcefully disclose the child's impairment "right she's blind". In bringing it up themselves, parents were taking control over the situation, initiating responses from others, allowing them to be curious and allowing the parent to respond to their curiosity. Nevertheless, uncertainty and apprehension over when to disclose the impairment was still experienced. This dilemma was illustrated by "you missed an opportunity … when shall I say?", indicating ongoing self-criticism at having missed an opportunity, along with vigilance of the 'right' time to disclose.

> Emma: "We had to tell our families … and I've found that quite hard, … especially my nan, … she got really upset over it…and I think I bottled it up a little bit … So as much as I was upset, I was keeping my … upset until it was just me and my husband, I wouldn't show anybody else".

Moreover, the emotional consequences of the child's diagnosis (rather than the diagnosis itself) was particularly challenging when disclosing to others. Contrasted with the reluctance to tell others for fear of pity, other parents felt a responsibility to protect extended family members from the emotional distress that they themselves were experiencing. This was achieved through suppressing their own negative emotions whilst around others "I bottled it up", in the hope that others would mirror this in also not expressing their negative emotions.

Pity from Others – "She's Not a Pet, She's a Human!" Mirroring the aforementioned reluctance to disclose the child's visual impairment to others for fear of pity directed at the family, mothers showed a strong rejection of pity directed at their child when encountering strangers. This was reflected in the phrase "She's not a pet, she's a human!", in that treating the visually impaired child with pity was equated with a failure to view the child as a "human" with their own independent thoughts and feelings.

> Rosie: “even now, when she uses the cane and we walk down the street, I’m not joking I would have about 4, 5 ‘oh poor wee pet, wee pet’… She’s not a pet, she’s a human! She can hear you!”

This was further emphasised by “she can hear you!”, demonstrating frustration that the child was almost seen as being invisible, aside from their impairment. There was an overall sense that the parent perceived others to be considering their child as an incomplete person in the absence of the child’s vision, which manifested itself in expressions of pity. Another parent described how others expression of pity initially echoed the parent’s own sense of loss for their child “I felt sad too when I found out”.

> Susan: “as soon as I would introduce my son … and say ‘he can’t see very well’ … they would go ‘aw bless, that is such a shame’ … and they would feel really sad and I felt sad too when I found out but that’s not helpful for him … it’s not helpful for any person with a disability to feel like they are a burden or feel pitied … so I have taken quite an active stance in trying to … get rid of that pity …and confront people and say what if they saw him now … … he is alive, he is having a good life …and the only issue is that he doesn’t see things our way!”

However, the mother rejected her own feelings of pity and loss upon the realisation that such feelings might be detrimental to the child, and to society as a whole when considering pity directed at “any person with a disability”. This latter consideration might have implied thoughts directed at the child’s future in a society that expressed pity towards disabled individuals “to feel like they are a burden or to feel pitied”, prompting the parent’s conscious effort for changing and challenging others perceptions towards the child “what if they saw him now … he is having a good life”. In challenging negative perceptions, the parent felt that the first step towards this was proving to others that “a good life” was still possible despite visual impairment.

Feeling Judged – “You Have to Explain to Everybody.” Several parents cited their feelings of being judged by others on the basis of their child’s impairment, and others’ perceptions of the child’s difference:

> Samantha: “some days it’s like, “god, does he have to go out with a t-shirt on…” “Like a banner!” … he’d be constantly running into people … and it’s like people’s attitude were like “oh, what’s he doing”, and “control your kid”, I say, … you don’t have to have a badge or be in a wheelchair, to have a disability!”

Throughout extracts, there was a clear sense of the parent’s mental exhaustion when encountering strangers, and the parent’s anticipation of negative perceptions. In one extract, it was possible to almost hear the parent's internal sigh of enervation and resignation, when stating "feeling like you have to explain to everybody".

> Laura: "feeling like you have to explain to everybody …what the situation is … what his condition is … what it means for him … having to explain … why he does … the things that he does … why he walks the way he walks … why he plays the way he plays … why he eats the way he eats … it's having to explain … at every point … why he does what he does."

The extract was also illustrated by repeated use of the questions "what" and "why", i.e., "what his condition is … what it means for him" and "why he plays the way he plays … why he eats the way he eats". These questions emulated the queries that the parent thought others might have about their child, where the parent was pre-empting these questions and felt a necessity to respond to them before they were even asked. The pre-empting on the part of the parent, was a possible attempt for them to avoid negative judgment from others, whereby responding with explanations was seen to alleviate curiosity and potential tension for others. However, this tension was not avoided by the parent themself, since they demonstrated anxiety and anticipated judgment in the absence of their explanations "having to explain". Other extracts depicted anger at others for making negative judgments of the child's behaviour resulting from their impairment. The only way to avoid judgement from others was to openly disclose the child's impairment to others (as with the previously discussed need for explanations). The use of a "T-shirt" or "banner" was an exaggerated metaphor for advertising the child's impairment, further portraying frustration at others misunderstanding of invisible disabilities "you don't have to have a badge or be in a wheelchair". Judgment from others was often directed at the parent rather than the child, illustrated by phrases such as "control your kid". Parents felt they were being labelled as inadequate in their parenting skills, leading to others assumptions that "oh god, this is a nightmare of a child", i.e. comments explicitly directed towards the child in fact had underlying direction towards parents. While some parents felt judged due to their child's behaviour, others felt they were being judged for the child's impairment itself. One parent described being regarded almost as the one to blame for her child's impairment "almost like accusatory … Like, why would your child have that". This feeling that others were casting blame possibly echoed the parents own insecurities and sense of guilt for the child's impairment (discussed previously).

> Helen: "you almost need to be quite resilient as well because when you are out and about with a very young child … with a cane … people give you funny looks … I can't quite get the right word but "look at you" … just almost like accusatory … Like, why would your child have that?"

Outside Support.

Feeling alone – "who's there on the other end of the phone? Who?"

Mothers often felt as though they were dealing with their child's impairment on their own, with little or no perceived support from outside of the family.

> Rosie: "it is very hard, 'cos it's like when we were taking her to the hospital, someone's going to come out and have a chat to us and tell us what's next, and nobody comes. You're very much on your own, I find that very, very isolating."

This sense of isolation was particularly prevalent during the child's initial visual impairment diagnosis, where parents expressed significant uncertainty, and wanted information and answers "I don't know how to do that, I don't know where to go, I don't know who to ask".

> Daisy: "I feel okay when I've got other people that I can ask … but when I was first dealing with it, we didn't know of any groups … I don't know how to do that, I don't know where to go, I don't know who to ask."

Repetition of "I don't know" emphasised this uncertainty, helplessness, and frustration, leading to isolation "there was nobody", and a further sense of inadequacy and incapability to deal with things alone "we can't do this". In one extract, the sense of being isolated and alone was described using third person speech "they feel like they are on their own".

> Pam: "sometimes they feel like they are on their own … other people … they don't live with it day in, day out …it's not something that you actually talk about …it's kind of like, we live it! Day in, day out … they don't actually see all the things that we do … the challenges that we come across and the hurdles that we have to jump to get to where we need to be … I do think there needs to be more! Support groups … Who, who, who listens to them when they are having a bad day, when they are crying for help who's there on the other end of the phone? Who?"

Here Pam was expressing feelings of isolation and abandonment, through the paradoxical recognition that other parents may also be experiencing these feelings. Therefore, although parents felt alone, they were united in this aloneness. There was a sense of being isolated from other families without visual impairment, where the impairment created perceptions of difference and separation from others “other people … they don’t live with it”. The phrase “day in day out” highlighted the parent’s exhaustion at having to deal with their child’s impairment without outside support or understanding from others “they don’t actually see all the things that we do”. The statement that “it’s not something that you actually talk about” suggested reluctance to open up about the struggles and challenges, possibly due to the fact that these struggles were not shared and therefore not understood by non-visually impaired families. This was supported by the affinity and unity towards other parents of visually impaired children “we live it!”. Aloneness was perceived to be a result of the lack of an outlet for parents to share their experiences and struggles. This lack of outside support then exaggerated the parent’s anxiety regarding their own capability to look after their child “is it the right way or the wrong way?”. Caring for a visually impaired child was likened to the oxymoron of “having a baby … this baby has grown up”. Therefore, all the uncertainties and doubts of early parenting persisted and could not be alleviated by calling on others for help. The striking portrayal of helplessness and abandonment resonated through the parent’s call of “where do they go? Who listens to them”, simultaneously signifying a cry for help and a demand for more readily available support.

Increased Connectedness. Following on from the negative implications of a lack of outside support for families of visually impaired children, increased opportunities for connecting with other families of visually impaired children was cited as being extremely important and meaningful both to parents, and to the visually impaired children themselves:

> Daisy: “So when he was little he used to do a lot of this “well I can’t get a job because I am blind”, … And then we started going to the RNIB stuff, and that was really helpful because there were kids there who were fully blind… who were going off and doing things … it would be really important for him going forward … to have other friends with visual impairment … ‘Cos I think, he is focussing on stuff that his mainstream friends are focussing on … because that’s all he’s got.”

Firstly, mothers felt that their child’s connectedness to other visually impaired children should be encouraged, since it was perceived as beneficial for positive growth, along with the child having new role models to aspire to “there were kids there who were fully blind… who were going off and doing things”. The potentially negative consequences of the child exclusively socialising with sighted children were voiced “he is focussing on stuff that his mainstream friends are focussing on … because that’s all he’s got”, implicating that the child might be socially limited without interacting with similar others. This linked back to the idea of managing the child’s realistic expectations in light of their impairment, since increased connectedness to other visually impaired children might make it easier for parents to manage unrealistic expectations, whereby the visually impaired child could be encouraged to manage their own expectations.

> Rosie: “we’ve made lots of friends with other families as well, and lots of people come and meet us or tell us when their child is born. I suppose that they like to have a chat and what our experience is as well, ‘cos I know what it’s like to be there, at that point…with a baby that’s born and you think they’re not going to see, … they have a thousand, thousands of questions about the future like, and you want to know, I think that’s just the way you are at that time as a parent, you want to know all those things.”

In addition to the positive implications of greater socialisation within a visual impairment context for the child, parents also found that increased connectedness with other visually impaired families to be of invaluable benefit. In contrast to the sense of helplessness and uncertainty resulting from feeling alone, families felt a sense of unity and empowerment at being able to offer support to other families sharing similar experiences “I know what it’s like to be there”. Parents felt they were making a positive difference to the lives of others by using their own experiences (often of uncertainty and isolation) to help and support others “you want to know all those things”. Parents recognised themselves as the true experts on living with visual impairment as a family, and felt ready and willing to share their knowledge with other families.

4.4 Discussion

4.4.1 Implications of Diagnosis Experience

The present study described an overwhelming experience for mothers at the time of their child’s visual impairment diagnosis. Previous studies have coined the term ‘rollercoaster’ when describing the spectrum of emotions for parents following diagnosis (Harvey et al., 2013). Mothers in the present study oscillated from the hopes and aspirations following the birth of their child, to fear of what ‘blindness’ might entail (e.g., Sikora & Janusz, 2014). Therefore, the rollercoaster reflected contrasting psychological reactions for mothers. For example, the devastation of a child not having sight was followed by relief when considering the potential for additional life-threatening disabilities.

Supporting prior research, receiving a visual impairment diagnosis for their child was met with a psychological response comparable to a traumatic crisis, encompassing feelings of helplessness, along with a sense of loss of a fulfilled life for both the child and the family's potential future (Barbieri et al., 2019; Gyllen, Magnusson, & Forsberg, 2019; Turriff et al., 2020). This reaction was repeatedly echoed throughout mother's stories, regardless of the diversity of the children's diagnoses. A mother's sense of having lost an 'idealised baby' following a disability diagnosis has previously been linked to the mother's pre-conceived negative attitudes/beliefs about disability, along with the vulnerability of caring for a child belonging to a social 'out group' (Harvey, 2015). Mothers must consequently assimilate with this outgroup in order to form attachments to their child, a process which conflicts with their pre-existing negative disability conceptualisations. This was the case for most of the mothers in the present study, who were not previously aware of visual impairment as an intricate real-life experience, apart from medical or societal depictions of blindness. However, one mother was herself living with a visual impairment, and therefore had an insider's perspective on the potential experience of her child i.e., she already belonged to the outgroup. Nevertheless, her position of parental vulnerability persisted, since she felt penned in by the negative perceptions of others in society, shaped by her own past experiences as a visually impaired individual. While there is some existing research on the experiences of mothers with visual impairments, the mother-child experience when both are visually impaired has not been explored. Since findings within this context are limited to one participant in the present study, this is an interesting avenue for future research.

The present study lends support to prior studies that have reported experiences of guilt and self-blame among parents of disabled children, particularly where the child's condition is genetic (Williams &Schutte, 1997; James et al., 2006; von der Lippe et al., 2017). The concept of the 'inadequate mother' was highlighted, indicating a sense of punishment for having done something “wrong” during pregnancy (e.g., Landsman, 2009; Huang et al., 2010). However, contrary to findings that mother’s guilt decreased over time (Turriff et al., 2020), for mothers in the present study, guilt was “always there”, since each negative experience encountered by the visually impaired child throughout their development triggered the mother’s sense of responsibility for causing the impairment. This finding highlights the importance of considering emotional impacts such as guilt across different lifespan stages, not just at the point of diagnosis. By anticipating feelings of guilt, service providers may in turn be able to help parents recognise and be open in discussing these responses. Moreover, the opportunity for families to connect with others in a similar situation (discussed below), might also create normalisation of the guilt response.

Following their child’s diagnosis, mothers applied strategies to accept, manage, and improve the situation for the child. One such strategy was driven by feelings of desperation and a need for action, where mothers frantically tried to seek medical answers/interventions, in order to “fix” their child’s impairment. As Landsman (2005) has noted, most women go through pregnancy and childbirth within the context of the medical model of disability, where a ‘morally responsible’ mother should aim to cure the pathology with medical assistance. This model was most available to the mothers in the present study at the time of their child’s diagnosis, as supported by their need to “fix” what they perceived as a problem. Therefore, within the medical model, the ability to define or treat disabled individuals lies with medical professionals, and it is up to the disabled individual (or in this case, the parent), to seek such treatment.

The increasing popularity of the social disability model (where disability is a consequence of societal barriers), offers a newly available sense of meaning for mothers to make sense of their child (Landsman, 2005). The social model would therefore view a parent’s efforts to “fix” their child as misplaced, instead preferring efforts towards addressing societal barriers. Supporting Landsman’s observations, mothers in the present study initially adopted the medical model, whereby parental success was measured against the level of proactivity in seeking a medical cure. However, over time this stance evolved into a more social model focused view of the child’s disability i.e., mothers accepted that their child could not be “fixed”, and wanted to prioritise enriching the life of their child rather than living around medical appointments. This also supports the later theme of parental advocacy in the present study, whereby mothers increasingly focused on campaigning for accessibility rights (a social model behaviour).

Mothers’ experiences of guilt, uncertainty, and a need for answers indicates a potential benefit of reassurance and hope, in order for parents to mobilise their ability to overcome adversity (Nygard & Clancy, 2018). Within the context of visual impairment diagnosis in children, professionals such as Optometrists, Ophthalmologists, and Vision Rehabilitation Therapists are in the position of being able to communicate meaning and outcomes of a diagnosis to parents, offering reassurance and hope for a ’worthy life’ for the child (Milde et al., 2023). This is further supported by McDowell’s (2021) research with parents of a child with cerebral visual impairment, where medical professionals were shown to be in a unique position for empowering parents by providing precise and relevant information during the diagnosis process. While the present study did not explicitly examine the effect of hope on parental reactions to diagnosis, it does highlight the absence of hope for mothers, which was perpetuated by negative language used by medical professionals, who seemed to accentuate the child’s inabilities rather than abilities (e.g., Hogan, 2012; Naseef, 2001). The present study therefore offers medical professionals within the field of visual impairment an insight into what approaches might help parents at the time of diagnosis, and what approaches might be detrimental to their psychological reorientation into a new situation.

4.4.2 Implications of uncertainty

Even after the child’s initial diagnosis, uncertainty for the mothers in the present study persisted for a number of reasons. The first reason was completely unique to having a visually impaired child, and was an unexpected response during interviews; several mothers expressed a wish to know what their child could actually see. There is very little research examining the experience of visually impaired individuals describing their vision, where the experience only appears to have been explored as an unforeseen issue during research with visually impaired adults (e.g., Koca-Atabey & Öz, 2017). In their study, Koca-Atabey and Öz (2017) noted the irony that all participants attempted to describe their vision when asked, even those who had been blind since birth. In the present study, mothers had voiced the question “what can they see?” however, the issue of knowing the child’s vision was further complicated by the child’s limited descriptive capability due to their age, but also the fact that the concept of vision is socially constructed (Koca-Atabey & Öz, 2017). For older children, the phenomenon seemed easier to describe to their parents, although a more enlightened answer was just as distressing for mothers. The experience of visual impairment is more than just the absence of sight; a sighted person would be unable to simulate true visual impairment, since they would still have visual memory of shapes, colours, or figures (French, 1992; Hull, 2001). Therefore, if sighted individuals cannot truly experience visual impairment, then it may seem unreasonable to expect visually impaired individuals to describe vision (Koca-Atabey & Öz, 2017). This disparity in experience may account for the sense that the mothers had lost a fundamental connection to their children through shared visual experiences, which reinforced their desire to achieve closeness to their child through knowing what they could see.

In addition to the anxiety over what their children could see, mothers in the present study were hyper-aware of their child’s development and behaviour, where they engaged in social comparison with other children to try and determine the ‘normality’ of their own child’s behaviour. Mothers making comparisons between their children and other children is not unique to the situation of raising a disabled child, where parental comparison arises at any given opportunity (Borget, 2014). These comparisons may be beneficial in some circumstances i.e., parents are often encouraged by paediatricians to compare their child’s development with that of other children, to gage normal development (Bellman, Byrne, & Sege, 2013; Bennett, 2013). However, a growing body of online parent blogs/magazines have proposed that parental comparison may be detrimental for the child (e.g., Thomson, 2013).

Despite anecdotal evidence and advice from paediatric specialists, little is known about the effects of parental social comparison on parents emotions and child development. Even less literature exists regarding parental comparison within the context of childhood disability. The potential detrimental effect of comparison may be particularly relevant to the context of childhood disability such as visual impairment. For example, findings from the present study suggest that, when comparing their visually impaired child to sighted children, parents are implementing a medical model view of their child, focusing on the idea of ‘normality’ and difference in their child (discussed above). Consequently, any disparity between children relating to development or abilities is presented as a downward social comparison for parents, leading to anxiety and a sense of loss. However, when comparing their children with other visually impaired children, mothers felt that these comparisons were more realistic, and empowered them to see the potential in their own child's abilities. This highlights the importance of social support for families living with visual impairment, that includes forming connections to other families in a similar predicament. This would allow the formation of parental social comparisons that are beneficial to both child and parent.

The concept of uncertainty was additionally linked to a need for planning. This was characterised by strict family routines, along with parental hypervigilance of any environmental changes/unfamiliarity that might trigger anxiety for the child. Therefore, the need for routine served to both alleviate the child's anxiety and manage parental stress when in unpredictable situations. Nevertheless, the process of maintaining stringent routine and awareness of surroundings was still often stressful and draining for mothers. Family routines allow for temporal order to daily life, along with structuring of family activities (Boyce et al., 1983; Larson, 2006). Using the literature example of Autism Spectrum Disorder (ASD), which often overlaps with childhood visual impairment (Mukaddes et al., 2007; Lund & Troha, 2008; Absoud et al., 2011), the concept of routine increases predictability for the child, allowing for easier family participation. However, this same predictability does not allow the child to experience improvisation (Larson, 2006). These sentiments were echoed in the present study. However, the need for planning and routine was also linked to high anxiety in the child, when in unfamiliar surroundings or in the absence of detailed environmental descriptions from mothers. This resulted in mothers feeling consumed by planning/routines (Marquenie et al., 2011), which increased their own anxiety (e.g., Boyd, 2002). Fear has previously been cited as a feature of childhood visual impairment (Ollendick, Matson, & Helsel, 1985; King, Gullone, & Staford, 1990; Salha, 2007), particularly in environmental contexts e.g., fear of unfamiliarity, falling, or social embarrassment (Jackson & Taylor, 2000; McKean-Cowdin et al., 2008; Ray et al., 2008).

Due to the loss of sight, visually impaired individuals must rely on their parents (particularly mothers) to access the physical world (Kekelis & Prinz, 1996;

Conti-Ramsden & Perez-Pereira, 1999; Perez-Pereira & Conti-Ramsden, 2001). For mothers in the present study, directive interaction was viewed as an appropriate response to their child's needs, despite the potential perpetuation of anxiety for both child and mother. However, mothers being hyper-attentive was also a response to parental guilt. This study offers a unique perspective on the impact of stringent family routine in visual impairment, beyond the early years of child development. Further research might examine the potential bidirectional link between family routine and ASD-type behaviours in visually impaired children.

4.4.3 Implications for Family Relationships

The present study highlighted the adoption of several roles in addition to the 'mother' role, due to the child's visual impairment. Within previous literature relating to childhood chronic illness, a loss of the 'parent' role has been identified (e.g., Fernandes, 2005; Rempel et al., 2013; Sikora & Janusz, 2014; Jordan et al., 2014). Having to relinquish parental choice/decision-making to others e.g., medical professionals resulted in a lack of autonomy, leading to loss of the 'mother' role (Fernandes, 2005; Jordan et al., 2014). Conversely, it has been suggested that parents are able to find new roles following diagnosis of their child's condition (Clark & Miles, 1999; Harvey et al., 2013; Kosta et al., 2015; Meakins et al, 2015). For example, Rempel et al., (2013) and Meakins et al., (2015) reported that parents gained a sense of autonomy when they were able to become more involved in monitoring/managing their child's condition. In line with this latter finding, the present study reported mothers gaining a new role in addition to their primary role as the child's parent, described as a "carer" role. "Carer" was an interesting self-terminology, since it implied the physical responsibilities/demands of caring for the visually impaired child. However, in reality, the carer role produced a far deeper emotional bond between mother and child, that was intertwined with the physical support-giving. The emotional aspects of 'caring' were appreciated positively by mothers, since they felt closer to their child. At the same time, mothers were aware of the potential for the "carer" role to cause friction within the relationship. As the first study in the present research series has indicated, adults with sight-loss may feel resentful of receiving practical support from others e.g., family members. However, this aspect of support-giving has not been explored in visually impaired children, which constitutes a potential area for further research.

The “advocate” role was taken on by most mothers in the present study, which had additional emotional dimensions to simply being a mother. Supporting prior research (e.g., Lee et al., 2014), mothers in the present study were frustrated at the lack of visual impairment awareness and availability of support for their children. Although responses were primarily child-focused, findings also indicated that lack of support extended to mothers themselves, where advocacy subsequently included fighting for their rights as mothers. Mothers therefore felt they had no choice but to advocate for their child, culminating in feelings of exhaustion and aloneness. Though the necessity of advocacy has been previously cited (Bacon & Causton-Theoharis, 2013), the present study gives insight into the emotional depth of the advocacy experience. For example, the extroverted position of being an advocate did not come easy to every mother, where some felt they needed to actively fight against their natural personality traits in order to fight for their child. The present study suggests that mothers may be susceptible to experiencing stress and anxiety as a result of having to advocate for their children (Sakkalou et al., 2018; Lupón et al., 2018). If mothers do not feel empathised with or listened to, they may subsequently experience isolation (Dunn et al., 2001). This again raises the idea of social support sources for parents, in order to cope with uncertainty and combat their sense of aloneness (Tröster, 2001).

In addition to raising awareness about visual impairment within wider society, mothers were tasked with communication to their children about what visual impairment might mean for them and their future. While mothers were very supportive of their child’s choices for their future, some felt that the child’s visual impairment might prevent them from pursuing certain vision-oriented careers. However, children became resistant to this ‘realism’, which resulted in mothers fearing that their opposition to the child’s wishes might encourage unrealistic career choices. Shah (2010), in their study on the role of parental empowerment within childhood disability also reported this conflict. It has been argued that parental attitudes toward their child’s career aspirations reflects medical model thinking, which emphasises the child’s inabilities, rather than a society that needs to change (Priestley, 1998). Therefore, parental preconceptions are shaped by the child’s impairment level, and result from bringing up a disabled child within a non-disabled world (Shah, 2005). However, present findings do not align with this explanation, since rather than perceiving their expectations as lowered, mothers instead regarded them as ‘realistic’ in terms of the child’s actual abilities (e.g., a visually impaired child would not be able to drive a bus). In fact, the overall stance of expectations of their children was one of empowerment and positivity. This is supportive of work by Wood (1973), proposing that parents who are nurturing and supporting of their child’s Self-esteem, provide optimum opportunities for the child’s development and potential. This parent-child relationship was apparent within several of the present narratives.

The present study findings made frequent reference to the parental behaviour of protection, where mothers felt they had to be more vigilant towards their child’s needs. This protection was often accompanied by self-criticism for what was perceived as taking the easy option i.e., physically assisting the child was seen as easier than teaching them independent skills. Mothers in the present study also described conflict between wanting to make life easier for the child through protection, versus being more proactive in promoting the child’s autonomy/independence (Anderson & Coyne, 1993).

The struggle to balance responsive parenting and overprotection has been shown in previous research, as demonstrated by the quote “How much do we protect her and how much do we just let her live life?” (Rempel & Harrison, 2007, p. 829). Mothers in the present study feared parent-child tension resulting from overprotection (e.g., Anderson & Coyne, 1991; Collins et al., 1995; Collins et al., 1996), demonstrating self-awareness and a desire to change behaviour, even though this clashed with the directive of protecting the child. One feature of ‘unwrapping the cotton wool’ was behavioural normalising, where mothers consciously tried to view and treat their child as “normal” e.g., “She’s very normal” (Lee & Rempel, 2011, p. 184). Carey et al. (2002) also reported normalising, characterised by parental cognitions/behaviour towards their child; “I treat him like a normal kid” (p. 19).

The present study adds an extra dimension to research on overprotectiveness within the context of disability, since it identifies parental desires to refrain from being too overprotective. However, ultimately, the overprotective behaviour over-rode this desire, which possibly accounts for the high levels of overprotection reported in previous studies. Given the high parental investment of time and energy into providing sensory stimulation to visually impaired children during early development, it is perhaps unsurprising that this parenting intensity would continue as the child grows, manifesting in overprotectiveness.

During narratives, mothers also described how their visually impaired child had impacted on sibling relationships, and how the mothers themselves perceived these relationships. In addition to parental guilt for the visually impaired child, mothers reported an extra layer of guilt for potentially neglecting their sighted children whilst having to provide extra help to the visually impaired child. However, this guilt was based more on parental anxiety over the asymmetry of their relationships with their children, than on actual expressed negative outcomes from siblings. Role asymmetry was also observed between the visually impaired child and their siblings, where the sibling often took on a ’carer’ role, placing them in a more dominant position (e.g., Stoneman et al., 1991; Knott et al., 1995; Cuskelly & Gunn, 2003). However, contrary to the concept of role strain for siblings of disabled children (e.g., Pearlin, 1989; Pearlin et al., 1990), the present study reported primarily positive effects of the ‘carer’ role, such as increased empathy for the needs of others (Flavell et al., 1968; Cuskelly & Gunn, 2003).

Present findings call for caution in the typical empirical response of pathologizing disability-related relationships and interactions, such as the theoretical position that childhood disability is ‘bad’ for siblings (Stoneman, 2005). Nevertheless, it should be noted here that the presently reported positive impact of sibling roles has only been described in relation to visual impairment; other childhood disabilities may well lead to role strain in siblings due to more demanding caring responsibilities. Despite some positive impacts, there was an element of parental sadness that some younger siblings had bypassed the visually impaired child regarding development, a concept termed role crossover (Farber, Jenne, & Kirk, 1963). Moreover, sibling conflict was described, particularly relating to visually impaired children making comparisons to their sighted siblings.

Although the content of sibling conflict/comparison was visual impairment-specific, this still raises the question as to what constitutes an ideal sibling relationship as a standardisation for disability-involved relationships. Much of the sibling literature within a disability context is not based on a universal theory

(Stoneman, 1993), which may explain contradictory findings within previous literature, as well as the present study.

4.4.4 Implications Beyond the Family

Along with psychological implications of childhood visual impairment for the immediate family unit, the present study has highlighted several findings relating to interactions outside of the family, such as mothers disclosing their child's impairment to others, and availability of family social support. Landsman (2009) has noted that, rather than the typical response of congratulations at the birth of a child, mothers of disabled children often experience treatment from others implying tragedy, as if they have "no baby to celebrate" (P. 57). Mothers in Landsman's study described feeling isolated due to others not knowing how to approach the concept of the child's disability. These sentiments were echoed in the present study, where extended family members were openly devastated by the news of the child's visual impairment. This contrasted with the mother's own need to remain strong both for her child and extended family. Awkward social interactions were also reported, particularly with mothers of non-disabled babies, where mothers in the present study were over-analytical of their desire to disclose their child's impairment; "the elephant in the room", versus anxiety over negative social reactions.

One such negative social reaction highlighted by mothers was pity, to which mothers responded with frustration since they felt it was devaluing to their child. Pity has been described as an ablest emotion from the non-disabled imagination (Hughes, 2014; Loja et al., 2013; Carel, 2018). Pity may stem from fear and acknowledgement of one's own vulnerability i.e., disability could happen to anyone (Michalko, 2009a). Such interactions leave disabled individuals (and by extent, parents of disabled children) feeling awkward and hurt. Beauchamp-Pryor (2013) suggested that non-disabled attitudes of pity reflect enduring medical model thinking i.e., disabled individuals have a deficit that requires care. Therefore, it is unsurprising that these attitudes create distance between disabled and non-disabled individuals (Hughes, 2014). This distance was also observed in the present study, where the mother's own passion for advocacy and equality for their children, felt far removed from a society full of pity and focus on the child's inabilities. Goffman (1963) argued that when non-disabled individuals increase their exposure and interaction with disabled individuals, they become “wise”. Taking this view, the present study highlights a need for more education and information in order to effectively evolve societal attitudes towards disabilities such as visual impairment (Heijnders & Van Der Meij, 2006).

In addition to experiencing pity from others, mothers noted a reoccurring sense of being judged when out in public with their child, often resulting from the child’s use of adaptive aids or exhibition of ‘different’ behaviours. These negative social encounters left mothers feeling exhausted, and as though their parental competency was being questioned. Societal stigma towards families with a disabled child has been frequently cited in disability literature (Heng-hao, 2009; Richardson& Fulton, 2011), which represents an additional challenge for parents, on top of having to manage their child’s disability (Kayama et al., 2017). This may result in parents feeling excluded from society, or that they are ‘bad parents’ (Green, 2003; Findler, Jacoby, & Gabis, 2016). In order to pre-empt and tackle negative social perceptions of their children, mothers in the present study reported feeling a need to ‘explain’ their child’s condition/behaviour to others, which they saw as a way of breaking down social barriers.

The perceived need for advocacy from mothers for their children was supported by Rocque’s (2010) study with mothers of children with Autism. Mothers in Rocque’s study were proactive in approaching others in order to explain their child’s disability, in order to mediate uncomfortable reactions. Again, this raises the need for increased awareness/education for wider society. As the present study indicates, parents are currently doing much of the work in this regard, and they are feeling the strain as a result of having to be the sole advocate for raising awareness.

Lastly, the present study demonstrated that visual impairment-specific family groups/charities provided a much-needed source of social support for both mothers, and the visually impaired children themselves. Participants reported benefits of connecting with other families, where they were able to share and receive information from others who understood their own experiences. These findings are in line with prior quantitative literature, which reported benefits of family support groups, such as learning from others’ experiences, and being able to problem-solve as a group (Law et al., 2002; Kingsnorth et al., 2011; Shilling et al., 2015; Hayles et al., 2015).

Another element of the need for peer-support was mothers' connectedness to others in a similar situation, which supports the idea of sharing a social identity within an alike group (Shilling et al., 2015) and a sense of belonging (Solomon et al., 2001). Along with receiving support from others, mothers in the present study reported benefits of being able to reciprocate support themselves, where they felt able to utilise their expertise as parents to make a positive difference to other families. This support reciprocity has also been previously reported as an essential element of social support for families living with disabilities (Kingsnorth et al., 2011; Reid et al., 2011; Shilling et al., 2015). Nevertheless, despite the positive impact of social support reported, several mothers in the present study experienced aloneness regarding their journey through parenting their visually impaired child. Feeling alone is consistent with findings by Mackey & Goddard, (2006) and Murphy et al. (2006).

A possible explanation for the connected/alone discrepancy in support experience is that, while mothers appreciated being able to share their experiences with others families, they also wanted a more regularly available outlet to voice their everyday challenges of raising a visually impaired child. This was portrayed by the expression of having someone "at the end of the phone". The experience of aloneness was even more interesting given that participants were recruited from an online support group page for families. This indicates that, although much progress is being made towards increasing support services, this has not yet eradicated families feeling that they are on their own. This may be due to the fact that use of social media support groups might feel less tangible (e.g., Hill, Bennett, & Hunter, 2022), whereas parents desire more support in the 'real' world.

4.4.5 Evaluation and Summary

All mothers in the current study were recruited via support groups, which indicated their proactivity and resourcefulness in seeking beneficial services for their families. This sample bias may in turn implicate increased availability of personal resources to psychologically adapt to their child's visual impairment over time as well as the perceived importance of social support. Thus, findings may not be generalisable to all mothers of visually impaired children. Moreover, several concepts discussed in the present study, such as the psychological impact on siblings, were filtered through the observations/interpretations of mothers. It cannot be assumed that the opinions and experiences of mothers are representative of the true experiences of other family members, such as siblings or the visually impaired child themselves.

The present study's findings are based on recall rather than direct observation of their interaction with others e.g., their child, healthcare professionals, or other relevant sources of relationships. Although this may constitute a study limitation, the main purpose of the study was to provide an insight into mother's subjective experiences of living with their child's visual impairment as a family. Consequently, data comprises memories of reactions, and not the true accuracy of events. What 'really' happened was not the focus of the study. Instead, retrospectivity allowed mothers to reflect on their thoughts/feelings (present and past) throughout their experience of their child's visual impairment. Again, it is not assumed that stories told in interviews were reconstructions of actual events.

While the present study was exploratory in nature, it offers several bases for further research (as mentioned in previous sections). Most significantly, replication of this study would be beneficial in order to widen the scope of insight from other family members, such as siblings, fathers, and extended family members. There is no perspective from fathers to draw on from this current data, and therefore their role in family psychological adaptation remains little understood. Hence, research with fathers is needed, along with the interaction of mothers and fathers relating to important events within the visual-impairment experience, such as initial diagnosis.

As stated above, mothers in the present study were largely able to be resourceful in adapting to their child's impairment. Future research should aim to explore how mothers with less access to such resources experience their child's impairment. Additionally, a real-time exploration of mother's experience of their child's diagnosis could compliment the current findings obtained from hindsight.

The present study aimed to explore the experience of living with childhood visual impairment as a family, drawn from narratives of mothers of visually impaired children. Attention was paid to emotional responses to diagnosis, familial relationships, and promoters versus barriers to interaction outside the family unit.

The presented themes highlight complex contributing factors to parental wellbeing and implicate the importance of outside agencies. The need and significance for family support services was stressed, both for mothers processing their child's diagnosis, and family life beyond diagnosis. Findings also demonstrate the resourcefulness and resilience of mothers, as they fight on a daily basis to raise their child to be valued within an inclusive society. Mothers wished to convey the message that the challenges of raising a visually impaired child should be better appreciated, but that their experiences as mothers are a testament to hope for other families with visually impaired children to live an enriched life.

Chapter 5 - Study 3: The Psychological Experience of Qualified Teachers for the Visually Impaired (QTVIs) Working with Visually Impaired Children.

5.1 Introduction

5.1.1 Background

A universal definition of visual impairment in children does not currently exist. Instead, the term ‘visual impairment’ refers to a broad spectrum of visual function loss (Douglas & McLinden, 2005). Children with visual impairment make up a diverse population, encompassing a wide range of vision-related conditions, along with varied adaptations to these conditions. Additionally, a large percentage of visually impaired children have additional disabilities (Keil, 2002; Ravenscroft et al., 2008). Categorisation of childhood visual impairment typically involves medicalisation of eye conditions and resulting functional limitations, as is evident within the child education literature (Hutchinson et al., 1998; Arter et al., 1999). However, purely medical descriptions of visual impairment do not allow for a true representation of how children may utilise their remaining vision functionally. It is worth noting here that most visually impaired children have some remaining vision that can be optimised and employed within daily tasks including reading or mobility. Therefore, it is generally agreed that educational service provision for visually impaired children should be informed by functional implications of visual impairment, in conjuncture with clinical assessments (Douglas et al., 2009). However, there are few studies which place emphasis on psychosocial aspects of childhood visual impairment within education contexts. Since psychological exploration is the focus of the present research, this introductory section will primarily focus on literature relating to a social as opposed to a medical stance on educating visually impaired children.

5.1.2 The UK Position on Educating Visual Impairment – The Role of the QTVI

In the UK, education for visually impaired children emphasises achieving two broad educational outcomes. The first desired outcome is optimum access to the school curriculum, whilst the second aims to ensure that children are given opportunities for developing independence and socialisation skills, to prepare children for adult life/employment. These areas of emphasis are underpinned by the philosophy that every child has the right to equal access for their education, whilst recognising the importance of independence and self-determination. Within the context of visual impairment, the distinction between academic access and ‘life’ skills is reflected in a dual model containing the terms “access to learning” and “learning to access” (McLinden & Douglas, 2014; McLinden et al., 2016; Hewett et al., 2017). This model offers a framework in which educational interventions and targeted outcomes can be implemented and combined. Access to learning approaches focus on providing a learning environment that is structured and modified to promote optimum access to the school curriculum, in addition to wider social inclusion. Learning to access approaches involve supporting the child to develop skills in independence and self-advocacy, which in turn promotes autonomous learning and social interaction. Interventions relating to both access to learning and learning to access are centred around the core school curriculum, but also an expanded curriculum i.e., areas not typically taught in school, such as mobility, access to information along with social and advocacy skills. Whilst there is an obvious rationale for these interventions, there is nevertheless controversy within inclusive education (e.g., Norwich, 2013). These dilemmas relate to the desired outcome of the intervention, rather than the intervention’s efficacy i.e., equal access versus independence development (access to learning versus learning to access). Within visual impairment, should emphasis be placed on teaching print alternatives such as Braille, or teaching computer/technology skills? Should anticipatory adjustments be preferred to teaching self-advocacy skills? Clearly these debates are grounded in the child’s best interest, however they still pose pragmatic issues for parents, teachers, as well as the visually impaired children themselves. One such difficulty is trying to navigate the child’s present needs, whilst simultaneously anticipating future issues that will need preparing for (Douglas et al., 2011).

For many visually impaired children, policies in place within their local educational authority mean that they will be included in early intervention strategies from infancy (Gale, Kelley & d’ Apice, 1998). Routine multi-agency assessments are carried out with the child, with a shared report detailing information that is central to planning individual education, personal learning, and transition (Gale et al., 1998). However, the most crucial aspect of this intervention is ensuring that each child is viewed and treated as a full member of the classroom. As such, the classroom teacher must provide a positive role model in order to encourage peer acceptance of the child with visual impairment (Gale et al., 1998). However, classroom teachers may require support to achieve this outcome.

One of the primary sources of support for classroom teachers is from a qualified teacher for the visually impaired (QTVI) (Keil & Clunies-Ross, 2003). QTVIs hold a qualified teacher status, in addition to a specialised qualification in visual impairment (RNIB, 2013). QTVIs are largely considered as facilitators, since they liaise with multiple agencies including special education needs co-ordinators (SENCOs), in addition to classroom teachers and parents. The ultimate goal is to ensure that the visually impaired pupil's journey through school is a smooth experience, achieved by the QTVI's advice on what adaptive equipment/materials would be best suited to the child's needs (Gray, 2008). QTVIs are placed in a unique position in relation to their support of visually impaired pupils, particularly as their role is seen as being transformative in helping the child both academically and in their successful transition to adulthood (Ravenscroft, 2018). Central to the role of a QTVI is the provision and delivery of an expanded curriculum for visually impaired pupils, allowing them to develop skills important for engaging with activities relating to the core school curriculum, as well as those that will enhance wellbeing (Hatlen, 1996; Sapp & Hatlen, 2010; Opie, 2018).

5.1.3 QTVIs as a Source of Empowerment

According to Symbolic Interaction Theory (Cooley, 1912; Stryker, 2002), an individual's self-esteem is based on the perception of others and other's subsequent behaviour towards that individual (Coopersmith, 1967; Johnson, Vincent, & Ross, 1997). Within the context of disability, the "looking-glass self" proposes that disabled individuals are aware of the potential negative perceptions of others, where these negative perceptions are incorporated into self-concept, with detrimental effects on self-esteem (Dawn, 2015). Within educational settings, teachers are a primary source of influence on their pupil's self-perception, academic achievement, and social efficacy, resulting from their evaluation of the pupil's behaviour (Dawn, 2015). Previous literature has demonstrated lowered teacher expectation of academic achievement of pupils with disabilities (Silva & Morgado, 2004). However, other authors have reported more positive teacher attitudes and enthusiasm towards providing a more inclusive educational experience (Keilbaugh, 1977; Whinnery, Fuchs & Fuchs, 1991; Dev and Belfiore, 1996; Sharma, 2001).

A key role for QTVIs is centered on the idea of empowering others, through consultancy and collaboration with classroom teachers and the visually impaired child's peers, to raise awareness of visual impairment implications. However, empowerment extends beyond simply raising awareness, since the goal is behaviour and attitude change towards the visually impaired child (Ravenscroft, 2016). Without this change, mere awareness-raising would be a one-way process, with the recipient (e.g., class teachers) adopting a passive stance without any responsibility for changing practice (Ravenscroft, 2016). As suggested by Coburn (2001) and Printy (2008), classroom teachers are more likely to significantly change practices following interaction with QTVIs, since they are allied with the teacher's own 'community of practice'. This therefore highlights the importance of not underestimating the role of the QTVI in providing empowerment for mainstream teachers (Ravenscroft, 2016). However, the obligation for initiating behaviour change does not lie solely with the QTVI; instead, classroom teachers must consider their own continuous learning as part of their professionalism (Stein & Nelson, 2003). Taking this view, empowerment is a synergistic process involving both QTVI and classroom teacher. The QTVI provides consultation and dialog that encourages optimum enablement of empowerment, whilst classroom teachers must utilise these conditions for their own self-agency in initiating change (Ravenscroft, 2016). Although the above discussion demonstrates the necessity for a successful collaboration between QTVI and classroom teacher, along with the teacher's own adoption of the 'right' attitude towards their visually impaired pupils, there is a lack of research that explores the reality of these relationships as they are experienced by the agencies involved. Moreover, little attention has been paid to potential mediating factors that could foster or hinder this working relationship, such as classroom teacher attitudes towards the support they are offered by QTVIs.

5.1.4 The Importance of Supporting Social Interaction and Inclusion

Another major role for QTVIs with particular relevance to psychological development within visually impaired children is facilitating positive social interaction between the child and their peers. As discussed in chapter 4, early developmental stages that foster effective social behaviour and communication are largely vision dependent (Brazelton & Cramer, 1991). Subsequently, visual impairment in infants may hinder intersubjectivity (Preisler, 1995), with potentially detrimental long-term impacts on socialisation (Warren, 1994), including communication, social relatedness, and social cognition (Dale & Salt, 2007).

Empirical findings have reported that parental use of descriptive/directive language, although interpreted by some authors as a characteristic of over-protectiveness (Kekelis & Anderson, 1984), are nevertheless central to the child's learning and language acquisition (Perez-Pereira & Conti-Ramsden, 1999). Moreover, Tobin (2008), argued that the absence of visual information restricts the child's conceptualisation of other's behaviour, and the intentions of others relating to play and social interactions. Webster and Roe (1998) proposed that the decreased one-to-one adult-child interactions within school settings compared to home life was potentially detrimental to the child's learning. This argument may therefore constitute another benefit of a QTVI, since expanded curriculum sessions are typically one-to-one based, where QTVIs can provide higher levels of directive/descriptive information.

Difficulties in interpreting social behaviour and cognition in others, place visually impaired children at a disadvantage in social skill development (Pring, Dowart, & Brockbank, 1998). Findings have indicated that visually impaired children are less likely to initiate interaction with others, and have lower levels of assertion, which becomes particularly apparent during adolescence, manifesting in engagement in more solitary activities (Wolffe & Sacks, 1997). This difficulty in establishing social contact may be due to misinterpretation or missing of social cues such as facial expressions or body language (Human, 2010), which may be the reason for greater social and communicative issues among children with more severe visual impairments (Dale & Salt, 2007). The above studies primarily assessed social functioning and inclusion through psychological measurement scales, however a small number of qualitative studies have utilised the experiences of visually impaired children themselves.

Research indicates that social challenges in visually impaired children may be attributed to the functional aspects of lack of vision, such as locating friends, participating in visual activities, and engaging in activities involving competition with sighted peers (Roe, 2008). In a focus-group study with 81 visually impaired and sighted adolescents, Khadka et al. (2012) reported similar activity interests between the two groups, but that the visually impaired group felt more restricted in engaging with such activities. These feelings of restriction were often a result of the presence of support-workers, or overprotectiveness by parents. Additionally, parental overprotection (McBroom, 1997) along with presence of support assistants (Ferrell, 2007) has been shown to inhibit the child's independent socialisation with their peers. Gaining a sense of autonomy and independence is central during the developmental phase of adolescence, since it fosters development of self-identity (Waddell, 2002). However, the already difficult task of mastering independence (due to visual impairment) may be exacerbated by parents not 'letting go', although the process of 'letting go' is complex and emotionally difficult for parents (see chapter 4).

Although lack of vision in itself is not an essential requirement for social interaction in childhood, it does enable easier, more spontaneous interaction between peers (Douglas et al., 2009). Therefore, it is accepted that visually impaired children might require socially targeted intervention (Brown, Odom, & Conroy, 2001). Such interventions can be related back to the 'access to learning' and 'learning to access' strategies discussed above. For example, socially oriented (access to learning) approaches aim to address the child's social environment, through awareness-raising for sighted peers. Alternatively, individually targeted (learning to access) approaches are centered on improving social skills in the visually impaired child, addressing specific areas of need (Brown et al., 2001). However, given that the presence of an adult delivering interventions such as awareness-raising could be a potential barrier to successful socialisation as described by visually impaired children (Ferrell, 2007), it may also be important to consider more generalized 'good practice' literature offers several strategies that may lead to improved social development. For example, improvement in independent mobility skills (e.g., Shapiro et al., 2005), may combat the functional challenges to socialization cited above, such as navigating opportunities for socialization (Roe, 2008). Additionally, assertiveness training has been shown to increase confidence in initiating social engagement (Kim, 2003).

5.1.5 Supporting Emotional Wellbeing

Public Health England (2014) has emphasised the importance of social and emotional competencies in children/adolescents, which in turn promotes positive impacts on health and wellbeing. Poor psychological wellbeing has both immediate negative consequences for the child (thus requiring support from medical and educational domains), and more prolonged issues that may persist into adulthood (Reynolds, 1994; Scott et al., 2016). Within the context of visual impairment, Harris and Lord (2016) reported an increased risk for psychiatric disorders among visually impaired children compared to their sighted counterparts. These findings were supported by a systematic review of mood disorder occurrence among visually impaired children (Augestad, 2017), highlighting several studies (e.g., Huurre & Aro, 1998, 2000; Pinquart & Pfeiffer, 2012, 2014; Brunes et al., 2015) corroborating Harris and Lord's findings. Several visual impairment-related factors have been associated with poorer emotional wellbeing, such as mobility difficulties (Kef, Hox, & Habekothe, 2000), challenges in social interaction (Hatlen, 2004), social isolation (Hadidi & Al Khateeb, 2013), and increased reliance on others for support (Sacks, Kekelis, & Gaylord-Ross, 1992). Augestad (2017) subsequently recommended that practitioners within educational settings (including QTVIs) should adopt a position of vigilance towards detecting risk for mental health issues in visually impaired children. However, despite these findings and recommendations, currently no specialised provision of mental health intervention exists for visually impaired children or their families (Petch & Mukhopadhyay, 2016). Additionally, there is a scarcity of research examining the role of QTVIs in providing emotional support to their visually impaired pupils.

To date, only one study has qualitatively explored QTVI perceptions of supporting wellbeing among their pupils (Pilson, 2022). During focus groups, QTVIs reported the essentiality of promoting emotional wellbeing, however they often felt restricted within their role due to interpersonal and intrapersonal barriers. Interpersonal barriers included difficulty in managing boundaries and role expectations, resulting from constrains of case-loads, input levels for each individual pupil, and the pupil's own reaction to receiving support. Subsequently, QTVIs questioned the efficacy of their role as wellbeing supporter, or even whether the role should be theirs in the first place (Pilson, 2022). Intrapersonal barriers included a lack of confidence in their ability to deliver interventions and resources, despite the QTVIs being professionally trained and highly experienced (Pilson, 2022). Given the lack of empirical literature in this area, Pilson (2022) recommended that future research address development of emotional wellbeing among visually impaired children, through qualitative interviews with QTVIs. This would allow for in-depth exploration of specific emergent details (Crabtree et al., 1993).

5.1.6 The Emotional Toll of Working in Special Education

Having identified the importance of QTVIs being heavily involved in delivering extra-curricular interventions for visually impaired pupils, such as supporting social and emotional development, it is therefore relevant to consider the potential for QTVIs to become emotionally 'involved' with their caseload, and the consequences for their own wellbeing. The profession of teaching is often physically, cognitively, and emotionally demanding (Naring et al., 2012), thereby requiring investment of both physical and mental effort and resources (Demerouti et al., 2001). Positive emotions (such as caring for pupils) may strengthen teacher-pupil relationships and motivate teachers to invest more effort into instructional practice; these positive emotions may be further reinforced by pupil success, thus triggering professional fulfilment (Nias, 1996; Hargreaves, 2001). However, teachers may also experience negative emotions including frustration, inadequacy, and anxiety, which may lead to disillusionment with teaching (Johnson & Birkeland, 2003; Chang, 2013).

The emotional complexity of working as a special education professional may be intensified by the nature of the role, along with the needs of the pupils (Mackenzie, 2012; Jones et al., 2013; Kerr & Brown, 2016). Tuxford and Bradley's (2015) model of emotional demands provides an explanation for special education teacher emotional experiences. This model contains three elements: involvement in intense emotional situations, engaging in emotional labour, and delivering emotional support. Firstly, teachers may be exposed to intense emotions within several situations, including interactions with pupils, colleagues, and parents involving conflict resolution or overcoming challenges (Sutton & Wheatley, 2003; Frenzel, 2014; Taxer & Frenzel, 2015). This emotional exposure may be increased for special educators, due to the specific emotional needs of their pupils, and by other's negative reactions to the pupil (Heiman, 2002; Carter & Spencer, 2006). Despite being exposed to such intense emotions, it may not always be professional for special educators to display their emotional experiences. Consequently, emotional labour, that is, managing feelings, enables display of contextually appropriate emotions that match emotional norms (Hochschild, 1983; Diefendorff & Richard, 2003). Therefore, special educators may need to supress or evoke specific emotions in response to several situations, such as emotion regulation difficulties in pupils, or when they perceive that their work is misunderstood by other education professionals (Kerr & Brown, 2016; Mackenzie, 2012). Finally, there is the expectation that teaching involves delivering emotional support (Strazdins, 2000), through creation of positive, safe and caring environments. The above literature appears to consider emotional experiences of special educators through a lens of ‘emotional toll’, that is, that the intensity of the emotional experience may be detrimental for special educators. Alternatively, Hargreaves (1998) has emphasised the role of positive emotions, namely passion, as being important within teaching:

> Teaching is not simply about knowing your subject … good teachers are not just well oiled machines. They are emotional, passionate beings who connect with their students and fill their work and their classes with pleasure, creativity, challenge and joy. (Hargreaves 1998, p.835)

These positive emotional experiences are also noted in Hebson, Earnshaw, and Marchington’s (2006, 2007) study, where teachers felt that the positive aspects of their work were largely under-reported within research, including the mutual benefits of teacher-pupil relationships. Therefore, the above discussion has highlighted the complexity of experiencing emotions (both positive and negative) whilst working in education, particularly in special education. This raft of emotions was noted in Mackenzie’s (2012) qualitative study with special educators, whose strong emotions stemmed from a passion for championing disability rights, or sometimes from being a parent/relative of a disabled child. Working in special education was equated with intense highs and lows, but it was the positive emotional experiences that sustained special educators in their role (Mackenzie, 2012). Given the impact of emotional experiences within special education, it is important to consider the potential emotional influence of working with specific disability populations, such as visually impaired children. However, the emotional impact on QTVIs has not received any empirical attention to date.

5.1.7 The Present Study

The rationale for the present study stemmed from a desire to provide a complimentary perspective on children with visual impairment, that is, from significant influences on the child's psychosocial development in addition to the family. QTVIs represent such an influential figure in the visually impaired child's life, and so gaining an insight into the experiences of QTVIs working with visually impaired children was hoped to augment findings from chapter 4, which explored childhood visual impairment from a parental perspective. However, when reviewing the existing literature on QTVIs, the researcher was struck by the lack of research focusing on promoting the child's psychosocial development throughout their education journey. Still less research has addressed potential confounds to achieving optimum inclusion and support from the visually impaired child, such as the QTVIs interactions with other educational professionals such as classroom teachers, along with the QTVIs own emotional relationship experiences with their pupils. Moreover, the present study responds to recommendations by McLinden and McCracken (2016) who, in reviewing QTVIs facilitation of inclusive education, proposed that future QTVI research utilise qualitative methodology. Though the role of the QTVI has been previously studied (e.g., Mason & McCall, 1997; Keil, 2012; Ravenscroft, 2015), little empirical evidence has incorporated the first-hand perspectives of QTVIs. The present study therefore aimed to explore QTVI experiences of working with visually impaired children, identifying key QTVI perceived priorities of support, key relationship/interaction experiences whilst delivering support, and their expectations/observations of their pupils achievements, both in and beyond education.

5.2 Methods

5.2.1 Participants

The data for this study was obtained from experiential accounts of ten qualified teachers for the visually impaired (QTVIs) (all female). All participants recruited in this research were required to have worked in their role as a QTVI for at least 12 months prior to their involvement in the present study. The definition of visual impairment included children who had either been registered as "sight impaired" or those registered as "severely sight impaired". Eligibility criteria was based on participants being a QTVI currently working with visually impaired children. Participant demographics are shown in the table below; note that names have been replaced with pseudonyms.

Table 5 Study 3 Participant Demographics

Participant number	Pseudonym	Age	QTVI Base Location
1	Rachel	44	mainstream peripatetic
2	Eleanor	51	mainstream and special school peripatetic
3	Christine	48	mainstream and special school peripatetic
4	Beth	42	fixed position at a single mainstream school
5	Katie	45	mainstream peripatetic
6	Sandra	56	mainstream and special school peripatetic
7	Lisa	36	mainstream peripatetic
8	Heather	49	mainstream peripatetic
9	Megan	53	mainstream peripatetic
10	Isabel	46	mainstream peripatetic

5.2.2 Materials

Semi-structured interviews (e.g., Kvale & Brinkmann, 2009) were employed to examine the psychological experience of QTVIs working with visually impaired children. Interviews aimed to explore how each QTVI perceived their unique experience of working with a visually impaired child, specifically how this related to aspects including teacher-child relationship, and wider relationships with the child's family members and classroom teachers, in addition to QTVI expectations regarding the child's performance (both academically and socially). Interviews were made up of 11 open-ended questions. Each interview started with an initial general dialog about experiences of working within the context of childhood visual impairment as a QTVI, covering several areas including what it psychologically means to be a QTVI, along with the complexities of teacher-pupil relationship involving visual impairment. The interview then progressed to more specific discussion of the psychological impact of education/socialisation for the visually impaired child, QTVI expectations of their pupils, as well as the perceived role of QTVIs within the context of working/maintaining relationships with the child's family. Following discussion of scheduled interview topics, participants were encouraged to ‘add’ any additional thoughts and feelings regarding the psychological QTVI experience. Following completion of the interview, an informal ‘chat’ lasting around 5 minutes allowed for a verbal debrief, as well as addressment of any queries from participants. A full schedule of interview questions is presented in appendix 14.

5.2.3 Procedure

Participant recruitment involved collaboration with QTVIs within the Swansea, Neath Port Talbot and Carmarthenshire area, in addition to online recruitment of QTVIs via the social media information-sharing group “VI Talk”. During local authority recruitment, an electronic recruitment advertisement (see appendix 10) was sent out by the researcher to QTVI teams within the Neath Port Talbot, Swansea and Carmarthenshire local education authorities. This advertisement outlined the purpose and requirements of the study, in addition to giving the researchers contact details. Should QTVIs be interested in participating or learning more about the study, they were able to contact the researcher to arrange a suitable time to be interviewed. They were then sent a copy of the participant information sheet and consent form in a method of their choice (e.g., by post or email). Three participants responded to this recruitment method, two from Swansea and one from Neath Port Talbot. The remaining seven participants responded to the study advertisement within the VI Talk group, which followed the same procedure as local authority recruitment. Written informed consent was obtained from all participants prior to interview commencement. Given the situation regarding Covid-19, all interviews were conducted via telephone, at a time most suitable to each participant. A written debrief was also issued to participants via email following each interview.

5.3 Results

5.3.1 Analysis

In keeping with IPA’s idiographic commitment and double hermeneutic (Smith & Osborn, 2003; Smith et al., 2009), primary analyses were undertaken with individual interview transcripts. Transcripts were frequently revisited to increase data familiarisation. Preliminary coding of content, linguistics, and abstract/probing remarks were made (Smith et al., 2009). Following this, emergent themes were noted, which reduced information volume whilst analysis intricacy was maintained

(Smith et al., 2009). The analysis produced three superordinate themes, subdivided into eight related themes and twenty subthemes. These are presented below in table 6.

Table 6 Study Emergent Themes

Superordinate theme	Theme	Subtheme
Relationships	Relationships with children and families – a deeper relationship	The balance between being “distanced” versus “that person you can ring up at midnight”
		Emotionally supporting children; “I just let them talk …cos that’s what they need”
		Providing emotional support to families – engagement versus resistance; “I had to be strong because mum couldn’t be strong”
	Relationships with teaching staff; “educating the educators”	Lack of VI awareness; “sometimes they forget”
		Walking on eggshells; “I don’t want you to feel like you are being watched or that you’re being checked up upon”
The rewards and challenges of being a QTVI	Expectations	Managing the child’s expectations – being “realistic”
		Expecting more from the child – “they have to try so much harder!”
		“Everybody expects us to know everything”
	“Championing” the children	Encouraging self-advocacy – for “when I am not there”
		The battle versus the excitement for greater VI awareness
Social development – observation and facilitation	Observed influences of social development	Family dynamics – being “wrapped up in cotton wool” versus “getting on with it”
		Feeling “alike” versus feeling “different”

	Facilitating social development	Managing anxiety around "making friends with children who don't know my vision"
		Acceptance through familiarity; "they are all aware"

5.3.2 Relationships

Relationships with Children and Families – a Deeper Relationship.

The Balance Between Being "Distanced" Versus "That Person That You Can Ring up at Midnight." Several QTVIs cited the difficulty of trying to maintain emotional distance from their work with visually impaired children (and their families). Becoming more emotionally involved was an inevitability from having a relationship with the child often over many years, from early childhood to late adolescence. Some QTVI-child relationships even extended into adulthood, as described by Rachel:

> Rachel: "One of our students is 25 now and I have been working with her since she has been 12! … It is a professional relationship, but … it's more than professional now. So if she rang me at seven o'clock at night and went "I have got a burst pipe and don't know what to do", I would go and help her with it …you get more of a bond, you have got a vested interest in that person. More of a friendship I guess really. I think the relationship is more intense … I think that they value that relationship that we have … we all know that person that you can ring up at midnight when you've got a problem … And I think they see me as that person."

For Rachel, being the person "you can ring up at midnight" seemed to evoke a sense of pride that she had been able to form a close "bond" with her pupil, even after they were no longer in a teacher-pupil position. Rachel felt trusted and valued by her pupil, which reinforced her desire to be a source of support. In some ways, she was maintaining what she valued in herself as a teacher i.e., being able to protect and problem-solve for her pupils. In this sense, it was difficult for Rachel to emotionally distance herself from her role as a QTVI, however, her response suggests that she did not want to be distanced. The concept of emotional distance was a more conscious feature for both Christine and Sandra:

> Christine: "I try to keep myself quite distanced really, … As much as you are trying to keep a professional distance there is always going to be an attachment … some people are able to detach themselves …Personally, I can't do that, I

> love my job …, I was in bed the other night and I had a text from a parent at about quarter past ten! Because we are so involved with the families, they trust us”
>
> Sandra: “you can’t help but be that kind of involved with it … I do take a step back - this is the emotional me talking now … you are full on! But you step back because you’ve got your own life, and my husband, and my family so … yes you kind of separate it out … But when you’re doing this … there’s all these joyful times that you have … and then you can celebrate that success of what they’ve achieved. But then, you take a step back and think “that’s really good, that’s lovely” but you carry on with your life too!”

Despite trying to keep a professional distance, like Rachel, Christine viewed her “attachment” to both her students and their families as an indication that she was better suited and more effective in her role as a QTVI. She perceived that families viewed her greater involvement as a basis for placing more “trust” in her, where she was gratified in feeling she was helping them. Her heightened involvement was equated with ‘loving’ her job, with the implication that others who might be able to remain emotionally detached were possibly less effective due to their lessened enthusiasm. For Sandra, there was a clearly expressed effort to try and “separate” her work versus “life” emotions. This separation was personified by the “emotional me” who was seen as being “full on”, contrasted against use of second-person speech to illustrate attempts at detachment “you step back because you’ve got your own life”. Becoming too emotionally immersed in her work relationships was seen as being potentially neglectful or detrimental towards other important people in Sandra’s life i.e., “my husband, my family”. Interestingly, Sandra made reference to needing to step back from the positive emotional aspects of her role i.e., celebrating success of the child. This indicates that, in addition to the challenges of working with visually impaired children, the job also required emotional regulation, in order to “carry on with your life”.

Emotionally Supporting Children; “I Just Let Them Talk … cos That’s What They Need.” Many participants felt strongly about the value of providing emotional support to their pupils. However, they sometimes felt constrained in their ability to provide this support:

> Katie: “I see from observation, as children move towards adolescence … they get very self-aware and they sometimes get quite negative about their vision impairment. That’s when we try and put some work in with them around their emotional wellbeing to … support them during that time. I guess sometimes it

> leaves me feeling like … I'm not doing enough for them … And it's difficult because … there's not a lot I can do in an hour or two a week."
>
> Beth: "I always make a point of asking them how their week's been … If they've had any problems, if they've managed to access all their lessons… we talk about things they've done over the weekend, … And I think cos I see them regularly … I think you just build up that rapport with them because it is a one-to-one situation … sometimes I just let them talk … cos that's what they need, a bit of counselling really."

The regularity and one-to-one nature of the QTVI-pupil relationship was again cited as a promoter of a more intense emotional involvement resulting from relationship consistency "you just build up that rapport with them". In addition to the earlier-mentioned closeness felt by QTVIs towards their pupils, the pupils themselves were perceived as viewing the QTVI as someone they could talk to about their emotional wellbeing. This self-awareness on the part of the child i.e., knowing whom emotional support was available from, was enhanced by the QTVI's strength of conviction that they should be the source of such support. For Lily, simply allowing children to talk about their feelings and experiences i.e., providing a kind of "counselling" service, was seen by her as satisfying the child's "need" to emotionally vent. This in turn gave Lily a feeling that she was fulfilling her role as a QTVI. However, Katie felt restricted in her ability to emotionally support her pupils, given the time constraints of her workload "there's not a lot I can do in an hour or two". There was underlying frustration and sense of helplessness, due to Katie's wish to 'do more' for her pupils, versus the logistical reality of her ability to do so. Consequently, Katie felt she was not fully able to carry out her role, and that this inability was at the detriment to her pupils "I'm not doing enough for them".

Providing Emotional Support to Families; "I Had to be Strong Because Mum Couldn't be Strong." In taking a holistic view of providing support to the visually impaired child, QTVIs anticipated that their support provision would naturally extend to include the child's family, particularly parents. Parents were seen as requiring a source of emotional strength, especially during the initial phases of their child's visual impairment. As with emotionally supporting children, QTVIs stressed the importance of their role in working with families, giving parents hope and confidence for their child's development. The fact that QTVIs had accumulative experience working with visually impaired children, meant they were able to provide an element of stability in a situation that was often uncertain for parents:

> Sandra: “I am there as that person … who knows … what’s going to happen and knows that there are chances available for their children …so hopefully you sort of can be a positive force in their life”

During the initial phase of the child’s diagnosis, or when the child’s condition was degenerative, provision of emotional support was seen as paramount to any other form of support i.e., practical skills training. QTVIs felt that the first step towards working with the child, was to work with parents, so that they felt they were being listened to, and that their emotional distress was being acknowledged. This relates back to the idea of QTVIs forming a deeper bond with the children and families they work with:

> Christine: “I have got a child who is losing his sight … mum went through a stage where she was very, very, very sad …And she just cried, she’d phone me early in the mornings and she’d be crying and crying… I had to be strong because mum couldn’t be strong … I think as a professional … We have to grit our teeth and we have to crack on”

Christine’s presence at the end of the phone for parents drew parallels with Rachel’s self-description as “that person you can ring up at midnight”. However, there was a sense that Christine was not immune to the emotional distress of parents, where the image of remaining “strong” amidst others inability to do so implied a sense of trying to maintain emotional separation from difficult situations “we have to grit our teeth”. However, this separation was later dismissed through Christine’s perceived connection and togetherness with children and families, captured through placement of herself in emotional proximity to the child “I have got a child”. This suggested a ‘we’re in this together’ attitude, which was again seen as being part of the QTVI role:

> Lisa: “The emotional support there is massive … Because they are the people who are spending the most time with the child, so they need to be supported as well … sometimes it is a little bit intense! Well a lot of the time it’s very intense, because you’ve got a parent going “my child this, my child that …”and wanting things from you. It’s difficult because you want to say “yes” to more, … I think it is our job to support parents, but sometimes what you are being asked to do … can be overwhelming in terms of workload … I do feel that … it would be nice if there was something else that we could offer them!”

The role as emotional supporter came with personal costs for Lisa, in that she often felt ‘overwhelmed’ by the ‘intensity’ of her emotional involvement with parents. There was a sense that QTVIs acted as the sole support-giver, and as a result parents were seen as projecting pressure and expectation of receiving support "wanting things from you" (even though this pressure might be unintentional). This perceived pressure further increased the feeling of being overwhelmed, coupled with the burden of responsibility at being the only one who could help. Lisa's statement that "it would be nice if there was something else that we could offer them" epitomised her need for release from this pressure, where the subtext of "something else" was in fact 'someone else' to share the role of emotional support-giver.

Relationships With Teaching Staff; "Educating the Educators."

Lack of Visual Impairment Awareness; "Sometimes They Forget." In addition to working with the visually impaired child, QTVIs were often involved in visual impairment awareness-raising for mainstream classroom teachers. These teachers were frequently described as having a dearth of knowledge about visual impairment, what this might mean for the child, and how best to support that child. This lack of awareness was particularly problematic during the child's early school years, where the child might be incapable of verbally articulating to teachers that they couldn't see. This was demonstrated in Eleanor's rather shocking example, where a school perceived a child as "thick", rather than recognising that they had a visual impairment:

> Eleanor: "he just blossomed! … And went from being this child that the school thought was a little bit thick … because he only stayed in this small area … to on his way to being probably one of the brightest boys I have ever taught."

Eleanor felt she had been instrumental in teaching the school about visual impairment behaviours and characteristics, that had previously been misinterpreted. While her description reflected a success story, the fact of her success carried undertones of what might have happened of a QTVI had not been involved in the child's education, i.e., the child might not have reached their full academic potential. When describing lack of visual impairment awareness on the part of classroom teachers, a distinction was made between teachers who were unaware but willing to be educated (as with Eleanor's story), versus teachers who seemed unwilling to raise their own awareness:

> Rachel: "I do have problems with the ones who just can't be bothered. Can't be bothered to make things accessible … or just don't get it … I find that frustrating. That's definitely the worst bit… I mean ignorance because you've never met somebody who's got a visual impairment before, I am okay with that

> … providing you are willing to be open minded …Just being ignorant … because you are … is just not acceptable."

Rachel distinguished between visual impairment 'ignorance' as either a lack of experience "because you've never met somebody who's got a visual impairment", and being "ignorant … because you are", suggesting a personal characteristic that was harder to change. The response to wilful 'ignorance' was frustration, both for the QTVI who now had a more difficult task of promoting accessibility and inclusivity for their pupil, but also for the pupil themselves, whose educational prospects might be suffering. Perceived deliberate lack of awareness created a perceived lack of fulfilment of the QTVI role, and a sense of helplessness that classroom teachers could not be made more aware of visual impairment, if they "can't be bothered" to become more aware. Additional QTVI frustration stemmed from lack of teacher awareness of what the QTVI role itself entailed. Classroom teachers were described as having a tendency to view the QTVI as a fellow 'teacher' in the sense of delivering curricular lessons to the visually impaired child, as opposed to providing practical vision-related support:

> Beth: "I think sometimes they forget … that the specialist working with the VI child is there to help and facilitate learning … rather than to teach. … some of our teachers have a nasty habit of kind of leaving the VI children to it, because they're working with an adult. And that really, really annoys me … and I spend my time banging on about it."

Despite the intention of providing the visually impaired child with additional support, a paradox was created, whereby the child actually received less educational support. In this respect, the QTVI viewed their own presence as detrimental to the child's learning, since the child was subsequently 'left to it'. This resulted in further frustration towards lack of role awareness, possibly where the QTVI felt torn between wanting to help the child in the classroom, stacked against the anxiety of leaving the child abandoned by teachers. The statement that "I spend my time banging on about it" suggested a constant reminder of this issue that required addressing. "Spend my time" (subtext: "waste my time"), reflected an added sense that this issue was drawing time and energy away from tackling other challenges.

Walking on Eggshells; "I Don't Want You to Feel Like You Are Being Watched or That You're Being Checked Up Upon." When discussing their relationship with classroom teachers, many QTVIs conveyed anxiety that they might be perceived as judgemental, or in a hierarchical position of superiority, due to their advanced visual impairment knowledge and role as advice-giver. QTVIs subsequently found themselves making conscious efforts to alleviate any dialog/behaviour that might be seen by the classroom teacher as a threat to their competence:

> Christine: “we have to ingratiate ourselves and remember that we’re guests … I am always conscious of teachers maybe feeling judged; I hope they don’t and I have never been told that they do but I always pre-empt it …you don’t want to add to that stress … I always try and join in the classroom support of the children if I can … you roll your sleeves up and get stuck in without interfering … they see that you are on their side then.”

Christine’s use of the term “guest” implied that hospitality from teachers and acknowledgment of her advice was dependent on the success of her ‘ingratiating’ herself. Being a “guest” placed her in a potentially fragile position of having her relationship with teachers break down if she did not behave respectfully towards her ‘hosts’. The conscious effort to remain on teachers good sides was an ever-present feature of being a QTVI “I am always conscious”, even before the QTVI actually entered the classroom “always pre-empt it”. Pre-empting potential setbacks to the QTVI-teacher relationship became a strategy for avoiding the actuality of such setbacks. However, Christine’s perception that she might “add” to teacher “stress”, was in fact adding to her own anxiety, in that she was constantly anticipating a negative working relationship. ‘Rolling your sleeves up’ and ‘getting stuck in’ were utilised as ways of playing an active and supportive role within the classroom, allowing teacher to affiliate with the QTVI, creating a sense of comradery “they see that you are on their side”. In addition to supportive behaviour, QTVIs used defusing speech to teachers, ironically highlighting what they were “not” there to do, before moving on to their actual purpose:

> Katie: “I do spend a lot of time with the teachers … I don’t come in and comment on your teaching, I’m not interested whether you’re an outstanding teacher all I am interested in, is giving you the skills and resources and recommendations you need for that particular child.”
>
> Lisa: “I’d said to anyone that I was giving advice to … ‘look, don’t feel as though I am criticising you here … I am not!”

Both Katie and Lisa’s speeches to teachers were very similar, suggesting a script that had been rehearsed and used on numerous occasions. This in turn implied that pre-empting teachers feeling judged had become automatic over time, where the QTVIs took a position of defence before teachers were able to.

5.3.3 The Rewards and Challenges of Being a QTVI

Expectations.

Managing the Child's Expectations – Being "Realistic." Making visually impaired children aware that their vision loss might have implications for their future career aspirations was seen as a facet of the QTVI role. However, rather than this realism being pessimistic towards the child's future, QTVIs were determined to highlight the availability of opportunities despite visual impairment:

> Eleanor: "All he wanted to do … the only thing he wanted to do when he left school … was become an airline pilot! Love him! But we never said … "you are never going to do that." We talked about all the jobs that he could do, in an airport … obviously he was not going to get the job of being a pilot, …but I would never knock that out of somebody … I would encourage him to find something that he could do that was related to the job that he coveted!"
>
> Christine: "I had one girl, and she really wanted to be a police officer … so I explained to her that wasn't gonna happen … because of her VI …she wasn't able to drive a car blah blah blah … but there were other roles in the police force so I took her quite a distance away to a police station and there's a guy there … a member of the police force and he is blind … and he gets all the calls that come in and then he triages them …we have to think about what do they want to do and how can we make that possible or find something very close to it …so that's our role! … we need to let them know what's out there and what they can do."

Both Eleanor and Christine took the position of encouraging children to pursue career ambitions that were as close to their "coveted" job as possible. While both QTVIs recognised the impracticalities of their pupil's career choices, their approaches to address this issue did differ. Eleanor avoided 'breaking the bad news' to her pupil, instead feeling that encouraging the child to "find something that he could do" would help foster a more realistic self-expectation. Eleanor felt sympathy towards the fact that the child's future career might be dictated by his disability "love him!" Consequently, she possibly did not want to further add to this sense of sadness by being the one to explicitly tell the child his aspirations were unrealistic "I would never knock that out of somebody". 'Knocking' the child's ambitions would result in a personal feeling of guilt, whereas taking a stance of positive (but less specific) encouragement would protect both Eleanor and her pupil from guilt and disappointment respectively. In contrast, Christine was more direct in her realistic approach to careers “I explained to her that wasn’t gonna happen”. Having been responsible for ‘explaining’ the potential limitations of visual impairment, Christine possibly felt she needed to sustain this active role. This manifested in her continued sense of responsibility for showing her pupil proximal career options, as well as visually impaired role models “we need to let them know what’s out there”.

Expecting More From the Child - “They Have to Try so Much Harder!”

Several QTVIs reported having heightened expectations of the visually impaired children they worked with. However, these higher expectations were not dictated by measurable academic achievement of the child, but rather to the outset expectation that the child would have to “work harder” compared to their peers:

> Christine: “I expect more from the child with a vision impairment … especially if they’ve got a really severe sight impairment … because life is going to be tough … so they have to work harder at some things …that’s just how life is … if something’s more difficult … you’ve gotta work harder and that’s kind of my ethos …I would never think “I’m not gonna ask them to do that because they can’t see it””

Christine’s statement that “life is going to be tough” conveyed consideration of the child’s potential future, where “working harder” would have to become a fact of life in order for the child to overcome the limitations of their impairment. This in turn reflected a robust attitude towards her role as a QTVI, whereby Christine felt that in adopting this stance, her pupils might mirror her own determination “that’s kind of my ethos”. The success of the end goal seemed irrelevant, instead, ‘more’ incapsulated extra effort from the child to achieve a goal. This idea of extra effort was further illustrated by Lisa:

> Lisa: “it’s like asking someone to do a lap of the track before the race has begun … And then wondering why they don’t come quite up to the front …But that doesn’t mean that the expectations that we are asking them for are going to be lower, it just means that they are going to be different! What you are asking them to do is … you are asking them to jump through two hoops rather than one!”

Lisa’s imagery of ‘jumping’ and ‘running’ communicated a sense of exhaustion that visually impaired children had to face, simply to remain on a level with their peers. Her use of second person speech i.e., “you are asking them to…” reflected a perceived lack of understanding from others e.g., classroom teachers, who she felt did not appreciate the need for extra effort, and for results not to necessarily reflect that effort.

“Everybody Expects Us to Know Everything.” Being a specialist teacher was equated with the expectation of having a universal supply of specialist knowledge. QTVIs felt a perceived pressure and expectation that they “should know” everything regarding visual impairment, and therefore they perceived themselves as the first (and often only) point of call:

> Lisa: “Before … I’ve always had somebody to go … “am I doing the right thing here?” and that would be fine because I was a trainee … But now I am almost expected to know … And I’ll worry that I am not doing the right thing. But I don’t know that I am doing the wrong thing. Sometimes I do feel isolated because, I don’t want to keep bothering the same person saying “am I doing the right thing?” because I am qualified now! So, there is a presumption that I should know.”

For Lisa, the transition from trainee to “qualified” QTVI was equated with the expectation that she should be more decisive, alongside the pressure of needing to have a wealth of knowledge “there is a presumption that I should know”. Lisa’s description of the expectations of her suggested that these ‘presumptions’ came from others e.g., other QTVIs, classroom teachers etc. however, the “presumption” may also have been self-directed, where the validity of her qualification was to Lisa, dependent upon perceived competency, which in turn related to being independent and ‘knowing everything’. This self-expectation to know everything did not match Lisa’s lack of confidence and uncertainty regarding decisions she made “I don’t know that I am doing the wrong thing”. There was also a sense of having to make decisions alone despite feeling unsure and anxious, since Lisa felt that her “qualified” status precluded her from seeking support “I don’t want to keep bothering the same person”. This sense of isolation was not present for all QTVIs, where for some, the opportunity for discussing decisions with colleagues helped to cancel out the pressure and uncertainty:

> Isabel: “you are looked upon for answers and sometimes, you just can’t say … I think you do feel a big sense of responsibility … Sometimes that can weigh on me, … because, ultimately I am the one that’s going to decide how they communicate, … you are trying to decide if they might be a print user, they might be a braille user, it’s quite a big responsibility because you’re the main call on that really … but then I always talk to my colleague about it and we thrash things out together and then you feel … you got somebody to talk to.”

Like Lisa, Isabel noted the pressure to provide answers, illustrated by the ‘weight’ of ‘responsibility’. The magnitude of these decisions was also highlighted i.e., being the “main call” on determining the visually impaired child’s method of written communication. This further accentuated the pressure and responsibility, not only for the child’s present education, but also for their potential future abilities “ultimately I am the one”. However, having colleagues to “thrash things out” with provided a sense of unity and sharing the burden of decision-making “you got somebody to talk to”. Lisa also gave the impression of having colleagues, however she viewed asking for help as “bothering” the other person. This was possibly because she still felt inferior as a newly qualified QTVI, whereas Isabel felt she was on a more equal plane to other QTVIs, characterised by her use of the collective term “we”.

“Championing” the Children.

Encouraging Self-advocacy – For “When I am Not There.” One of the key roles of being a QTVI was taking the long view i.e., helping children to manage and self-advocate for their visual impairment needs not only during school, but beyond into their future lives. QTVIs were keenly aware of their own inevitable absence, and were subsequently determined to impress the importance that their pupils continue practising their learnt skills. In addition to raising visual impairment awareness for teachers in the classroom, the visually impaired children themselves were in training by QTVIs to become more aware of what their impairment might mean for them, and how to be autonomous in addressing any issues. There was a shift away from QTVIs acting as a voice for visually impaired children (as suggested in earlier themes), with an evolution towards encouraging children to use their own voices. This was seen by QTVIs as a process of emancipation, as illustrated by repeated use of power-related language and a passionate focus on “the children” throughout Katie’s response:

> Katie: “Ultimately … it’s the children and young people that I work with who can tell me how it is for them! So it’s about empowering them to use their voice in the right way …To get the support and help that they need. And I think that for me is one of the most powerful things that I can give them and support them in developing. Because when I am not there … they need to be able to say when they can see something and when they can’t … and what the people around them can do to help them.”

> Beth: “Just kind of getting them to speak up for themselves as well … and I’ll just constantly remind them that they need to be asking those things …it’s not the wrong thing to do, they need to be able to do it! They don’t always do it but

> … [laughs] once they don’t have a QTVI shouting for them anymore, they’ve got to do it themselves really”

Despite the encouraging and liberatory stance adopted by QTVIs, there were hints that promoting self-advocacy was a potentially challenging role. This was revealed in Beth’s response, where her assurances that “it’s not the wrong thing to do” suggested that self-advocacy attempts might be associated with embarrassment/fear of social rejection for the visually impaired pupil. In spite of any anticipated negative consequences, the fact that the QTVI would not always be there was seen as being pivotal in the unavoidability of the child having to self-advocate “they don’t have a QTVI shouting for them anymore”. In the silence following the QTVI’s absence, the visually impaired child would have to find their own voice.

The Battle Versus the Excitement for Greater Visual Impairment Awareness. Being at the forefront of raising awareness regarding visual impairment, QTVIs experienced a cost-benefit ratio stemming from this responsibility. At the ‘cost’ perspective, being the primary advocate for visual impairment felt like a “battle” against obliviousness and inexperience. Alternatively, raising awareness about visual impairment (particularly novel concepts such as Cerebral Vision Impairment), was a source of enthusiasm:

> Eleanor: “So our service is currently under review … and we’ve battled it off once that they were going to withdraw my support from the special schools … But I can already feel that I am gonna have to have that battle again. Surely it’s better … that they are independent, they are able to get some joy, and some happiness from life … seems important to me … It should be obvious that kids should have support with their vision.”
>
> Christine: “Cerebral Vision Impairment is my particular area of interest …because it’s very … under-researched … so for me … that’s what ticks all my boxes … And keeps me awake at night … because we can improve vision for CVI … whereas you can’t improve vision for a child who is blind … but when it is to do with the brain … you actually can improve the vision … and I find that very exciting … and very interesting … and I quite enjoy putting them all in my calendar and thinking “right no child is going to be missed out.”

Eleanor’s response conveyed a sense of mental enervation following her “battle”, with negative anticipation that the “battle” would be ongoing i.e., there would always be lack of visual impairment awareness “I am gonna have to have that battle again”. She expressed frustration that lack of understanding from others was creating over complex barriers towards her QTVI role, where others were seen as trivialising the importance of her work “It should be obvious that kids should have support”. By extent, lack of awareness was seen as undermining the potential for the visually impaired child to gain “joy” and “independence”, implying that life skills were being undervalued in place of emphasis on academic achievement. In contrast to a “battle” (suggesting resistance from others), Christine phrased her response as a collective quest for greater visual impairment knowledge, “we can improve vision for CVI”. This resulted in a far more energised outlook, driven by excitement rather than frustration “that’s what ticks all my boxes”. Repetition and emphasis of the word “improve” reflected a reinforced belief that awareness-raising was having its desired reach and effect. Christine’s statement that “no child is going to be missed out” possessed a double meaning, demonstrating her determination to provide effective support to her case load, whilst simultaneously ensuring that each child’s needs would not be overlooked by others.

5.3.4 Social development – observation and facilitation

Observed Influences on Social Development.

Family Dynamics – Being “Wrapped Up in Cotton Wool” Versus “Getting On With It.” Parenting style was cited by several QTVIs as having an influence on the visually impaired child’s social development. Parents who encouraged their children to experience new things were seen as promoting the child’s resilience within other new experiences, particularly socialisation:

> Christine: “We got blind children who ride bikes up and down outside their houses … they’re left to get on with it … and fall over and they patch them up and they get back on it and … those children learn to take risks …they’ll take the risk of talking to somebody who they don’t know.”

Here the image of ‘falling off a bike and getting back up’ could be a metaphorical representation of the child building up social flexibility despite their impairment. Although there might be social set-backs due to visual impairment (i.e., falling off the bike), if parents had given the child the opportunity to experience and overcome challenges, the child was better equipped to psychologically “get on with it”. Building up new social relationships was described as a “risk” for visually impaired children, indicating that QTVIs were aware of the difficulty for socialisation with a visual impairment. This further strengthened the QTVIs perception of necessity for visually impaired children to build up the psychological tools for ‘risk-taking’, for which parents were seen as being instrumental. Although there was no sense of judgement of parents by the QTVIs, there was a differing mood portrayed by the QTVIs descriptions of the visually impaired child's experiences:

> Eleanor: "The little girl that I was working with this morning … it's her birthday this weekend and they'd gone to the water place that they go to and she'd been on a jet ski …and Mum is just like "yeah, she's gonna have every experience that she can possibly have!" And then other children who are very much wrapped up in cotton wool … don't go and do anything."

There was a sense of enthusiasm and exhilaration when discussing children who were given the opportunity to explore new activities and experiences. Possibly this also reflected the QTVI's own excitement when considering the child's potential if they were allowed to "flourish". In contrast, the description of children who were "wrapped up in cotton wool" conveyed a sense of safety, but uneventfulness. In keeping their children 'safe' from potential "risks", parents were seen as playing it 'safe' with regards to preventing the child from encountering and overcoming challenges.

Feeling "Alike" Versus Feeling "Different." When discussing influences on the visually impaired child's social development, QTVIs cited two distinct observations. Firstly, social interaction with other visually impaired children was seen as important for promoting a sense of connectedness and alikeness with others. This was contrasted against the sense of 'difference' that visually impaired children often experienced in comparison to their sighted peers. In attempting to alleviate any potential social isolation, several QTVIs had set up visual impairment-specific social groups, in order to encourage opportunities for connecting with others who shared similar experiences:

> Rachel: "Because they are children who are often isolated in schools in terms of they might be the only one with a visual impairment …they often talk about … being visually impaired … One story stood out, I remember a boy, he said "does anybody else get that thing where when you are in the playground with your mates, and you're all chatting, and then suddenly it's gone quiet and you realise they've all walked off?" … and a couple of the others went "oh yeah, I get that, I get that …" … they're not gonna talk about that stuff with the sighted peers because their sighted peers would be like "What are you talking about?"

> Christine: "the VI youth group is really important for them … to get together … nobody is in competition with anybody who's sighted, they all have the same issue so that's really important … and we do trips …activity weekends … we don't do anything mixed. We just find that, for us, to build confidence and self-esteem … is … for them to be together and not … have to compete. 'cos they

> are competing all day at school … you see, aren't they, they are competing all day …with sighted kids in school"

Both Rachel and Christine illustrated a sense of belonging and understanding from other visually impaired children, who were able to share experiences common to visual impairment, such as the difficulties of interpreting social cues "I get that, I get that". This was compared with a perceived lack of understanding by sighted children "What are you talking about?" There was appreciation of the fact that children shared one similarity i.e., being visually impaired, promoting empathy with others within the group. Socialisation with other visually impaired children was not necessarily viewed as superior to socialisation with sighted children, rather the visual impairment-specific groups existed as a space to feel comfortable sharing experiences that might be relatable to others. Interestingly, Christine made repeated references to the idea of "competition" between visually impaired and sighted children. This illuded to the idea of social inequality when considering "mixed" social interactions. Christine seemed aware of the potential struggle relating to visual impairment socialisation, where visual impairment only interactions were seen as providing children with a relief from "competing" against the visual pressures of social interaction. This sense of social inequality was further carried through by the notion that visually impaired children perceived themselves as "different" from their sighted peers, and thus became actively resistant to physical identifiers of their "difference":

> Beth: "I've got one girl, who is in year ten … and she's struggling big style, doesn't want any modifications … would rather strain her eyes, struggle, doesn't want to sit near the front of the classroom…Hates it when I come into the classroom, she like glares at me … why are you even here?" …And it's because she doesn't want to be singled out, she's scared."

Being "scared" of potential social rejection by peers due to visible difference led to feelings of frustration towards anything or anyone (i.e., the QTVI) that highlighted this difference "she like glares at me". Anxiety regarding being seen as "different" was seen as being detrimental to the QTVI-pupil working relationship, since QTVIs felt that their offered support was being rejected by the child "why are you even here?" There was a conflict between the QTVI, who viewed their support as a step towards the child being more equal with their peers, and the child who only saw help as a social barrier. Nevertheless, QTVIs took an empathetic stance towards the struggles around being “different”, as illustrated by a triple hermeneutic i.e., QTVIs were in turn interpreting the child’s perspective:

> Rachel: “Withstanding out … it’s okay if it is your choice …If you choose to have green hair and a nose piercing … you’ve chosen to do that. Nobody’s chosen to have a visual impairment and I think that’s possibly where the difference is … I do think some kids struggle with that.”

A sense of helplessness and loss of personal control was encapsulated through a lack of “choice” i.e., “Nobody’s chosen to have a visual impairment”. Visual impairment was also seen as taking away further choice, in that visually impaired children could no longer ‘choose’ not to “stand out”.

Facilitating social development.

Managing Anxiety Around “Making Friends with Children Who Don’t Know My Vision.” In addition to supporting visually impaired children with classroom learning accessibility, QTVIs reporting having a role in assisting the child’s social development and interaction with their peers. There was significant anxiety for visually impaired children surrounding the issue of socialising with a visual impairment. This became particularly relevant when the child’s impairment was not visibly obvious to sighted children, raising the concern of disclosing their impairment to others:

> Katie: ““I don’t know how to make friends with other children who don’t know my vision.” “Who won’t know that I am visually impaired.” Neither of them you can tell by looking at them that they’ve got a vision impairment. So they were both anxious about “what happens if they are talking to me and I don’t look at them?” there’s those social cues so it it’s a little bit about giving them the tools to talk about how their vision impacts on them socially, but they’ve got to have the confidence to do that. One of them probably will, the other, definitely won’t.”

Again, there was an element of the QTVI taking the visually impaired child’s perspective, where “I don’t know” and “what if” captured the child’s sense of anxiety and uncertainty in social situations. The visually impaired children seemed aware of social cues i.e., ‘looking at’ someone when speaking to them. However, they were also aware that they may lack these cues due to their impairment, further intensifying their anxiety and sense of social inferiority. In tackling this challenge, self-disclosure was seen by QTVIs as a “tool” for the child to take back a sense of social control (also lining to the afore-mentioned benefits of self-advocacy). However, the QTVI’s input could only stretch so far; the child themselves would have to possess the “confidence” to self-disclose their impairment “One of them probably will, the other, definitely won’t”. There was a hidden sense of disappointment for the social potential of children who lacked confidence; despite the QTVI giving them social tools, the child’s personality would inevitably win.

Building Acceptance Through Familiarity. Having previously discussed the importance of raising visual impairment awareness for mainstream classroom teachers, QTVIs also felt a responsibility to extend this awareness-raising to sighted children who would be socially interacting with the visually impaired child. Using the natural curiosity of children to their advantage, QTVIs proceeded to use their ‘teacher’ role to build the “life lesson” of becoming familiar with other people’s difference:

> Katie: “If they’re new into a class then children are quite often curious and … will ask questions. It’s giving the children the skillset to answer those … because children when they are four and five they’re very curious … so … “why do you come in and work with that little boy, why don’t you work with us?” … if I am doing something in the classroom, I’ll try and include them as well if I can.”

In Katie’s response, there was a transition from a novel social experience i.e., a “new” child with a ‘new’ difference, to a far more inclusive stance. Sighted children were given the opportunity to be part of the learning process for the visually impaired child “I’ll try and include them as well”, and thereby part of their own learning process i.e., they were becoming more aware of visual impairment through experience. Hence, as a result of the QTVI’s role, there was a shift from viewing the visually impaired child as a socially separate entity (focusing on difference), towards a sense of togetherness. Additionally, the importance of language was cited as an opportunity for awareness-raising:

> Sandra: “I was in a nursery last week and they were looking very carefully at this little girl’s eyes; and I was saying “yes, she can’t see what you can see” and we use the same language as everybody else. And I say, “come and look at this, let’s go and look at something”. We don’t say “come and touch this, come and feel this”! And then the other children get to know that she can’t see what they can see!… it’s a life lesson for them, too!”

There was an emphasis on using visual language e.g., “see” and “look”, in order to accentuate the fact that, while a child’s vision might be affected, they were in other ways like “everybody else”. Again, there was a drawing away of focus on difference, to instead promote alikeness i.e., ‘we all use the same language despite what we can/cannot see’.

5.4 Discussion

5.4.1 Implications for QTVI Relationships and Interactions

The present study has highlighted the psychological challenge for QTVIs as they struggled to balance the inevitability of becoming emotionally close to their pupils (and by extent the pupil’s family), with a professional and personal need for emotional distance. This echoes the ‘head’ versus ‘heart’ dilemma of working in special education described by MacBeath et al. (2006): “Teaching takes place both in the heart and the head. … it is the heart that more often rules the head” (P. 14). Likewise, in the present study, the ‘heart’ often won, with QTVIs gaining a sense of gratification and accomplishment from a more emotionally involved relationship with their pupils. Emotional investment was reciprocated by the visually impaired pupil (and their families) through trust and value of the QTVI, which further reinforced relationship strength. These findings support previous literature (e.g., Pugliesi, 1999; Sutton & Wheatley, 2003; Wharton, 2009), which reported the empowering elements of work-related support-giving, that is, the sense of reward and satisfaction gained through providing care. The present study indicated that genuine and strong positive feelings of care and protectiveness towards their visually impaired pupils, in turn protected against, and outweighed any potential negative emotional consequences including burnout (e.g., Wharton, 2009). This was further emphasised by the fact that some QTVIs did not seem to want to give up their emotional involvement, instead wanting to remain “that person you can ring up at midnight”. Therefore, emotional “attachment” to visually impaired children and their families was seen as central to being effective and enthusiastic within the QTVI role.

Despite the mutual benefits of a strong bond between QTVI and pupil, several participants reported trying to maintain a professional distance, so that their QTVI role would not detract from other important aspects of their life. This emotional labour (e.g., Hochschild, 1983; Diefendorff & Richard, 2003) related to supressing positive, as well as negative emotions, if these were deemed too intense for work, and ‘life’ in general. This finding demonstrates how emotional labour can extend beyond the workplace, since displaying intense emotions such as illation at a pupil’s success, might not be contextually appropriate in ‘life’ after work (that is, others might not understand the emotional aspects of the QTVI role). In both instances (emotional involvement and emotional suppression), QTVIs viewed their response as the ‘right’ solution for them, and did not indicate any detrimental effects from their level of involvement; although emotional detachment did appear to be difficult at times.

Following the sense of closeness felt by QTVIs to their pupils, and the consequences of this for emotion regulation within their role, QTVIs also perceived themselves as a source of subsequent emotional support for their pupils. They felt that pupils wanted to come to them with difficult issues, and therefore felt that their role should be responsive to this. Some QTVIs felt that simply having someone to talk to was enough for their pupils, however others reported feeling they should be “doing more”. The highlighted importance of providing emotional support to pupils in the present study was comparable to that in Pilson’s 2022 focus group study with QTVIs. However, QTVIs in the present study did not appear to lack confidence in their ability to deliver emotional support; what they did lack was sufficient time and specific training. Also, in contrast to Pilson’s study, present participants did not doubt their perceived responsibility as emotional supporter, which only heightened their frustration and helplessness when they felt constrained to do so. Differing findings between Pilson (2022) and the present study may reflect the methodology used; had participants in the present study been able to share and compare experiences with similar others (Morgan, 1996), they too may have felt more comfortable reporting a lack of confidence and role insecurity.

As an extension of emotional support provision to visually impaired pupils, QTVIs found themselves in the role of supporting the child’s family, particularly mothers. Again, the essentiality of this role was stressed, where families were seen as needing a sense of hope and stability during what was an uncertain situation for them. The family’s need for emotional support was particularly prominent during initial phases of the child’s visual impairment diagnosis, or if their eye condition was degenerative. As discussed in chapter 4, the uncertainty and need fo ‘answers’ experienced by families living with visually impaired children requires counterbalancing with provision of hope and reassurance (Nygard & Clancy, 2018). The present study demonstrates that QTVIs also exist as a source of reassurance for the child’s successful development (although such reassurance may be provided from other professionals such as Optometrists or Ophthalmologists; Milde et al., 2023). Moreover, given the intense and long-standing relationship that QTVIs have with their pupils and subsequent families, it is likely that their empowering influence would be more keenly felt by parents, thus having a greater beneficial impact on their wellbeing. However, parent's perception of QTVIs as their sole source of support sometimes came at an emotional cost to the QTVI, who subsequently felt increased demands on them to provide all the answers. This emotional link between QTVIs and families of visually impaired children has not yet received empirical attention. Therefore, future research should explore this in more detail from both QTVI and parent perspectives. Parents in study 2 of this research series reported a perceived lack of support with the day-to-day psychological challenges associated with caring for their children. Thus, if QTVIs are considered by parents as a supplement for this support, ascertaining the exact nature of parent-required support might alleviate strain on the QTVI.

The importance of visual impairment awareness-raising was frequently emphasised in the present study, particularly where mainstream classroom teachers were concerned. QTVIs made the distinction between classroom teachers who were receptive to awareness-raising (with subsequent positive outcomes for the child), and those who seemed reluctant to change their attitude or behaviour. Prior evidence proposed that QTVI empowerment of classroom teachers should extend beyond simply raising awareness, since awareness-raising is a passive, one-way process (Ravenscroft, 2016). This one-way process was sometimes a feature of the QTVI experience in the present study, which provoked frustration that the "ignorance" of classroom teachers was becoming a barrier to positive behaviour change, and subsequent increased support for the child. In addition to awareness-raising for the visually impaired child, QTVIs found themselves having to raise awareness of their own role, that is, explaining to classroom teachers what they were there to do, and what was not part of their role. For example, one QTVI was frequently perceived as a one-to-one support assistant for their visually impaired pupil, where classroom teachers consequently 'left' the child 'to it'. This element of lack of awareness has not been highlighted in previous literature, and thus offers a fresh insight into potential barriers to success of the QTVI role.

When interacting with classroom teachers, QTVIs often felt apprehensive that their advisory position might be perceived by classroom teachers as having hierarchical superiority. Consequently, QTVIs felt they were often walking on eggshells, and pre-empting negative responses from teachers. QTVIs interpreted the classroom teacher’s feelings of judgement as similar to that experienced during school inspections, which have been shown to evoke negative emotional responses such as anxiety, tension, frustration, and humiliation (Dündar, 2005; Ciğer, 2006; Akyıldız, 2007; Tunc et al., 2015). QTVIs always tried to adopt a position of respect and ingratiation, which became an anticipatory strategy before negativity could arise. Moreover, taking a position of comradery was thought to allow classroom teachers to see that QTVIs were “on the same side” (e.g., Coburn, 2001; Printy, 2008). However, it should be noted that the pre-emptive nature of these strategies meant that no actual experience of judgement had been present in classroom teachers, rather, it was anxiety of negativity in QTVIs that prompted careful planning. This apprehension was sometimes an extra strain on the QTVIs personal resources. In attempting to alleviate this, future research could explore the perception of QTVIs by classroom teachers, particularly, whether QTVIs are in fact seen in a judgmental or ‘inspector’ capacity.

5.4.2 Implications of Rewards and Challenges

Although the experience of being a QTVI was an overall positive one as described by participants in the present study, the ‘rewards’ were often accompanied by, or resulted from, overcoming challenges. One such complex experience surrounded the concept of ‘expectations’, that is, what QTVIs felt was expected of them, what they expected from their pupils, and what the pupils expected for themselves; particularly their future. Regarding self-expectations, QTVIs perceived pressure and expectation for them to ‘know’ everything regarding visual impairment. This pressure was felt particularly keenly for recently qualified QTVIs, who felt that “qualified” status precluded support-seeking, leading to a sense of isolation in their role. However, isolation was not a feature for all QTVIs, where others found solace in being able to discuss difficult issues with colleagues. Therefore, QTVIs might benefit from having a forum in which they could share good practise from several levels of experience and expertise (Pilson, 2022). This might prove useful for newly qualified

QTVIs, and also QTVIs who might be geographically isolated in their local educational authority.

In addition to self-expectations, teacher expectations of their pupil's achievements have important contributions to the pupil's education experience (Harnett & Naish, 1993; Weinstein, 2002; Rubie-Davies et al., 2006). Within disability education literature, classroom teachers have reported having lowered expectations regarding the achievement of pupils with disabilities (Silva & Morgado, 2004). This is despite the fact that some disabled pupils (including those with visual impairment) actually display higher academic achievements compared to their non-disabled peers (Haider, 1990; Beaty, 1994). QTVIs in the present study reported "expecting more" from their visually impaired pupils compared to sighted pupils. These heightened expectations did not relate to the child's academic achievements, but rather to expectation that they would have to "work harder" due to their impairment, in order to gain level achievements to that of their peers. Not all classroom teachers were seen as understanding the need for extra effort, which further reinforced QTVIs perceived need to maintain their high expectations. High expectations also related to teacher efficacy (e.g., Brownell & Pajares, 1999; Ruble, Usher, & McGrew, 2011), that is, QTVIs who were self-assured in their success of working with visually impaired children, felt that their own determination would be mirrored by their pupils. These present study findings thus offer an alternative perception of 'teacher expectations' that focuses more on the importance of individual characteristics such as resilience. These are deemed essential for positive psychological outcomes later in life for people with disabilities, more so than academic achievement, which has been the primary focus for many teacher expectation studies (e.g., McKown & Weinstein, 2008; Riley and Ungerleider, 2012; Glock & Krolak-Schwerdt, 2013).

QTVIs also played a significant role in managing their pupil's expectations of their potential future with visual impairment; a concept which has received little empirical attention. QTVIs viewed their role as central to preparing visually impaired children for life beyond education. One such preparation included managing the child's expectations surrounding potential career opportunities for people with visual impairment. This theme was also present in study 2 of this research series (see chapter 4), where mothers reported feeling like the 'bearer of bad news' when trying to offer 'realistic' career advice that acknowledged the potential limitations of visual impairment. QTVIs also walked a tightrope of being both ‘realistic’ and empowering, however, empowering positive career choices seemed easier for QTVIs, possibly because they were equipped with more advanced knowledge of what might be available for visually impaired individuals in the workplace. This finding stresses the importance of communication and collaboration between parents and QTVIs prior to, and during the child’s transition to adulthood, to ensure that neither party feels isolated in having to address potentially impractical ambitions.

Preparation for adult life also involved QTVIs promoting self-advocacy skills among their visually impaired pupils, helping them to become aware of, and fight for their own needs/rights, both during school and beyond. Within the context of disability, self-advocacy is the process of demonstrating one’s ability to ‘speak up’ regarding one’s needs and rights as a disabled person (Schreiner, 2007). Self-advocacy becomes particularly important during the transition to adulthood phase (Berry et al., 2012; Hamblet, 2014), whereby the success of self-advocacy is dependent on deliberate and repeated instruction from others, along with ample opportunities for practising this skill prior to the actuality of needing to use it (Daly-Cano et al., 2015). Therefore, self-advocacy is not possible if others (e.g., parents and teachers) continue to advocate on the child’s behalf (Brinkerhoff et al, 2002; Schelling, 2010; Mamiesishvili & Koch, 2011).

QTVIs in the present study were keen to move away from a dependency model of advocating for their pupils, with an evolution towards visually impaired children learning to use their own ‘voices’. QTVIs were aware of their inevitable absence in their pupil’s lives, and thus wanted to instil a sense of empowerment and liberation. This is indicative of the ‘learning to access’ educational outcome (McLinden & Douglas, 2014; McLinden et al., 2016; Hewett et al., 2017). However, the role of encouraging self-advocacy was not without challenges for QTVIs, particularly when pupils were anxious or embarrassed about discussing impairment-related needs with others. This is in accordance with findings by Joseph (2010), where visually impaired adolescents avoided disclosing their impairment due to perceived negative stereotypes from others. For some visually impaired children (particularly adolescents), proving ‘independence’ may rely more on displaying ‘normality’ than asking others for help. This is in accordance with Reeve’s (2002) and Watermeyer and Swartz’s (2008), who suggested that oppressive attitudes from a non-disabled society are internalised by the disabled individual, who responds by trying to conform to expected behaviour. Therefore, by practising self-advocacy, visually impaired pupils are forced to confront their impairment, along with any internalised negative attitudes, which would conflict with their desire to be seen as ‘normal’. As such, it is imperative to acknowledge the influence of interacting individual factors (e.g., acceptance of one’s own impairment) and social factors (e.g., disability stigma) on actual practise of self-advocacy skills. Moreover, future research is warranted regarding the potential time-sensitivity of self-advocacy practise, that is, do potential barriers such as social anxiety diminish as the visually impaired individual matures both personally and socially?

The process of raising awareness for visual impairment was also perceived by QTVIs as both challenging and rewarding. There was a cost-benefit ratio between the “battle” to educate others about visual impairment, versus enthusiasm to enlighten the inexperienced. The “battle” metaphor was also used by mothers of visually impaired children within study 2 (see chapter 4), culminating in feelings of exhaustion and isolation from support. Although exhaustion was also felt by QTVIs due to realisation that the “battle” might be never-ending, this negative aspect was counter-balanced by excitement for being at the forefront of visual impairment knowledge and expertise. Whereas parents often felt alone and lacking in support, QTVIs perceived themselves as that support source, which gratified and reinforced their determination to continue awareness-raising. Additionally, since parents perceived being an “advocate” for their children as an ‘extra’ role, this might explain their sense of psychological strain. In contrast, QTVIs viewed advocacy as part of their role rather than a role extension, hence the associated feelings (both positive and negative), were more congruent with the QTVI identity.

5.4.3 Implications for Facilitating Social Development

Prior to discussing their own role in facilitating social development for their pupils, QTVIs noted several observed influences on pupil’s socialisation that could potentially compound intervention input. One such factor was the influence of parenting style, where a discrepancy was observed among visually impaired children whose parents had ‘wrapped’ them in ‘cotton wool’, versus parents who had encouraged their children to experience new things. Parental systems have previously been identified as important for successful social inclusion of visually impaired pupils within mainstream education (George & Duquette, 2006), where high academic, behavioural, and social expectations from parents were noted as significant contributary factors. However, finding a balance between nurturing and 'letting go' may be difficult for parents to negotiate, which may have consequences for the visually impaired child gaining independence, and forming their identity (Lewis & Wolffe, 2006; Wolffe, 2006). For example, parental overprotection can hinder independent mobility among visually impaired adolescents (Hewett et al., 2013), as well as limiting opportunities for learning about self and others, which is essential for social inclusion (Roe, 2008).

The present study indicated that children who had been exposed to novel experiences within their family life, were more likely to be resilient and confident in social situations. Social interaction for visually impaired children was compared to 'risk-taking', where parents were seen as instrumental in providing the psychological tools for social flexibility early on in the child's development. Although QTVIs were non-judgemental of parents whether they were perceived as overprotective or not, these findings do raise questions regarding a recommendation for providing support to parents who may be psychologically struggling with 'letting go'. A critical period in which this support might be most impactful surrounds the time of the child's diagnosis, where professional advice enables parents to understand their child's impairment, and how to best support the child to reach their optimal potential (Cole-Hamilton, 1996).

The concept of visually impaired children feeling 'different' to their sighted peers was frequently highlighted within the present study. In attempting to counter this sense of difference, several QTVIs reported encouraging social interaction between children with visual impairments, to promote a sense of belonging, and giving the opportunity to share visual impairment-specific experiences. This connectedness to similar others echoes previous findings that children with visual impairment are able to empathise with each other: "where everyone knows what it is like to be visually impaired or blind" (George & Duquette, 2006, p. 156). Hatlen (2004) stated that interaction between visually impaired children were the 'best' types of social experiences for them. The present findings do not support this, since socialisation between visually impaired versus sighted peers were not viewed by

QTVIs as superior, but rather impairment-specific social groups existed as a ‘space’ to open up about experiences that might not be relatable to others. Although not explicitly stated in the study, the creation of visual impairment-specific groups may constitute another for QTVIs supporting emotional wellbeing among their pupils. While Hatlen (2004) did not specify the meaning behind ‘best’ social experiences, the present study has highlighted the concept of social inequality between visually impaired and sighted children due to the limitations resulting from absence of sight (Tobin, 2008). Therefore, impairment-specific interactions were seen as removing this inequality, although arguably some social hierarchy may still exist, since not all impairments resulted in the same level of sight-loss (e.g., Deal, 2003).

In contrast to the similarity afforded by interacting with other visually impaired children, the sense of ‘difference’ to sighted peers was palpable. Perceived difference often created challenges for QTVIs, since visually impaired children became resistant to using assistive aids designed to help them, for fear of social rejection from classmates. This demonstrates the influence of social disability understandings on personal disability experiences such as self-image, whereby “visually impaired people are highly self- conscious and self-critical about their appearance and behaviour in public” (Butler and Bowlby, 1997, p. 423). This is due to stigma, both actual or perceived, although perceived stigma is more relevant since it relates to subjective experience of perception and emotion (Hess, 2010). Consequently, being in a public space (e.g., school) is a constant struggle for young people with disabilities, as they are frequently confronted with the fear of ‘standing out’ (Cresswell, 1996). In the present study, this psychological struggle was more pronounced during the transition to adolescence; a time where appearance and self-presentation is experimented with, (Furlong & Cartmel, 2007). Therefore, refusing to use assistive aids that made visual impairment ‘visible’, was a strategy for concealing the impairment from others, and thereby avoiding anticipated social rejection. Social acceptance was preferable to independence. Moreover, supporting earlier findings that visually impaired children view the presence of ‘support-workers’ as a barrier to social inclusion (Ferrell, 2007), the presence of a QTVI was also a ‘symbol’ of impairment, resulting in challenges to the QTVI-pupil working relationship. These findings are important since they suggest that, when considering efficacy of socially targeted interventions for visually impaired children, ‘good practice’ interventions (e.g., Kim, 2003; Shapiro et al., 2005) may be more beneficial, since they encourage autonomy, rather than placing emphasis on social deficits.

When supporting visually impaired children to develop friendships, QTVIs in the present study tended to use individually focused approaches, such as helping to manage the child’s anxiety surrounding disclosing their impairment to peers. Self-disclosure was seen as a way for visually impaired children to gain more control over social situations, thus implicating the benefits of self-advocacy discussed above. However, the potential pitfalls of self-disclosure were noted by QTVIs, demonstrating that their input could only be deemed successful if the pupil felt comfortable putting their learned skills into practise. In addition to encouraging self-disclosure, QTVIs were keen to encourage sighted children to become more familiar with and accepting of visual impairment through interaction with the visually impaired child. This resonates with findings by Bunch and Valeo (2004), who proposed that increased opportunities for social interaction between disabled and non-disabled children promotes social acceptance in mainstream school settings, compared to specialist schools where classrooms may be segregated. While sighted children would not be able to fully understand what it is like to live with visual impairment, the fact of their willingness to try to understand may actually be more meaningful for visually impaired children, since it could promote a greater sense of belonging to the school community, which is central to the idea of inclusion (Warnock, 2005).

5.4.4 Evaluation and Summary

The findings of the present study are significant in developing understanding of the QTVI role as it is subjectively experienced in relation to interactions with teachers, visually impaired pupils and their families. Findings have also highlighted the importance of individual characteristics in the context of psychological adaptation to visual impairment, along with social and family influences. Findings are also relevant for educational institutions and professionals, since the concept of acknowledging individual differences both inside and outside the classroom is imperative for providing an accessible, inclusive learning experience.

Due to its small sample size, generalisability of the present study may be inhibited. Moreover, during recruitment, no inclusion/exclusion specificity was made regarding how long QTVIs had been in their role. As findings revealed, length of employment may have influenced psychological factors such as being self-critical for seeking support (for newly qualified QTVIs) versus more experienced QTVIs feeling more comfortable within their role. To overcome this, different cohorts of QTVIs could be studied, and comparatively analysed. This might reveal other group differences relating to time of qualification, such as the perceived confidence in supporting emotional wellbeing in visually impaired children, since more recently qualified QTVIs may have undertaken more advanced training in supporting wellbeing due to an increasing focus on mental health within course content (Pilson, 2022).

To build upon and triangulate present findings, future qualitative research exploring the QTVI role could extend to the inclusion of mainstream classroom teachers, parents, and the visually impaired pupils themselves. This would help contextualised the QTVI role within a multiagency system. Inclusion of visually impaired pupils is all the more important, given that opportunities for active participation in generating knowledge about visual impairment support is in keeping with the disability studies paradigm (Oliver, 1992; Davis & Watson, 2000).

Several themes highlighted in the data raised the implication of visual impairment identity, particularly when concepts such as ‘normality’ and ‘difference’ were raised. Hence, the very nature of providing visual impairment educational support could be implicated in the formation or rejection of a ‘visually impaired’ identity, or even leave children conflicted between the two. This would be an interesting concept for future research to explore, particularly since many local educational authorities differ regarding the extent of support available to visually impaired children (RNIB, 2013).

Providing educational and psychosocial support to visually impaired children is a uniquely challenging process (Mason & McCall, 1997; McLinden & Douglas, 2014; McLinden et al., 2016), and as such, equipping professionals with the appropriate skills, knowledge, and experience is paramount in overcoming these challenges (McLinden et al., 2017). The present study has demonstrated the importance of QTVI involvement in support beyond the classroom, with particular relevance to social development, along with emotional wellbeing for both the visually impaired child and their family. However, findings have also stressed the need for awareness of personal factors in managing one’s own emotional involvement, and perceived availability/confidence for support-seeking, which may impact on psychological resources necessary to the QTVI role. This implies a benefit of team networking, along with collaboration throughout educational professional agencies, in order to provide cohesive support that empowers visually impaired children to become aware of themselves, their emotions, capabilities, and social opportunities.

Chapter 6: Reflection

6.1 Introduction

In the following chapter, I will reflect upon my personal experiences during this research process. This review has been informed by reflective notes taken throughout the research process, along with several discussions with my research supervisors. Since my research is entirely qualitative, it is vital to recognise the bidirectionality between the participants and researcher (e.g., Murphy et al., 1998). Therefore, the structure of this chapter represents the flow of both my influence on the research, and how the research has influenced and affected me.

6.2 Conceptualising my Research Ideas

Following completion of my MSc dissertation (exploring the use of social media by visually impaired individuals), I knew that I wanted my PhD to continue investigating visual impairment-related experiences on a wider scale. I wanted to produce research that was interesting and meaningful, not just in an academic sense, but also in a real-life sense, that could offer information and understanding to those affected by visual impairment. I met with several diversions and false starts creating an interesting and unique research thesis. My research topics arise from my core interest areas: the psychological impact of sight-loss, what it means to experience visual impairment as a family, and educational/social implications of childhood visual impairment.

The influences on a researcher's topic decisions, as well as the researcher's own experiences, should be considered via reflexivity (Yardley, 2000), since the values/beliefs of the researcher may impact on the interpretation of participant experiences (Smith, Jarman & Osborne 1999). Qualitative research emphasises an interpretivist stance on knowledge as being both constructed and changeable (Chapple & Rogers, 1998). This reflects my own view that the lens of our own experiences, culture and beliefs, shape how we see the world. While being entirely objective throughout the research process is unrealistic, being reflexive allows for increased awareness of the researcher's own experiences and assumptions (Ahern, 1999). My interest in these areas of research has been influenced both by my experiences conducting past research within the field of chronic illness and visual impairment, along with my experience of the medical world on a personal level as a disabled individual. When conducting this research, I brought myself as a woman, a disabled individual and a psychologist; these influences will be further discussed when relevant throughout this chapter.

6.3 Balancing Duality of Roles

Throughout my research, I have positioned myself as an insider researcher, since I have experience of the explored phenomena in all three studies. I was born with Fraser Syndrome (an extremely rare genetic condition), which has meant that I have been visually impaired since birth, along with having several other health issues/disabilities. Therefore, although I have not experienced sight-loss (since my impairment has remained stable since birth), I am nevertheless aware of the issues surrounding navigating life as a visually impaired individual, and more generally as a disabled person. I also have some awareness of the struggles faced by my family, particularly my parents, in dealing with my disability. Moreover, my visual impairment has meant that I have experienced several aspects of visual impairment-related education, from being educated in a specialist ‘Deaf-Blind unit’, to experiencing more mainstream educational settings. Subsequently, my position as an insider researcher has prompted a need for me to consider the benefits and potential drawbacks of being an insider researcher, and the possible limitations this imposes on my research.

DeLyser (2001) has noted that there is often difficulty in balancing role duality, with the risk that the research/analysis process may become overly influenced by personal experience. IPA is underpinned by phenomenology, and therefore acknowledges the researcher’s subjective role in interpreting participant accounts. Smith et al (2009) propose that the fact that we are often unaware of our potential biases and preconceptions, means that bracketing off our preconceptions and taking a reflective approach is essential. Smith’s (2010) explanation of becoming aware of one’s preconceptions and biases within the ‘hermeneutic circle’, offered a useful guide to my own reflexivity. Within this description, the researcher transfers from the ‘whole’ of their preconceptions and experiences, to a ‘part’, i.e., when they meet another individual. During this phase, the focus should be on the other individual’s story, where the researcher should bracket out their own preconceptions as much as possible. The researcher then moves back to the ‘whole’ position within the circle, whereby participant experiences are considered within the context of both the researcher’s own biography, and the research in its entirety.

Balancing my researcher self against myself as a visually impaired person became a source of apprehension for me before, during, and after my data collection. As such, the double hermeneutic within IPA, positioning the researcher as being simultaneously similar and different to the participant, became essential within the context of being an insider researcher (Smith et al., 2009). The idiographic commitment within IPA enabled me to acknowledge that, whilst some of my own experiences may appeared to be similar to my participants, in reality each individual’s experiences are unique, since they are shaped by diverse socio-cultural contexts. Throughout my research notes, in addition to supervision meetings, I have paid close attention to the way in which my own experiences have influenced the research process. Throughout interviews, I found myself relating to the participants stories, particularly relating to feelings of frustration and uncertainty, but also hope and pride. However, several participant stories did not mirror my own, particularly in relation to discussing the uncertainty surrounding further deterioration of sight-loss. These occasions highlighted the need for me to be aware of ensuring that the participants voices were being heard.

When considering the concept of disability-related research being conducted by a disabled researcher, I would like to raise a cautionary note regarding the proposal that a researcher sharing the same disability as their participant is automatically considered as having an insider perspective on the experiences of others with the same disability. The researcher needs to be cautious in considering their own identity, recognising that there are multiple identities that impact on their work as a researcher (Rasmussen, 2006). Rasmussen has argued for researchers to include their personal biographies within their research, whilst also being able to “destabilise unified understandings of identity” (2006, p. 38). Moreover, researchers must consider the historical and contextual influences on their own identity, not just that of their participants (Mayo, 2007). This consideration of identity construction is arguably more important for disabled researchers conducting disability research (Sheldon, 2017). Taking this view, as a researcher, I needed to curb my assumption that, just because I identify myself as ‘visually impaired’ (as did participants in my first study), I have an advantageous insight into visual impairment, and subsequently do not need to consider my own identity. My own visual impairment by no means makes me an ‘expert’ on visual impairment. In fact, I have gained more knowledge and understanding by talking to participants in my three studies, than I have ever achieved either though my background reading, or through my own life experiences. As a person with a visual impairment, I am passionate about promoting a more accessible and inclusive society, therefore it makes sense that I should reflect this through research into visual impairment. Nevertheless, I cannot merely project my own experiences onto my participants due to us both being visually impaired.

6.4 Disclosing my Own Visual Impairment

Consistent throughout the three studies, was the finding that individuals often struggled with the issue of when and how to disclose their visual impairment to others. Likewise, as a visually impaired researcher, I faced the unusual dilemma of whether to tell my participants I was also visually impaired. I was in conflict regarding whether my disclosure would enhance the research process, by way of building rapport and making participants feel more comfortable talking to me, versus anxiety that my disclosure might negatively affect participant responses i.e., they may omit or not elaborate on issues if they assumed I knew what they were talking about. The dilemma of disclosure was taken out of my hands on the occasions that my interviews were conducted face-to-face with my participants. My form of eye condition means that facially I have a ‘visible difference’. Also, I entered participants homes using my long cane, since this was an unfamiliar environment for me to navigate. The participants I interviewed had some remaining vision, and were therefore aware of my impairment, without me needing to verbally disclose it to them. My own visual impairment became the source of some discussion during the initial phase of interviews, and also during the ‘chat’ following completion of the interview. I tried to keep the discussion surrounding myself as neutral as possible, particularly prior to the interview. I did not shy away from the fact of my impairment, but neither did I want to sway participant responses with my own experiences.

The issue of self-disclosure became more prominent when I was conducting interviews over the phone, since participants would have no visible indications about my impairment. I was unsure whether, or at what point, to bring it up, and was concerned that doing so might be a kind of self-indulgence which might detract from the focus of the research. I came to the decision to be led by my participants as to whether/when to disclose my impairment. When interviews were conducted over the phone, I only made mention to my impairment when it seemed relevant, or when participants explicitly asked about my own background. I was surprised to find that all participants wanted to know ‘whether you are blind too’. Upon confirming that I also had a visual impairment, they seemed pleased and more engaged regarding their own experiences.

When considering disclosure, I found Pizer’s (2016) description of working as a visually impaired therapist an interesting insight into the dilemma of self-disclosure. Pizer described feelings of embarrassment surrounding his impairment, often feeling relieved when the impairment was undetected by his clients. Although these feelings did not echo my own during my research; I did not want to ‘pass’ as sighted to my participants, like Pizer, I was worried that I was over-emphasising the issue of my impairment. This dilemma is the bottom line of the question surrounding disability research being conducted by disabled individuals; should we disclose our disability in order to be fully reflexive? (Sheldon, 2017). By choosing not to disclose, disabled researchers may pay the price of losing an opportunity to express their identity, and by extent may lose the chance of exploring how this expression may impact on participants (Sheldon, 2017). Although there is an abundance of literature describing how participants use stories throughout their interaction with the researcher during interviews, there is less exploration of using self-narratives or disclosure by the researcher. Holstein and Gubrium (1995) noted that traditionally, researchers are expected to “keep their ‘selves’ out of the interview process” (P.13). Conversely, those arguing for a less structured approach to interviewing suggest that occasionally, a researcher’s self-disclosure can be useful in encouraging participant responses, particularly when the interview is centred around sensitive topics (Jourard, 1971; Reinharz & Chase, 2003). Since visual impairment was an emotionally-charged topic for many of my participants, I felt that disclosing my impairment helped bridge the gap between the participants and myself, where they felt that I had an understanding (to some extent) of what they had been through.

6.5 Being ‘Involved’ With my Analysis

Although I was somewhat prepared to be responsive to my participants from a visual impairment perspective, I also found myself surprised by my emotional responses to the challenges faced by mothers of visually impaired children in my second study. The difficulties faced by these mothers, and the often negative emotional consequences, led me to consider my own perspective of having been ‘the visually impaired child’, with feelings of guilt that my own parents might have gone through these same negative experiences. As such, I needed to make a conscious effort to bracket out these thoughts, using the double hermeneutic to acknowledge that my own experiences had shaped how I interpreted the mother’s accounts. Despite my psychology background, I was unprepared for the emotional toll of my data analysis, particularly reading through the interview transcripts. I had initially expected that my study on adults living with sight-loss would emotionally affect me the most. However, I found the second study (with mothers of visually impaired children) extremely powerful and emotive. This was possibly because I had assumed a position of distance from my participants (not being a mother myself), although this assumption was misplaced, since I had some experience of how my own impairment impacted on my family. The emotional effect of conducting qualitative research is well-recognised (Dickson-Swift, James, Kippen & Liamputtong, 2007). My emotional response to my analysis highlights the extent to which it is possible for us to be connected to and touched by the experiences of strangers. This accentuates the benefit of qualitative research within health psychology, providing a deeper connection and awareness of individuals experiences, which could prompt greater compassion/understanding among healthcare professionals for the complexity surrounding visual impairment.

As stated by Stanley and Wise (2002), “the researched will have feelings about us as much as we will about them, and also feelings (and theories) about the research itself” (P.160). The fact of my own impairment may have represented a reminder to my participants of their own impairment-related challenges. Equally, the fact that I am a proud, independent ‘blind woman’, conducting research as part of a doctorate, may have instilled a sense of optimism. I felt this particularly keenly when interviewing mothers of visually impaired children, where they were extremely interested in ‘how far’ I had come, and seemed hopeful for their own child’s potential future as a result.

6.6 The Wider Influence of My Research

The emergent themes from my research studies have led me to consider the broader societal assumptions surrounding disability and visual impairment. Reading through participant accounts, I was struck by the psychological challenges they faced daily. However, their descriptions of gaining strength and resilience prompted me to re-evaluate my own assumptions. Why had I perceived their experience as a ‘loss’; who was actually losing, me, them, or society? When a health condition is life-threatening, there is the threat to losing life. My research has highlighted more equivocal, but nevertheless real losses, such as loss of physical/social skills following sight-loss, as well as loss of expectations for the future. Although I am visually impaired myself, I have never really seen my own impairment as a ‘loss’, possibly because my sight has remained stable. However, when I think about people experiencing ‘sight-loss’, or parents of visually impaired children, I have equated their experiences with having lost something they previously had, or expected to have. Reflecting on this, I remembered a recommendation from one mother in my second research study that I read a poem that she had found helpful in summarising her experience as the mother of a visually impaired child. The poem was by Kingsley (1987) entitled “Welcome to Holland”. Kingsley captured the process of adjusting to life with a disabled child, likening it to the metaphor of planning a holiday to Italy, but instead arriving in Holland. This poem has had differing receptions by parents, with some stating that it misses the point, since all parents, regardless of their child’s health status, experience unpredictability and uncertainty (Stern & Bruschweiler-Stern, 1998; Dulock, 2014). Moreover, a quote by Sinclair (1993) offered an insight into the effect of parental grief on a disabled child:

> “Grieve if you must, for your own lost dreams. But don't mourn for us. We are alive. We are real. And we're here waiting for you. Better than being sad about it, though, get mad about it-and then do something about it. The tragedy is not that we're here, but that your world has no place for us to be” (Sinclair, 1993).

Sinclair was expressing a wish for grief resulting from an anticipated event or relationship, to be separated from viewing the individual’s disability as the source of that grief. This perspective demonstrates the complexity relating to two separate experiences; that of the child and the parents, and how these experiences interact. Within my study on parents of visually impaired children, there was a contrast between feelings of loss versus gain. These complex responses have emphasised the value of a systemic approach to studying visual impairment, and the importance of both the child and the parent’s perspectives and needs. There is also need for a wider consideration of how society views disabilities such as visual impairment; the very term ‘sight-loss’ suggests the expectation of grief.

My research with adults experiencing sight-loss indicated that there was a societal pressure for individuals to self-identify as ‘disabled’ (e.g., Watson, 2002). Reflecting on this, as a society, we tend to problematise health conditions such as visual impairment, however it is our reaction to visual impairment, along with physical/social barriers, that creates a challenge for individuals. Through viewing visual impairment as a ‘problem’, we thus create a problem, thereby making the impaired individual a problem, which impacts on their identity. It is my hope that this research brings to light society’s assumptions (including my own) about a visual impairment diagnosis. Placing these assumptions to one side, we should instead engage in the experiences of the individual. I also want my research to highlight the strength-promoting aspects of visual impairment, so that we can celebrate difference.

6.7 Summary

Consideration of my position as a researcher, my assumptions, and beliefs are vital within the context of qualitative research. Throughout the process of conducting my research, I have acknowledged my own influence on my research, but also how the research has simultaneously impacted on me. These studies have both confirmed my values as a visually impaired person, whilst also raising some issues that had previously been unconsidered by me. Though this research has developed from tentative beginnings, and has been a challenging process, writing this thesis has ultimately been fascinating and rewarding. It has given me the opportunity to connect with the experiences of others, and to grow from their insights.

Chapter 7 – General Discussion

This chapter will present a discussion of the key messages and considerations from all three research studies, in addition to a critical evaluation of completing this thesis. Specific reflections will be given to the experience of conducting research during the Covid-19 pandemic, how this disrupted plans, and required changes were adapted to. The chapter will then discuss some broader limitations of the thesis, before concluding with final thoughts.

Since this thesis has been rooted within IPA, 'take-home' messages may be difficult to supply for professionals to simply insert into practice; especially since present findings have highlighted implications for wider society. This thesis chose to focus on individual lived experiences, which are equally revealing for their differences as in their similarities. Nevertheless, key points are discussed below, which may be of great use for both professionals and general readers to reflect upon.

7.1 Key Messages

7.1.1 Study 1

Although sight-loss presents numerous psychosocial challenges, the present study highlights enlightenment through adversity, along with advocacy for positive change to visual impairment rights and support. Visually impaired individuals wish to carry on discussing their experiences and needs, in the hope that their voices will educate others. Although frequent reference is made to visually impaired individuals living in a 'sighted world', this world can sometimes be 'blind' to the challenges and strength-promoting features of sight-loss, which visually impaired individuals work tirelessly to counter.

1. At the point of sight-loss diagnosis, patients wish to receive a more in-depth explanation of their diagnosis, and comprehensive information regarding what the diagnosis might mean for their future lives. When this information is lacking, patients may feel alone and uncertain about what to expect from their sight-loss journey. This uncertainty also may lead to anxiety about further sight deterioration, particularly when individuals are feeling their way through the dark of their own prognosis in the absence of medical reassurance. Therefore, clinicians have an

important role to play in relaying the positive message of achieving a fulfilled life despite sight-loss, since delivery of diagnoses will have a lasting psychological impact on the individual (Dean et al., 2017; Ferrey, Moore, & Jolly, 2022).

2. Although precisely predicting future outcomes of eye conditions is often difficult for clinicians, visually impaired individuals would nevertheless value provision of existing medical information regarding their condition in a sensitive and empathetic manner. Ultimately, visually impaired individuals wish to feel able to ask questions following their diagnosis, and this is only possible when the individual feels they are an equal and active participant in their diagnosis process, as opposed to the passive patient role that often accompanies medical diagnosis and treatment (Britten, 2017).

3. When discussing the concept of loss following onset of disabilities such as visual impairment, the present research has provided an argument for viewing loss as a socially oriented response to disability. For example, several participants denial and rejection of their visual impairment diagnosis reflected fear of being viewed and labelled as ‘disabled’ by others. The nature of acquired disabilities such as sight-loss warrant considering the individuals pre-existing social attitudes toward disability, which may persist despite becoming disabled later in life. In the present research, these pre-existing attitudes created psychological conflict between participants wanting to maintain their previous non-disabled behaviours, versus recognising the reality of their new physical limitations. Moreover, the social imposition of loss was demonstrated further when participants described the pressure to be seen as having accepted their sight-loss, when in reality they were still facing daily physical and psychological struggles. The present study therefore argues for a move away from stage approaches to concepts such as loss, towards recognition that individuals may constantly be fluctuating in their psychological response to sight-loss, especially when the sight-loss itself might be prone to change.

4. Anxiety regarding social interaction was a prominent psychological feature following sight-loss, where individuals felt their impairment was preventing them from fully being able to socially engage with others. However, despite visually impaired individuals holding themselves responsible for social interaction difficulties, these challenges can only be alleviated with increased public awareness of the social

impact of sight-loss. With greater understanding, sighted individuals can better appreciate the challenge of socialising with a visual impairment, and therefore learn to engage in interaction that uses more verbal cues e.g., introducing themselves upon greeting visually impaired individuals, and addressing the visually impaired individual by name during conversations involving multiple people. Ultimately, we as a society are responsible for breaking down barriers (including social interaction) that may impede the full and equal inclusion of visually impaired individuals within society. Participants in study one wanted to convey the message that social interaction with other visually impaired individuals could be an empowering and supportive experience, however it could also lead to feeling socially pigeonholed and excluded from the 'sighted' social world. Again, it is important to be mindful of the role played by non-disabled society in continuously accentuating 'inabilities', prompting visually impaired individuals to want to 'fit in' to a sighted world (Popel et al., 2020).

5. Study one revealed the issue of disclosing one's visual impairment to others, which has wider psychosocial implications such as increased positive social interactions and social support that is emancipatory to the visually impaired individual. Disclosure may therefore represent a means of gaining a sense of control over the negative psychosocial consequences of visual impairment. However, choosing not to disclose one's impairment may perpetuate lack of public exposure/awareness of sight-loss, which could have longer-term negative implications for socialisation between visually impaired and sighted individuals. Disclosure is a complex and sometimes uncomfortable social experience for visually impaired individuals, and future research should aim to develop interventions for ameliorating this experience. Visually impaired children are extensively involved in self-advocacy skills development throughout their education programmes (as shown in study three). However, little attention has been given to the importance of these same skills for individuals acquiring sight-loss in later life.

6. Social context further linked to visually impaired individuals self-identifying with the term 'disabled', which was equated with negative social connotations such as being less capable/independent. This draws parallels with the 'loss' concept, in that individuals felt they had lost their non-disabled status in society, and were now labelled as 'disabled'. These experiences reiterate the validity of the social disability

model (e.g., Olkin & Pledger, 2003), and call for a continuation of the debate surrounding subjective thoughts and feelings about the term ‘disability’. The ‘disability’ or ‘visual impairment’ label is further compounded by how the impairment is visibly presented to others. For some, using a cane offers a visible symbol of visual impairment to others. Therefore, the individual can forgo the social discomfort of verbally disclosing their impairment to others, and the impairment ‘label’ becomes an asset since it may elicit support without having to ask for it. Without symbols such as canes, visual impairment may be invisible to others. This creates conflict between passing as ‘normal’ through impairment concealment, and using disclosure to educate others about sight-loss. Whether impairment visibility/invisibility is viewed as a benefit or a cost, societal attitudes (including those preconceived by visually impaired individuals) are at the forefront of how disability and disability identity are conceptualised. Visual impairment is unique in this regard, since there are many symbols of ‘blindness’ such as a cane, guide dog, or dark glasses. Visual impairment research (particularly in psychology) therefore has a unique opportunity to further explore how these visible symbols impact visual impairment identity, anddisability disclosure.

7.1.2 Study 2

Ultimately, the reoccurring implication of study two’s findings is a need for support, both for the visually impaired child, and their families. While support in the areas of initial diagnosis and advocacy is perceived by some as inadequate, the value of connecting with other families living with visual impairment cannot be overstated by parents. Just as visually impaired adults may share a social identity through interacting with others in similar situations, parents of visually impaired children may also reap the rewards of belonging to their own social in-group (Shilling et al., 2015). Parents view themselves as the true experts on their children, and this expertise is subsequently recognised and valued by other parents, hence the dyadic support system becomes all the more meaningful.

7. Echoing the psychological challenges of adults receiving a visual impairment diagnosis, mothers of visually impaired children also experience this “emotional rollercoaster”, culminating in feelings of loss, guilt, and uncertainty for their child’s potential future. As with individuals acquiring impairment later in life who

may have preconceived conceptualisations of disability, mothers of visually impaired children also may have these prior attitudes and beliefs, resulting from rudimentary societal depictions of what life with disability might be like. Even when mothers share an ‘insider’ perspective on their child’s impairment based on their own impairment-related experiences, the perceived negative societal attitudes towards disability may still contribute to parental uncertainty and vulnerability. Additionally, uncertainty may persist due to parents having no precise indication of how much their child is able to see. Their anxiety may be further compounded by making comparisons to non-disabled children, or indeed, having no meaningful comparisons to make. When delivering diagnoses of childhood visual impairment, there is a need to acknowledge the potential for long-term emotional family challenges in addition to the physical, especially where mothers might experience guilt following diagnosis of a genetic/congenital condition. By anticipating and validating negative emotional responses from parents, clinicians and service providers can support parents through open discussion of these responses, adopting a position of reassurance and hope (Nygard & Clancy, 2018).

8. In the present study, mothers wanted to emphasise that they not only considered themselves as mothers, but also viewed themselves as ‘carers’ and ‘advocates’ for their visually impaired children. These extra roles sometimes overshadowed the joys of motherhood, along with the time and energy available to invest in the child’s siblings. However, additional roles may provide a sense of having a deeper emotional mother-child bond, which added an extra dimension to simply providing physical support. Hence, there is scope for considering the mother/carer role as a strength-promoting aspect of raising a visually impaired child, since it may heighten parental autonomy and emotional closeness, although these positive features may not always be felt by the visually impaired child themselves. Moreover, mothers often take on an ‘advocate’ role, which is perceived less favourably compared to ‘caring’ for their child. This is because mothers often feel they are the sole ‘advocate’, reflecting a perceived lack of support from outside agencies both for the visually impaired child, and parents themselves. The present research therefore calls for awareness of the potential susceptibility to stress and anxiety in mothers advocating for their children (e.g., Sakkalou et al., 2018; Lupón et al.,2018), along with the importance of outside agencies such as medical and educational

professionals adopting an empathic and supportive response to parents fighting for their child's needs.

9. When raising a visually impaired child, there is sometimes conflict between being protective, versus 'letting go' and allowing the child to practise their own independence (Anderson & Coyne, 1993). Despite this inner struggle for parents, the anxiety of parent-child conflict resulting from overprotection is often eclipsed by the need to protect the child. When the child's impairment has prompted loss and uncertainty in parents, they do not wish to add to these feelings. Again, this emphasises the need for outside agencies to be encouraging in envisaging a life of independence for children in spite of their visual impairment, where parents feel they are taking an active role in promoting this independence.

10. In alignment with the experiences of adults with sight-loss, parents of visually impaired children also face the challenge of when and how to disclose their child's impairment to others. Disclosure is fraught with anxiety of disability-related stigma or social awkwardness during interactions with both parent and child. Parents do not wish for their child to be pitied by others, as it undermines their efforts to advocate and educate others to promote equality for their children within society. Despite the ever-increasing awareness of disabilities such as visual impairment, there is still distance between a society still holding medically based conceptualisations of disability, versus disabled individuals (and by extent their families) who do not want to live life dictated by their inabilities.

7.1.3 Study 3

The 'alike' versus 'different' observation of social interaction in visually impaired children has drawn parallels with the theme of 'connection' versus 'segregation' in study one, along with the desire to connect with other families with visually impaired children in study two. As with visually impaired adults, visually impaired children also appear to enjoy connecting with other visually impaired children, which contrasts against their perception of feeling 'different' compared to their sighted peers. Study three adds an extra dimension to the 'alike' versus 'different' contrast described throughout this thesis, since QTVIs have taken an active role in promoting connection and socialisation within visual impairment-specific social groups. However, a combination of social interaction between visually impaired only and visually impaired and sighted children has been described by QTVIs as providing a holistic social experience that has long-term psychological benefits for visually impaired children.

11. Not only is visual impairment psychologically challenging for the individuals that experience it and those in their immediate proximity such as family members, those working within the context of visual impairment such as QTVIs may also experience the psychosocial rollercoaster as they work towards supporting visually impaired children, their families, and other educational professionals. Findings from study three have highlighted the dilemma for QTVIs in developing a strong emotional bond with both visually impaired pupils and their families, versus attempting to maintain professional emotional distance to protect their own wellbeing. Nevertheless, QTVIs expressed genuine strong positive feelings towards caring for their pupils, which were protective against potential negative emotional impacts of their job such as burnout (e.g., Wharton, 2009). Findings therefore offer a unique perspective on the specialist teacher-pupil relationship in the context of visual impairment. Tied in with emotional closeness, the value of providing emotional support to visually impaired pupils has also been stressed as a central role for the QTVI. This role for supporting emotional wellbeing has also extended to include family members, given their perception of lacking support from other agencies, as described in study two. However, QTVIs may feel the pressure to provide extensive support to parents more keenly if they are unable to share the potential burden of this with other agencies. Moreover, QTVIs may sometimes feel they lack specific training and tools to provide the level of support that fits with both their own perceived responsibility to their pupils/families, and expectations of these support recipients. This issue may become exacerbated when QTVIs hold self-directed expectations that they should “know everything” due to their qualified status. Therefore, QTVIs might benefit from having a forum in which they could share good practise from several levels of experience and expertise (Pilson, 2022). This might prove especially useful for newly qualified QTVIs, and also QTVIs who might be geographically isolated in their local educational authority.

12. Parallel to the ‘advocate’ role described by mothers in study two, QTVIs view their role as central to the awareness-raising and education of mainstream classroom teachers regarding visual impairment. However, QTVIs sometimes

encounter barriers to their awareness-raising role, particularly if classroom teachers are not always receptive or proactive in learning from QTVIs. The QTVI response can subsequently involve pre-empting resistance from classroom teachers, adopting a position of camaraderie and ingratiation in anticipation of negative responses. These findings shed a new light on the potential barrier to success of the QTVI role, in addition to demonstrating the QTVIs own receptiveness and sensitivity in addressing these barriers independently.

13. The QTVI experience has been described as primarily positive, although the rewards often stem from experiencing and overcoming visual impairment-related challenges. One such challenge relates to promoting self-advocacy skills among visually impaired pupils in preparation for the transition to adulthood. QTVIs may encounter resistance from pupils, who are reluctant to emphasise their perceived “difference” by disclosing their impairment to others. Disclosure has also been a significant challenge for adults with sight-loss as discussed in study one. Again, findings are referencing perceptions of a non-disabled society that are internalised by visually impaired individuals, prompting behaviours that conform to a ‘sighted world’ (Reeve, 2002; Watermeyer & Swartz, 2008). Consequently, we must recognise influences of the interaction between individual factors including visual impairment acceptance, and social factors including disability stigma on practise of self-advocacy skills.

14. QTVIs in study three wished to raise awareness of potential influences on social development in their visually impaired children that they had themselves observed throughout their role. The role of the family; particularly parents, has been identified as a central influence on whether visually impaired children feel confident in overcoming social challenges associated with their impairment. A discrepancy has been highlighted between parents who ‘wrap’ their children in ‘cotton wool’, versus parents who encourage autonomy, where parental overprotectiveness may hinder resilience and independent initiation of socialisation with others. Findings are reminiscent of the parental struggle between protection and ‘letting go’ described in study two, prompting a recommendation that parents be given greater support in navigating potentially difficult emotions surrounding ‘letting go’. This raises a further question as to who should deliver this support, that is, since QTVIs are aware and directly affected by the consequences of parental overprotection, should they indeed

include supporting parents with this as part of the wellbeing support they already offer.

7.2 Synthesis

Taken together, all three studies have relayed key messages relating to social determinism, disability labelling, disability disclosure, and the importance of maintaining/developing personal autonomy. Whilst considering resonation and contradiction of the present findings to prior empirical evidence, the relative lack of supportive research in the areas of visual impairment that have been reported here, especially relating to qualitative data, may pose limitations in this regard. Nevertheless, several reported themes, such as visual impairment-related social challenges, familial relationships in the context of disability, and importance of promoting ‘life skills’ within visual impairment education, have been reflected. More generally, present emergent themes fit within psychological paradigms and disability theory, thus allowing the phenomenon of visual impairment-related experiences to be relevant for understanding broader experiences and psychological responses to disability, both from the individual, and wider society. When examining findings from all three studies in conjunction, it becomes apparent that participants have emphasised psychosocial as opposed to medical features of visual impairment, and it is these psychosocial aspects that have had the greatest impact on lived experiences of sight-loss, parenting, and working with visually impaired individuals. It is for this reason that this thesis has made frequent reference to the social model of disability, since this aligned with how participants responded to, and made sense of their experiences. Almost all of the psychologically challenging experiences described by participants can be related to societal barriers, whether it be the diagnostic process, navigating social upheaval, and exploring one’s identity. This research has therefore been empowering and emancipatory for both visually impaired individuals and those closest to them, giving them the freedom and scope to have their voices heard in a conversation that puts their needs at the forefront.

Throughout this thesis, research findings have been consistently linked to the social model of disability, since many of the participant’s psychological difficulties resulted from social as opposed to medical features of disability. This was frequently demonstrated in the awkward, often anxiety-filled social interactions between participants and their peers, along with perceived societal ‘pressure’ to label oneself as ‘disabled’ and ‘accept’ one’s impairment. However, the nature of the social model itself is a dichotomy between impairment (i.e., medical and psychological factors) and disability (entirely based on social and environmental factors). Once a line has been drawn between these two groups of factors, the social model continues to provide an argument based entirely on social processes (Terzi, 2004; Shakespeare, 2006; Anastasiou & Kauffman, 2013). This entirely socially based theorising means that any underlying medical or psychological features of disability are dismissed, and we thus lose a significant part of a disabled individual’s experiential existence (Anastasiou & Kauffman, 2013). Therefore, the individual is not considered as a person with ‘full’ properties i.e., social, biological, and psychological, but instead becomes a ‘half person’ with only social aspects (Anastasiou & Kauffman, 2013). Any biological or psychological characteristics of disability are viewed by the social model as social illusions that are determined by social context and values (Anastasiou and Kauffman, 2011). If this were the case, subsequent removal of societal ‘disabling’ barriers would irradicate the concept of disability, or at lease render disability as a neutral concept (e.g., Finkelstein, 1980; Oliver, 1996a).

Indeed, in support of the social model, the social stigma, hostility, and exclusion were the most prominent barriers to psychological wellbeing following visual impairment for many participants in the present three studies. However, other features of visual impairment, such as the persistent fear of sight deterioration in study one, along with mothers feeling a need to “fix” their child’s impairment in study two, were related to medical rather than social aspects of disability. Moreover, in study three, QTVI introduction of assistive equipment to visually impaired pupils (aimed at reducing learning access barriers), became barriers themselves since they highlighted the ‘difference’ of the child’s impairment. Therefore, these findings demonstrate that, when stripped of social barriers, disability is not a neutral concept (Harris, 2000; Kauffman & Hallahan, 2009), and that the social model in this thesis is only a ‘best-fit’ model, that does not fully bring psychological factors of visual impairment from background to forefront. As such, the present research findings could be better suited to a model of ‘evolution and perpetuation’, which places equal emphasis on biological impairment, psychological response, and social influences. While a model of this nature does not currently exist within the literature, findings from the present research support a need to acknowledge the synergy and influence of medical, social, and psychological factors in disabilities such as visual impairment.

The ‘evolution’ aspect can be seen in study two, where mothers initial focus on medically ‘fixing’ their child, evolved over time into social advocacy for their child’s needs within a society full of potential stigma and misunderstanding. Both medical and social factors held equal significance to mothers at the time of their experience, and it was their psychological reaction and need that mediated this shift in focus. This shift was also seen in study one, where participants moved from questioning the meaning of their medical diagnosis; “why have I had it?” to a stance of using their impairment to support others and break down negative social attitudes. However, when no clear medical meaning could be placed on the impairment, this perpetuated ‘medical focus’, which might leave little remaining psychological resources available to shift focus to more socially oriented factors. In both examples, the evolution between medical and social elements of visual impairment only occurred when there was a psychological realization and acceptance that the impairment could not be changed, and that medical preoccupation became obsolete in favour of addressing social barriers that might be possible to influence positively.

The synergy between medical and social aspects of disability also showed bidirectionality within the present research. For example, in study one, the awkward social encounters between visually impaired participants and their sighted peers prompted self-blame for one’s impairment having caused the difficult interactions. Likewise, the dilemma of when and how to disclose visual impairment seen in all three studies, prompted participants to heighten psychological awareness of their ‘difference’, and how this difference would be perceived by others. Within the social model of disability, participant’s feelings of anxiety or frustration might be downplayed, where focus would instead be entirely devoted to the stigmatizing barriers of society’s misunderstanding. While this was indeed the case for many participants, their psychological reactions cannot be dismissed, since these social barriers perpetuated awareness of their own medical impairment. Therefore, although there is plenty of responsibility for society in relation to creating ‘disabling’ barriers, present findings demonstrate that the medical impairment itself is equally crucial for shaping psychological reactions and subsequent adaptation. As such, psychology has an important role within development of disability models that capture the entirety of the disability experience, since medical and social models alone are not adequate to give the full picture. This point further reinforces the need for full inclusion of individuals with disabilities throughout disability research, in order to promote continuous development of the disability concept, and how disabled people make sense of disability within their day-to-day lives.

7.3 Methodological Suitability

In keeping with the research aims, Interpretative Phenomenological Analysis (IPA) was selected since it offers an appropriate idiographic and phenomenological approach to exploring individual lived experience (Smith et al., 2009). IPA allowed in-depth exploration of participant's subjective experiences, while simultaneously enabling convergence and divergence within the data. IPA's idiographic commitment is concerned with the voice of the participant, as opposed to responding to specific hypotheses. Whilst IPA is a transparent and replicable methodology, exact duplication of these studies does not guarantee emergent themes that match those reported here. As stated by Smith et al. (2009), IPA is not concerned with generalising findings to a wider population; instead, it offers an alternative method of bringing together shared experiences. As such, I have avoided making generalisations from my findings, however I have cautiously considered emergent themes within the context of pre-existing psychological theory and research, which I feel has enriched the current analysis.

When conducting qualitative research, emphasis is often placed on data saturation, that is, the 'adequacy' point at which no new information is obtained through data collection (Guest et al., 2006; Creswell, 2012). Failure to reach saturation of data has been equated with poorer research quality, along with hindering content validity (Bowen, 2008; Kerr, 2010). Despite its deemed importance, there is controversy surrounding the point at which data saturation has occurred (Sebele-Mpofu, 2020), and how this saturation point is reached (Aldiabat & Navenec, 2018; Aguboshim, 2021). Due to the wide range of qualitative research designs, the concept of data saturation does not provide specific pragmatic guidelines for determining the point of saturation (Guest et al., 2006). Authors such as Morse (1995; 2007) have proposed that data saturation is a theoretical as opposed to a practical construct, since we can only assume the 'true' saturation of information.

The issue of data saturation becomes more complex when considering the theoretical underpinnings of IPA, which has extended beyond traditional phenomenology, towards a commitment to idiography (Pietkiewicz & Smith, 2014). Within IPA, the idiographic commitment refers to the fact that each participant's narrative provides a context for that participant's experience, before the researcher can then move on to making comparisons with other participant accounts in order to establish similarities and differences within the data set (Smith, 2004; Allan & Eatough, 2016; Smith & Nizza, 2022). Therefore, IPA's main concern is with the specific as opposed to the general (Smith et al., 2009), giving an in-depth representation of each 'case'. This concern is reflected in the use of a small sample of participants, due to the time-consuming nature of the idiographic commitment (Pietkiewicz & Smith, 2014). Traditionally, phenomenological approaches have emphasized convergence within a particular phenomenon (Finlay, 2011), whereas the intention of IPA is a preference for equal value of each individual participant (Pietkiewicz & Smith, 2014). Therefore, when viewing data saturation through an idiographic lens, the concept of saturation does not make sense as a validity criteria, since IPA's focus is on individual interpretation, and not collective saturation of themes (Brocki & Wearden, 2006). Given the idiographic nature of interpretation, it would be unrealistic to expect to reach saturation, even if this was the goal of the research (Miller, Chan, & Farmer, 2018).

7.4 – Disruption to Research Method – Impact of Covid-19

Prior to the declaration of the Covid-19 pandemic by the World Health Organisation, with ensuing impositions of national lockdowns, I had already completed data collection for study one, and was making preparation for study two participant recruitment. However, when the UK government announced lockdown restrictions on 23rd March 2020, it became apparent that my prior use of face-to-face interviews would no longer be plausible. Moreover, the 'family event' that I had organised as a springboard for accessing families with visually impaired children and advertising participation in my research had to be cancelled. With this in mind, any future participant recruitment would warrant significant adaptations. I therefore turned to online recruitment, which had proved successful during my clinical MSc dissertation. Given the low-incidence nature of visual impairment in children, I found online recruitment to yield a higher number of interested parents, than perhaps would have been possible during the family event. I was also grateful that Covid-19 had not coincided or impacted study one data collection. In hindsight this could have been detrimental to the recruitment process, since NHS prioritisation of Covid may have meant that potential participants were waiting longer for CVI registrations and referrals to the ECLO, which was the point at which individuals would have been informed about this research.

Along with the impact of Covid-19 restrictions on my research, I experienced several personal impacts. I now found myself completing a thesis during a national lockdown, having to adjust to the new normal of remote as opposed to face-to-face supervision and support. I experienced isolation from my fellow PhD students, and the group supervision meetings we had enjoyed prior to lockdown. Coinciding with the pandemic, I had been awaiting enucleation surgery to alleviate chronic eye pain. However, the unprecedented strain on the NHS during this time meant that my scheduled surgery was cancelled. Whilst I fully understood this decision, I was nevertheless left with the prospect of continuing daily life on strong medications, including morphine, with the uncertainty of when (or even if) my surgery might be re-scheduled. Chronic pain has always been part of my life, so, in a similar vein to many of my participants, I had to ‘carry on’; that included continuing to write my thesis.

7.5 Wider Limitations and next Steps

One of the most striking findings from the present research, was the struggle and conflict surrounding adopting new behaviours that could aid visual impairment adaptation, both in terms of re-building life after sight-loss, along with navigating a new family life following a child’s visual impairment. As such, drawing on these findings, next steps should consider the potential benefit of interventions that seek to help individuals overcome the dilemma and uncertainty of adopting new behaviours. One such intervention is motivational interviewing, a collaborative intervention designed to facilitate and engage with an individual’s intrinsic motivation for behaviour change, in accordance with specific therapeutic goals (Miller & Rollnick, 2012). Motivational interviewing utilises empathy and a person-centred approach in order to prepare individuals for behaviour change within numerous life contexts, such as implementing new behaviours, changes to pre-existing lifestyles, and adherence to treatments (Newnham-Kanas et al., 2020). This is particularly relevant within health psychology, since it offers a tool for positive patient-health professional communication, through heightened awareness of the individual’s willingness to change, as opposed to more traditional advice and instruction provision within healthcare and rehabilitation (Pearson et al., 2013; Mirkarimi et al., 2015; Mirkarimi et al., 2017). Motivational interviewing is based on an empathic approach that is supportive of individuals self-efficacy, focusing on advantages of changing behaviour.as such, a discrepancy is created between the individual’s current situation, and the situation they wish to be in, where there is also acknowledgment of resistance to change resulting from uncertainty (Rowicka, 2015). According to Miller and Rollnick (2012), use of ‘change talk’ i.e., auto-motivating assertions in place of arguments against change, enables individuals to overcome change uncertainty. Motivational interviewing has been implemented within a variety of health contexts, such as drug and alcohol addiction, diet, exercise, and somatic conditions (Lundahl & Burke, 2009; Miller & Rose, 2009; Miller & Rollnick, 2012). Several studies have reported successful use of motivational interviewing within these contexts (Rubak et al., 2005; Lundahl et al., 2013), thus demonstrating the applicability of this intervention for a broad range of health conditions that are to some extent influenced by behaviour.

Motivational interviewing has potential suitability as a psychological intervention in the context of visual impairment, since its goals emulate the model of psychological adaptation to visual impairment outlined by Hayeems et al. (2005; see chapter 3). Within both Hayeems et al.’s model and motivational interviewing, the importance of motivation is recognised, along with the goal of strengthening influential factors and processes on behaviour change (Emmons & Rollnick, 2001; Spencer et al., 2006; Cangöl & Şahin, 2017). Within study one of the present research, resistance to behaviour change was apparent, particularly relating to some participants reluctance to disclose their impairment to others, and by extent, using assistive equipment such as a cane, that would visibly identify them as having a visual impairment. There is currently no research regarding the use or efficacy of motivational interviewing as an intervention for promoting increased use of assistive equipment for visual impairment. However, there are several studies that have investigated the use of motivational interviewing as a tool for increasing use of hearing aids among individuals with hearing impairments (Aazh, 2016; Ferguson et al., 2016; Solheim et al., 2018). As with visual impairment-specific equipment, individuals requiring hearing aids also may experience social stigma surrounding use of a device that creates a visible ‘label’ of disability (Hogan et al., 2011; Claesen & Pryce, 2012; Hickson et al, 2014; Chang et al, 2016). However, the existing studies on motivational interviewing and hearing aid use have reported inconsistent findings, due to research limitations including small sample sizes, lack of control groups, and the fact that these were pilot investigations. Therefore, these limitations warrant recognition when implementing future research into motivational interviewing as a potential intervention in visual impairment. Since much of the psychological ambivalence to change occurs during the initial phases of visual impairment diagnosis, precisely when behaviour change is vital for improved psychological adaptation, introducing motivational interviewing as an adjunct to sight-loss rehabilitation early on may prove more significantly beneficial. However, issues surrounding cane use and impairment disclosure persisted long after the initial phases of sight-loss, which would call for long-term consideration of the outcomes of motivational interviewing, and whether this intervention would lead to persistent behaviour change over time.

Extending the potential benefit of motivational interviewing beyond individuals with visual impairment, this intervention may also be helpful to parents of visually impaired children. When applied to parenting interventions, motivational interviewing has been shown to improve parenting, as well as behavioural adjustment over a prolonged time frame (Nock & Kazdin, 2005). Moreover, motivational interviewing has been associated with increased attendance and engagement in parenting interventions among populations that are typically difficult to involve in treatment (Nock & Kazdin, 2005; Sibley et al., 2016; Winslow et al., 2016). This point may be relevant for parents of visually impaired children who feel as if they are ‘on their own’ with less perceived access to support, since motivational interviewing introduced early on could overcome their ambivalence for seeking help from sources external to the family. In study 2 of the present research, many mothers already possessed the motivation to change some of their behaviour and interaction with their visually impaired child, namely the conflict between being ‘protective’ versus ‘letting go’.

Therefore, motivational interviewing may help bridge the gap between current parent-child interactions, and those that allow the child to be more autonomous. This would allow parents more time and psychological space to engage more with other family members, thus reducing their sense of guilt for neglecting others e.g., siblings. Given the fact that all mothers in the present research were already motivated to help their visually impaired children thrive despite their disability, motivational interviewing could capitalize on this motivation by providing additional individualised support that is accepting and empathetic towards the struggles that these mothers face.

Increasing empirical support is also emerging for the use of motivational interviewing within educational settings (Strait et al., 2014; Rollnick, Kaplan, & Rutschman, 2016), as a useful communication method to support both teachers and pupils (Svensson et al., 2021). When pupils received empathy and validation, this increases their self-efficacy and personal growth (Rollnick et al., 2016). Subsequently, this increases the pupil's desire to learn and engage in school, as well as enhancing their intrinsic motivation and overall wellbeing (Cheon, Reeve, & Moon, 2012; Cryer & Atkinson, 2015). Since QTVIs in study three reported supporting pupil wellbeing and overcoming resistance to using assistive technology as vital to success of the QTVI role, motivational interviewing may prove a useful tool that is well-suited to the QTVI's autonomy- supportive teaching style. Previous research has recommended that motivational interviewing is better suited to older children, due to its cognitive and neurodevelopmental demands (Nelson et al. 2005; Strait et al., 2012a; Svensson et al., 2021). Therefore, since QTVIs reported the greatest resistance to behaviour change occurring in adolescence, motivational interviewing is further supported as a timely intervention to help QTVIs strengthen their visually impaired pupils motivation and recognition of potential challenges and opportunities both in school and beyond. Moreover, research has increased awareness of motivational interviewing as having potential to enhance collaborative relationships between teachers and parents (Herman et al., 2014); another vital aspect of the QTVI role identified in study three. As such, motivational interviewing could assist QTVIs in empathically managing and responding to parents' feelings, creating opportunities for constructive conversation (e.g., Svensson et al., 2021). According to Sabol and Pianta (2012), relational training should be incorporated into teacher education and professional development. Given the increasing focus on supporting wellbeing among visually impaired children within QTVI course content (Pilson, 2022), future research should aimt to explore the utility of motivational interviewing as a professional tool incorporated into QTVI training.

Not only should the present research findings be considered in terms of future directions and potential application to beneficial interventions, but they also need to ensure that the research is meeting the current research priorities of the individuals involved, and that these individuals are optimally included within the research process. As stated in Duckett and Pratt’s (2001) study, visual impairment research needs to bring individuals ‘out of the woodwork’, so that their needs and aspirations can be heard and addressed. This issue of reluctance to participate in visual impairment research therefore warrents consideration during the participant recruitment phase, where strategies need to be developed to better engage with individuals who may be ‘hidden’ from the recruitment process. One such strategy might include using ‘proxies’ i.e., individuals who are close to the potential participant, and who could approach that participant on the researcher’s behalf, as opposed to using more impersonal methods of initial recruitment such as mailing invitations to participants (Duckett & Pratt, 2001). Although this recruitment method may be more time-consuming, and complicate ethical and confidentiality issues, it may also provide a greater sense of safety for the individual considering taking part in research (Pratt & Wilkinson, 2001).

Another issue related to the inclusion of visually impaired individuals within visual impairment research, is the fact that not all individuals may wish to participate in such research, and researchers should avoid making this assumption (Duckett & Pratt, 2001; Scholvinck et al., 2017). One reason for this reluctance is aversion to being identified as ‘visually impaired’, and the potential unattractiveness of having to associate with other visually impaired individuals. Both issues were discussed within themes of study one (see chapter 3). As such, visually impaired individual’s identity, and the potential impact of research on this identity are important points for researchers to be cautious about throughout research activity. Within Duckett and Pratt’s (2001) study on the research priorities of visually impaired individuals, out of thirty conducted individual interviews, none of the participants showed interest in a group interview as a method of research. Hence greater attention should be paid to potential research settings that allow participants to share their experiences, strengths and concerns.

When discussing the relationship between researcher and researched in chapter 2, power dynamics within the research setting were raised as a potential issue that created disillusion among disabled participants. As frequently reported throughout the present research, participants felt frustrated and disheartened by the disempowering relationship between themselves and medical professionals, and the lack of a relationship that encouraged collaboration and equal involvement in their healthcare. Therefore, it is unsurprising to imagine that visually impaired individuals might view their role within research as passive and compliant, with a perceived inability to ask questions. In addressing this, the researcher-researched relationship should avoid mirroring that of a doctor-patient, where research setting should give a sense of informality that enables participant to feel comfortable to question the research and satisfy their own information needs. Ultimately, it is the visually impaired individual who owns the pool of expertise, and visual impairment research needs to place visually impaired individuals within a more empowering role, learning from existing expertise, rather than generating ‘new knowledge’ (Duckett & Pratt, 2001; Scholvinck et al., 2017).

This thesis has identified several gaps within visual impairment literature, particularly concerning raising a visually impaired child, and the specific roles and experiences of QTVIs. As such, research questions and aims were intentionally broad and wide-ranging. Since present findings have made steps towards filling research gaps, it would be interesting to continue exploring novel issues, including choices about impairment-related socialisation, and perceptions of visual impairment-related stigma, that have been revealed in each data set. Additionally, since research questions were drawn from both existing and lacking prior research, this thesis may not truly reflect the direction of visual impairment research that matters to the individuals who might benefit from its findings, since these individuals were not consulted prior to the studies. In addressing this, future research could consist of a preliminary phase whereby the direction and aims of research are determined by the relevant subjects, that is, visually impaired individuals, their families, and QTVIs. Nevertheless, this thesis represents the perspectives of these groups of individuals, and is an unapologetic account of the experiences of living and working with visual impairment. Throughout writing this thesis, I have been conscious that frustration and disappointment has been directed towards health, social, and educational agencies, and that these agencies may also lack a ‘voice’ beyond their professional roles. Future research might therefore be beneficial in encompassing any concurring or contrasting perspectives from these agencies, and how such perspectives can provide a more rounded narrative of systems and processes referenced by participants in this research.

7.6 Summary

This thesis has both reflected and contrasted against previous findings relating to visual impairment and disability in general, highlighting the significance of several psychological processes including emotional responses, social challenges, and identity/role dilemmas. Participants across all three studies wanted to advocate and support both themselves and each other, despite their own personal challenges and emotional labour. Visual impairment prompts people to view themselves and others in different ways, to think about the future, and establish new connections and a sense of belonging. My research is congruent with the social model of disability, in which individuals are ‘disabled’ by societal barriers as opposed to their own medical diagnoses. Although outside agencies were often viewed with frustration, study three has demonstrated the fact that visual impairment-related professionals can make a real and positive difference to the lives of visually impaired individuals and their families. While focus on what needs to change is important, the present research has also emphasised resilience, personal growth, and wisdom.

Appendix 1

Participant information sheet

Title of research: A qualitative study of psychological wellbeing among visually impaired individuals, following a recent diagnosis and experience of sight-loss.

You are being invited to take part in some research. Before you decide whether or not to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research? We are conducting research on the psychological impact of living with visual impairment. This will focus on several aspects, such as emotional reaction to visual impairment, coping with visual impairment, experience of fatigue, and perceptions about identity. The purpose of the study is to explore the psychological wellbeing of individuals who have experienced onset of sight-loss. Your participation in this study will take approximately one hour.

Who is carrying out the research? The data are being collected by Kirsty Hill in the Department of Psychology at Swansea University. The research has been approved by the departmental Research Ethics Committee.

What happens if I agree to take part? The study will involve a one to one interview with the researcher. During this interview, you will be asked to talk about your visual impairment, and how this may impact your everyday life i.e. practically, emotionally, and socially. You will also be asked questions regarding your identity perceptions, coping strategies, and about any positive impact that your VI has had. This interview will be tape-recorded (with your permission). The interview will end with a 5-10 minute chat about general issues, along with any questions you may have for the researcher.

Are there any risks associated with taking part? There are no significant risks associated with participation. It is possible that talking about your experience in this way may cause some distress.

Data Protection and Confidentiality. Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file on the researcher's laptop. All paper records will be stored in a locked filing cabinet in the Swansea University psychology department. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach. Please note that the data we will collect for our study will be made anonymous during the data analysis and write-up of the study, thus it will not be possible to identify and remove your data at a later date. Therefore, if at the end of this research you decide to have your data withdrawn, please let us know before you leave.

What will happen to the information I provide? An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be anonymous and unidentifiable.*

Is participation voluntary and what if I wish to later withdraw? Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw at any time, without giving a reason and without penalty.

Data protection privacy notice. The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office: VCO@swanseauniversity.com. Swansea University's Data Protection Officer is Bev Buckley and she may be contacted at [redacted]
Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the departmental Research Ethics Committee.
If you are concerned about how your personal data is being processed, please contact Swansea University's Data Protection Officer at [redacted] Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What if I have other questions? If you have further questions about this study, please do not hesitate to contact us:

Kirsty Hill Department of Psychology Swansea University [redacted]	Professor Paul Bennett Department of Psychology Swansea University [redacted]

Appendix 2

A qualitative study investigating the experience of social media by individuals with a visual impairment, in relation to identity perceptions and social connectedness.

Consent Form

I……………………………………agree to participate in this research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview to be tape-recorded

I understand that I can withdraw from the study, without repercussions, at any time, whether this be prior to the study, or whilst I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the project and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed…………………………………. Date……………….

Print Name: ……………………………………………………

Appendix 3
Debriefing Form

Study title: A qualitative study of psychological wellbeing among visually impaired individuals, following a recent diagnosis and experience of sight-loss.

Thank you for agreeing to participate in this study! The general purpose of this research is to explore the psychological impact of living with a recently diagnosed visual impairment.

We invited both males and females over the age of 18, who had been registered as severely sight impaired within the last six months, to take part in this study. In this study, you were asked to participate in a one to one interview with the researcher, lasting for approximately 60 minutes. During this interview, you were asked to talk about your visual impairment, and how this impacts on your everyday life i.e. practically, socially and emotionally. You were also asked to discuss other factors relating to your visual impairment, such as identity perceptions, use of coping strategies, and any positive impacts. The interview ended with a 5-10 minute chat about general issues, and any questions you may have had. Because this study used interviews in order to collect data, there was no concrete aim/hypothesis at the beginning of this study. However, any repeating themes that may occur during the interviews may be due to your participation. The themes/results obtained from this study may be beneficial in developing and enhancing our understanding of the psychological impact of sight-loss.

If you feel especially concerned about having discussed issues such as your visual impairment (since this may be a sensitive topic for you), please feel free to contact:
Sue Neale at Susan.Neale@rnib.org.uk
Swansea University Counselling Service on 01792 295592, internal extension 5592, or e-mail: Wellbeing@swansea.ac.uk
The Samaritans on 01792 655999.
Anxiety UK on 08444 775 774.

Thank you for your participation in this study. If you have further questions about the study, please email me at [redacted] or my supervisor: Professor Paul Bennett at [redacted]

Appendix 4

Interview schedule

1. Could you start by telling me about your VI? Prompt: when and how did your VI start?

2. Can you tell me about what impact your visual impairment has had on your daily life? (Prompt: to include practical impact: e.g. carrying out daily activities, mobility, use of adaptive aids/technology etc. psychosocial impact: e.g. fatigue, emotions, stress, coping. What's the hardest thing about being visually impaired for you?

3. What has been the emotional impact of your visual impairment? (prompt: to include thoughts/feelings about impact on daily life, use of adaptations, etc).

4. How has your VI impacted on you socially? Prompt: social interaction, how might your family/friends be feeling about your sight-loss? How are they helping you? Thoughts/feelings about this?

5. How has your VI affected you as a person for good or bad? (confidence, how about your sense of identity, do you think is has changed how others see you? (family, friends, strangers?)

5a. Do you see yourself as being “ill”? prompt: how might you define “illness”? How about “disability”? Do any of these fit with how you might perceive yourself?

6. Are there ‘good’ vision days and ‘bad’ vision days for you? What factors do you think might influence a good or bad vision day? Prompt: mood states e.g. stress, anxiety, depression, anger/frustration

7. What are your current thoughts and feelings about the future?

8. Can you tell me about any positive impact that your VI Has had?

9. Is there anything else you would like to say or add?

Appendix 5

Participant information sheet (for adults)

Title of research: A qualitative study of psychological wellbeing among families of visually impaired children.

You are being invited to take part in some research. Before you decide whether or not to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research? We are looking for family members (e.g. parents or guardians) of children with a visual impairment to take part in our research study. The study aims to look at the psychological impact of living with visual impairment as a family. This will focus on several aspects, such as emotional reaction to your child's visual impairment, how you cope with visual impairment as a family, and the positive effects of having a visually impaired child. The purpose of this study is to explore the psychological wellbeing of family members of visually impaired children. Your participation in this study will take around an hour.

Who is carrying out the research? The data are being collected by Kirsty Hill, in the Department of Psychology at Swansea University. The research has been approved by the departmental Research Ethics Committee.

What happens if I agree to take part? The study will involve a one to one interview with the researcher. The interview will last for around one hour. Before you take part in the interview, you will be asked to give written consent by signing the attached consent form. During the interview, you will be asked to talk about your child's visual impairment, and how this may impact on family life i.e. practically, emotionally, and socially. You will also be asked questions about how you might be coping with your child's visual impairment, and about any positive impact that your child's visual impairment has had. This interview will be tape-recorded (with your permission). The interview will then end with a 5-10 minute chat, where you will be able to raise any issues or questions you may have.

Are there any risks associated with taking part? There are no significant risks associated with participation. It is possible that talking about your experience in this way may cause some distress.

Data Protection and Confidentiality. Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file on the researcher's laptop. All paper records will be stored in a locked filing cabinet in the Swansea University psychology department. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach. Please note that the data we will collect for our study will be made anonymous during the data analysis and write-up of the study, thus it will not be possible to identify and remove your data at a later date. Therefore, if at the end of this research you decide to have your data withdrawn, please let us know before you leave.

What will happen to the information I provide? An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be anonymous and unidentifiable.*

Is participation voluntary and what if I wish to later withdraw? Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw at any time, without giving a reason and without penalty.

Data protection privacy notice. The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office: VCO@swanseauniversity.com. Swansea University's Data Protection Officer is Bev Buckley and she may be contacted at [redacted]
Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the departmental Research Ethics Committee.
If you are concerned about how your personal data is being processed, please contact Swansea University's Data Protection Officer at b.y.buckley@swansea.ac.uk. Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What if I have other questions? If you have further questions about this study, please do not hesitate to contact us:

Kirsty Hill Department of Psychology Swansea University [redacted]	Professor Paul Bennett Department of Psychology Swansea University [redacted]

Appendix 6

A qualitative study of psychological wellbeing among families of visually impaired children.

Consent Form

I……………………………………agree to participate in this research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview to be tape-recorded

I understand that I can withdraw from the study, without repercussions, at any time, whether this be prior to the study, or whilst I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the project and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed………………………………….   Date………………

Print Name: …………………………………………………

Appendix 7
Debriefing Form

Study title: A qualitative study of psychological wellbeing among families of visually impaired children.

Thank you for participating in this study! The general purpose of this research is to explore the psychological impact of living with childhood visual impairment as a family.

We invited both male and female parent/guardians of visually impaired children, to take part in this study. In this study, you were asked to participate in a one to one interview with the researcher, lasting for approximately one hour. During this interview, you were asked to talk about your child's visual impairment, and how this impacts on family life i.e. practically, socially and emotionally. You were also asked to discuss other factors relating to your child's visual impairment, such as impacts on relationships, use of coping strategies, and any positive impacts.

We are looking to see what experiences are found in families and whether these are found across different families. We intend to analyze the information you gave us and to identify common issues faced by families and the young people in them. The results obtained from this study may be beneficial in developing and enhancing our understanding of the psychological impact of sight-loss on the family. I would be happy to send you a copy of our findings when the analysis is complete.

If you feel especially concerned about having discussed issues such as your child's visual impairment (since this may be a sensitive topic for you), please feel free to contact:
Sue Neale at Susan.Neale@rnib.org.uk
Liz Rolfe at Elizabeth.rolfe@swansea.gov.uk Tel: 01792522829
Sherley Francis at Sherley.francis@swansea.gov.uk
The Samaritans on 01792 655999
Anxiety UK on 08444 775 774

Thank you for your participation in this study. If you have further questions about the study, please email me at [redacted] or my supervisor: Professor Paul Bennett at [redacted]

Appendix 8

Interview schedule

1. Could you start by telling me about your child's VI? Prompt: when and how did it start? How did you feel at the time of diagnosis?

2. Can you tell me about what impact your child's visual impairment has had on family life? (Prompt: to include practical impact: e.g. carrying out daily activities, mobility, use of adaptive aids/technology etc, what does this mean for you? What are your thoughts/feelings about this?

3. What has been the emotional impact of your child's visual impairment on family members?

4. What coping strategies do you use in dealing with any challenges associated with caring for your child?

5. Are there any other ways in which your child's visual impairment has impacted on you as a family? Prompt: parenting, family dynamics, your relationship with your child and vice versa, impact on your relationship with other family members e.g. partner, siblings of the child etc.

6. How have other people outside of your family reacted to both you and your child? Prompt: at school, members of the public, thoughts/feelings about this?

7. What does it mean to you to be the parent of a child with visual impairment?

8. What would you say is the hardest thing about having a child with a visual impairment?

9. Can you tell me about any positive impact that your child's VI has had?

10. What are your current thoughts and feelings about the future?

11. Is there anything else you would like to say or add?

Appendix 9

Dear parent or guardian,

You are invited to take part in a research study, as part of a psychology PhD at Swansea University. This will involve an informal one-to-one interview

Please note that, given the current situation, interviews will be conducted over the phone.

The interview will explore how having a child with a visual impairment impacts on the family; particularly on parents and guardians. We want to hear about the experience of both parents. We are therefore offering one or both parents the chance to be interviewed separately. We are happy to work around times that suit you best.

The interview will last about one hour. In it, you will be asked about how your child's visual impairment affects your family life, how you cope with your child's visual impairment as a family, and about any positive effects your child's visual impairment has had.

The interview will be recorded and then copied into a written text. After this we will destroy the recording. We will also change any personal information to make sure no one can identify you.

If you would like to take part, or if you would like to know more about the study, please contact the researcher by email: [redacted]

Or by phone[redacted].

Thank you for your time.

Yours faithfully,

Kirsty Hill

Psychology PhD student.

Appendix 10

Study title: A qualitative study of the psychological experience of qualified teachers for the visually impaired (QTVIs) working with visually impaired children.

You are invited to take part in a research study, as part of a psychology PhD at Swansea University. This will involve an informal one-to-one interview over the phone.

The interview will explore your experiences of working with a visually impaired child as a QTVI. We are happy to work around times that suit you best.

The interview will last about one hour. You will be asked about your role as a QTVI, what your relationship is like with the child you work with, and about any challenges and rewards you experience as a result of your work.

The interview will be recorded and then copied into a written text. After this we will destroy the recording. We will also change any personal information to make sure no one can identify you.

If you would like to take part, or if you would like to know more about the study, please contact the researcher by email: [redacted]

Or by phone: [redacted].

Thank you for your time.

Yours faithfully,

Kirsty Hill

Psychology PhD student.

Appendix 11

Participant information sheet (for adults)

Title of research: A qualitative study of the psychological experience of qualified teachers for the visually impaired (QTVIs) working with visually impaired children.

You are being invited to take part in some research. Before you decide whether or not to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research? We are looking for qualified teachers for the visually impaired (QTVIs) currently working with visually impaired children to take part in our research study. The study aims to look at the psychological experiences of working with visually impaired children in an educational setting. This will focus on several aspects, such as teacher-pupil relationships in the context of visual impairment, educational and social expectations of achievement in comparison to sighted pupils, along with the QTVI's role in communicating with the visually impaired pupil's family. The purpose of this study is to explore the psychological wellbeing of QTVIs working with visually impaired children. Your participation in this study will take around an hour.

Who is carrying out the research? The data are being collected by Kirsty Hill, who is a PhD student in the Department of Psychology at Swansea University. Any participation in this study will contribute to the psychology PhD. The research has been approved by the departmental Research Ethics Committee.

What happens if I agree to take part? The study will involve a one to one telephone interview with the researcher. The interview will last for around one hour. Before you take part in the interview, you will be asked to give written consent by signing the attached consent form. During the interview, you will be asked to talk about your role as a QTVI, and how this may psychologically impact on both you and the child you work with, i.e. practically and emotionally. You will also be asked questions about the challenges and rewards of working with a visually impaired child, in addition to your thoughts/feelings about the future for the child that you work with. This interview will be tape-recorded (with your permission). The interview will then end with a 5-10 minute chat, where you will be able to raise any issues or questions you may have.

Are there any risks associated with taking part? There are no significant risks associated with participation. It is possible that talking about your experience in this way may cause some distress.

Data Protection and Confidentiality. Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team. All electronic data will be stored on a password-protected computer file on the researcher's laptop. All paper records will be stored in a locked filing cabinet in the Swansea University psychology department. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach. Please note that the data we will collect for our study will be made anonymous during the data analysis and write-up of the study, thus it will not be possible to identify and remove your data at a later date. Therefore, if at the end of this research you decide to have your data withdrawn, please let us know before you leave.

What will happen to the information I provide? An analysis of the information will form part of our report at the end of the study and may be presented to interested parties and published in scientific journals and related media. *Note that all information presented in any reports or publications will be anonymous and unidentifiable.*

Is participation voluntary and what if I wish to later withdraw? Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw at any time, without giving a reason and without penalty.

Data protection privacy notice. The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellors Office: VCO@swanseauniversity.com. Swansea University's Data Protection Officer is Bev Buckley and she may be contacted at [redacted].
Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you. However, the legal basis on which this task is being performed is public interest, approved by the departmental Research Ethics Committee.
If you are concerned about how your personal data is being processed, please contact Swansea University's Data Protection Officer at [redacted] Details of your individual rights are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What if I have other questions? If you further questions about this study, please do not hesitate to contact us:

Kirsty Hill Department of Psychology Swansea University [redacted]	Professor Paul Bennett Department of Psychology Swansea University [redacted]

Appendix 12

A qualitative study of the psychological experience of qualified teachers for the visually impaired (QTVIs) working with visually impaired children.

Consent Form

I……………………………………agree to participate in this research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview to be tape-recorded

I understand that I can withdraw from the study, without repercussions, at any time, whether this be prior to the study, or whilst I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the project and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed…………………………………. Date………………

Print Name: ……………………………………………………

Appendix 13

Debriefing Form

Study title: A qualitative study of the psychological experience of qualified teachers for the visually impaired (QTVIs) working with visually impaired children.

Thank you for participating in this study! The general purpose of this research is to explore the psychological impact of working with visually impaired children as a QTVI.

We invited both male and female QTVIs currently working with visually impaired children, to take part in this study. In this study, you were asked to participate in a one to one interview with the researcher, lasting for approximately one hour. During this interview, you were asked to talk about your role as a QTVI, and how this impacts on you psychologically i.e. your relationship with the child that you work with, and what it means to you to be a QTVI. You were also asked to discuss other factors relating to working as a QTVI, such as your expectations about your student's educational and social achievements, and whether this differs from that of sighted students, along with your role in communicating with your student's family.

We are looking to see what experiences are found in QTVIs and whether these experiences are shared by other QTVIs. We intend to analyze the information you gave us and to identify common issues faced by QTVIs and the young people they work with. The results obtained from this study may be beneficial in developing and enhancing our understanding of the psychological impact of visual impairment within the education setting. I would be happy to send you a copy of our findings when the analysis is complete.

If you feel especially concerned about having discussed any issues during the interview, please feel free to contact:
The Samaritans on 01792 655999
Anxiety UK on 08444 775 774

Thank you for your participation in this study. If you have further questions about the study, please email me at [redacted] or my supervisor: Professor Paul Bennett at [redacted]

Appendix 14

Interview Schedule

1. What is the first thing that comes to mind when you think of the term ‘QTVI’? what is the most important part of your job?
2. How do you feel about providing instruction to students with visual impairment. What is that like for you?
3. How do you work with students who are newly diagnosed with visual impairment? Does this differ from how you might work with a child who has been visually impaired since birth?
4. Tell me about the experiences of students with visual impairment who you work with? Prompt: use of practical adaptations in class, how about the psychological/emotional experience of your students in class, how does this impact on you?
5. How do you feel that your students interact with peers? Prompt: how do others (e.g. peers) interact with the student? do you have any role in your student’s social interaction? How do you think this might be perceived by the visually impaired student?
6. How would you describe your relationship with the students you work with? What factors might influence this relationship?
7. What are your expectations regarding your students educational and social achievements? Do you think these expectations might differ from those of sighted students?
8. How would you describe your relationship with family members (e.g. parents) of the students you work with? What factors do you think have the most impact on this relationship? How do you think you are perceived by family members? What kind of role do you think you play in terms of working with the family as a whole?
9. What would you say are the most challenging aspects of working with visually impaired students? Which aspects do you find most rewarding? What does it mean to you to be a QTVI?
10. What comes to mind for you when you think about the future for your students? Prompt: education, social, transition to adulthood?
11. Is there anything else you would like to say or add?

Appendix 15

Study 1 Ethical Approval

3 July 2019

Dear Professor PAUL Bennett, Ms Kirsty Hill, , Professor PAUL Bennett,

Re: 1492 , A qualitative study of psychological wellbeing among visually impaired individuals, following a recent diagnosis and experience of sight-loss

Your application - https://swansea.forms.ethicalreviewmanager.com/ProjectView/Index/1492 - has been reviewed and approved by the Department of Psychology Ethics Committee.

The list of additional students (if any) are included in the table below:

Other student applicant - first name	**Other student applicant - Surname**	**Other student applicant - email**
Kirsty	Hill	[redacted]

additional researcher or student - first name	**additional researcher or student surname**	**additional researcher or student email**

The conditions of this approval are as follows:

1. To conduct your study strictly in accordance with the proposal that has been approved by the committee, including any approved amendments
2. To advise the ethics committee chair of any complaints or other issues that may warrant ethical review of the project
3. To submit for approval any changes to the approved protocol before implementing any such changes
4. To keep any information obtained from your participants absolutely confidential

Please note that failure to comply with these conditions of approval may result in the withdrawal of approval for the project.

To advertise your study on the departmental Participant Pool: You will need to send send a request for your study to be made visible, via the link on the Experiment Management System website (see Researcher Documentation for details). Please ensure that you attach this letter to your request. (If you are unable to attach the Ethics approval, send it in a separate email to Dr. Phil Tucker [redacted]).

For students: Please ensure that the signed copy of this Ethical Approval, together with any other paperwork associated with your research, is included in your final write up.

Yours Sincerely,

Dr Daniel Zuj (Reviewer of Application)

Dr Gabriela Jiga-Boy (Committee Chair)

Appendix 16

Study 2 Ethical Approval

6 March 2020

Dear Professor PAUL Bennett, Ms Kirsty Hill, , Professor PAUL Bennett,

Re: 3799 , Quality of life in parents of children with visual impairment

Your application - https://swansea.forms.ethicalreviewmanager.com/ProjectView/Index/3799 - has been reviewed and approved by the Department of Psychology Ethics Committee.

The list of additional students (if any) are included in the table below:

Other student applicant - first name	Other student applicant - Surname	Other student applicant - email
Kirsty	Hill	[redacted]

additional researcher or student - first name	additional researcher or student surname	additional researcher or student email

The conditions of this approval are as follows:

1. To conduct your study strictly in accordance with the proposal that has been approved by the committee, including any approved amendments
2. To advise the ethics committee chair of any complaints or other issues that may warrant ethical review of the project
3. To submit for approval any changes to the approved protocol before implementing any such changes
4. To keep any information obtained from your participants absolutely confidential

Please note that failure to comply with these conditions of approval may result in the withdrawal of approval for the project.

To advertise your study on the departmental Participant Pool: You will need to send send a request for your study to be made visible, via the link on the Experiment Management System website (see Researcher Documentation for details). Please ensure that you attach this letter to your request. (If you are unable to attach the Ethics approval, send it in a separate email to Dr. Phil Tucker [redacted].

For students: Please ensure that the signed copy of this Ethical Approval, together with any other paperwork associated with your research, is included in your final write up.

Yours Sincerely,

Associate Professor CRISTINA Izura (Reviewer of Application)

Dr Gabriela Jiga-Boy (Committee Chair)

Appendix 17

Study 3 Ethical Approval

December 2020

Dear Dr Kim Dienes, , Dr. Paul Bennett, Kirsty Hill, ,

Re: 4995 , A qualitative study of the psychological experience of qualified teachers for the visually impaired (QTVIs) working with visually impaired children.

Your application - https://swansea.forms.ethicalreviewmanager.com/ProjectView/Index/4995 - has been reviewed and approved by the Department of Psychology Ethics Committee.

The list of additional students (if any) are included in the table below:

Other student applicant - first name	**Other student applicant - Surname**	**Other student applicant - email**

additional researcher or student - first name	**additional researcher or student surname**	**additional researcher or student email**

The conditions of this approval are as follows:

1. To conduct your study strictly in accordance with the proposal that has been approved by the committee, including any approved amendments
2. To advise the ethics committee chair of any complaints or other issues that may warrant ethical review of the project
3. To submit for approval any changes to the approved protocol before implementing any such changes
4. To keep any information obtained from your participants absolutely confidential

Please note that failure to comply with these conditions of approval may result in the withdrawal of approval for the project.

To advertise your study on the departmental Participant Pool: You will need to send send a request for your study to be made visible, via the link on the Experiment Management System website (see Researcher Documentation for details). Please ensure that you attach this letter to your request. (If you are unable to attach the Ethics approval, send it in a separate email to Dr. Phil Tucker [redacted]).

For students: Please ensure that the signed copy of this Ethical Approval, together with any other paperwork associated with your research, is included in your final write up.

Yours Sincerely,

Dr GABRIELA JIGA-BOY (Reviewer of Application)

Dr Gabriela Jiga-Boy (Committee Chair)

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